House of Commons
Health Committee

Managing the care of people with long-term conditions

Second Report of Session 2014–15

Volume I

Volume I: Report, together with formal minutes, oral and written evidence

Additional written evidence is contained in Volume II, available on the Committee website at www.parliament.uk/healthcom

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The Health Committee

The Health Committee is appointed by the House of Commons to examine the expenditure, administration, and policy of the Department of Health and its associated bodies.

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The Reports and evidence of the Committee are published by The Stationery Office by Order of the House. All publications of the Committee (including press notices) are on the internet at www.parliament.uk/healthcom. A list of Reports of the Committee in the present Parliament is at the back of this volume.

The Reports of the Committee, the formal minutes relating to that report, oral evidence taken and some or all written evidence are available in a printed volume.

Additional written evidence may be published on the internet only.

Committee staff

The staff of the Committee are David Lloyd (Clerk), Martyn Atkins (Second Clerk), Laura Daniels (Senior Committee Specialist), Stephen Aldhouse (Committee Specialist), Daniel Moeller (Senior Committee Assistant), Nathan Hug (Committee Assistant) and Alex Paterson (Media Officer).

Contacts

All correspondence should be addressed to the Clerk of the Health Committee, House of Commons, 7 Millbank, London SW1P 3JA. The telephone number for general enquiries is 020 7219 1234; the Committee’s email address is healthcom@parliament.uk

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1 Mr Stephen Dorrell was elected as the Chair of the Committee on 9 June 2010, in accordance with Standing Order No. 122B (see House of Commons Votes and Proceedings, 10 June 2010). The Speaker announced his resignation as Chair on 4 June 2014. On 10 June 2014 the Committee chose David Tredinnick to act as Chair of the Committee for all further meetings until a new Chair is elected by the House.
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Summary

The challenge of managing long-term conditions

Effective management of long-term conditions (LTCs) is widely recognised to be one of the greatest challenges facing the 21st-century National Health Service in England. Thanks to advances in the care and treatment of many common long-term conditions, a greater proportion of the population is now able to lead a longer and more active life: but this care and treatment consumes a greater proportion of the NHS’s finite resources. 70% of total expenditure on health and care in England is associated with the treatment of the 30% of the population with one LTC or more, and the number of people in England with one or more such condition—currently 15 million—is projected to increase to around 18 million by 2025. Care for LTCs presently accounts for 55% of GP appointments, 68% of outpatient and A&E appointments and 77% of inpatient bed days. Cost pressures on the health and care system deriving from management of LTCs and treatment of the increasing prevalence of comorbidities is likely to add £5 billion to the annual costs of the system between 2011 and 2018.

The NHS Call to Action in 2013 demanded improvement in the service provided to support the needs of people with LTCs and to help them manage their own condition. The Health Committee has in the past recognised the structural challenge to the NHS from a lack of integration and coordination of support across the health and care system. In this inquiry we found that in many cases commissioning of services for LTCs remains fragmented and that care centred on the person is remote from the experience of many. The NHS and social care services also face significant financial challenges: demand for services is exceeding the funding available at present, a situation which on present demographic projections is only likely to worsen.

Strategic direction of services for long-term conditions

The Department of Health has committed to improving care for people with LTCs in order to enable them to have an independent and fulfilling life and to receive the support they need to manage their health. An integrated approach to the delivery of health and care services is central to this improvement. We note the commitment of system leaders to ensuring that all localities in England have models for the commissioning and delivery of integrated care and support by mid-2015. In a separate inquiry we will be examining in greater depth the work of the “integration pioneer” sites set up to develop integrated approaches.

The Secretary of State’s Mandate to NHS England contains four specific objectives for the management of LTCs, supported by nine progress indicators, though we note that for four of the nine indicators there is as yet little reliable data to measure progress. We call for greater clarity in the setting of baseline indicators and greater transparency and rigour in the measurement of progress against these indicators.

The Department of Health ceased work on developing a cross-Government strategy for LTCs in 2013, following transfer of responsibilities for this work to NHS England. NHS
England has not taken forward a national approach to strategic planning for LTCs. It is not clear how effective cross-governmental working is being taken forward in the absence of a national strategy engaging all relevant Government departments. The strategic response from the Government and NHS England to the pressures arising from increased incidence of LTCs is unclear and lacks urgency.

**Clinical care for people with long-term conditions**

Challenges in defining and recognising LTCs are exacerbated by the increasing number of people who present with more than one LTC, or people with physical health LTCs who subsequently develop mental health conditions. People with such multimorbidities risk experiencing poor coordination of treatments primarily designed to address single conditions. We recommend that NICE take the increasing prevalence of comorbidities into account when developing and revising clinical guidelines for the treatment of LTCs, and take into account the potential risks of polypharmacy—the simultaneous prescription of several medications to treat multiple conditions—to patients with multiple morbidities.

The working definition of LTCs used by the Department of Health no longer captures the complexity inherent in many patients with multiple morbidities, and does not sufficiently emphasise the policy objective of treating the person, rather than the condition, and of treating the person with multiple conditions as a whole. We recommend that the definition be revised to better capture this complexity.

We examined issues arising from the provision of care for people with diabetes, and drew the general conclusion that care pathways needed to be rebalanced to provide greater integration of treatment across all care settings, as well as support for patients to manage their own conditions. The change required can best be delivered through the adoption of individual care planning models centred on the needs of the patient, and we endorse the principles behind the House of Care approach to care planning.

We have identified a systematic and cultural shift towards greater personalisation of health and care services, and greater involvement of service users in constructive discussions about how their LTCs are treated. There is clearly scope to increase the choice patients have over the way their conditions are treated: the challenge for commissioners will be how to evaluate and measure the effectiveness of, for instance, complementary and alternative medicine in cases where a patient feels it is likely to be effective.

Another aspect of personalisation of health and care services for those with LTCs is the greater availability of medical records. While we recognise the considerable benefits in managing LTCs of engaging better-informed “digital patients” with their care, we believe that technological advances to benefit the well-connected patient must not be pursued to the disadvantage of those unable to access digital services.

The substantial structural and cultural changes in clinical care of those with LTCs described in the report will be extremely challenging for health and care services, and will, require medical professionals in all disciplines to adapt their ways of working and develop effective collaborations with those in other disciplines. If more treatment of LTCs is to take place in primary and community care, then the recruitment and workforce planning required must take place as a matter of urgency, in particular to address a work force
Managing the system to deliver better long-term conditions care

The Government is keen to reduce the number of unplanned acute admissions for conditions which could be better treated in primary or community care. We are not convinced that focusing on measures to reduce admissions to the acute sector will effectively address the underlying issues in management of LTCs which seem to drive patients with chronic ambulatory care-sensitive conditions into acute care.

While the prevailing wisdom appears to be that patients with LTCs can be better and more effectively treated in primary and community care, we have not discerned any conclusive evidence that a large-scale shift in services will provide clinical or economic benefits, though a change in service mix may well be beneficial overall in supporting those with LTCs. We recommend the commissioning of long-term studies of the effectiveness and economic benefit from integrated services for the management of LTCs, with regular and rigorous evaluation of outcomes.

We strongly support the development of new payment systems in the NHS, such as the Year of Care tariff, which are based on care planning approaches rather than the funding of individual episodes of care. The integrated care pioneer sites are authorised to experiment with tariff flexibilities, and we recommend that the use of these flexibilities is thoroughly evaluated with a view to developing models of care centred on the needs of the service user. NHS England and Monitor must support parity of esteem between physical and mental health services through the present and reformed tariff system.

What change means for the present structure of services

We were told by the Minister of State at the Department of Health that “significant change” in health and care services for LTCs would be seen across England by 2015, boosted by the introduction of the Better Care Fund and the pooling of a proportion of health and care budgets. It is of course unlikely that the changes in local health systems necessary to support full-scale individual care planning for LTCs will be in place by 2015: the scale and pace of the promised change will only become apparent once clinical commissioning group plans for the shape of local services to 2018/19 are collated and assessed by NHS England.

It is not certain that changes in service design to better support the management of LTCs will be cost-neutral or result in savings in the short term, and it is likely that in the current situation of little or no growth in the overall health budget, the expense of service redesign will have to be met by reductions or efficiencies elsewhere.

Moving care for LTCs to primary and community care and self-management is intended to reduce unplanned admissions to the acute sector. Reducing the activity of acute hospitals on LTCs, and their income from such activity, is bound to have a consequential impact on services. The likely impact of service redesign on the acute sector in particular must be explicitly recognised and openly debated, in order to secure broad public understanding of, and agreement to, proposals for change.
1 Introduction

Our inquiry

1. The Committee set out to examine the way in which the NHS and social care system in England supported people with long-term conditions. In our call for evidence we sought comments on the following issues in particular:

- The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness
- The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community
- The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions
- The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions
- Obesity as a contributory factor to conditions including diabetes, heart failure and coronary heart disease and how it might be addressed
- Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions
- The implications of an ageing population for the prevalence and type of long-term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand
- The interaction between mental health conditions and long-term physical health conditions
- The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes)

We address below several of the themes to emerge from the volume of evidence we received in the course of the inquiry.

2. In response to the call for evidence we received almost one hundred written submissions. We took oral evidence from Professor Alan Maynard OBE, Professor of Health Economics, University of York, Dr Karen Lowton, Senior Lecturer in Ageing and Health, King’s College London, Dr Sue Roberts CBE, Chair, NHS Year of Care Partnerships, Dr Judith Smith, Head of Policy, Nuffield Trust, Professor Alan Silman, Medical Director and Director of Policy and Health Promotion, Arthritis Research UK, and other witnesses.

2 Written evidence received by the Committee is listed on page 85
Baroness Young of Old Scone, Chief Executive, Diabetes UK, Dr Peter Aitken, Chair of the Faculty of Liaison Psychiatry, Royal College of Psychiatrists, Don Redding, Director of Policy, National Voices, Liz McAnulty, Trustee, The Patients Association, Dr Peter Fisher, Clinical Director and Director of Research, Royal London Hospital for Integrated Medicine, Professor George Lewith, Professor of Health Research, University of Southampton, Professor Nigel Mathers, Vice Chair of Council, Royal College of General Practitioners, Alastair Buxton, Head of NHS Services, Pharmaceutical Services Negotiating Committee, Emily Holzhausen, Director of Policy and Public Affairs, Carers UK, Victoria Matthews, Assistant Long Term Conditions Adviser, Royal College of Nursing, Dr Martin McShane, Director, Improving the quality of life for people with long term conditions, NHS England and Norman Lamb MP, Minister of State for Care and Support, Department of Health.3 We are grateful to all those who submitted written evidence and who appeared before us as witnesses.

3. The oral evidence in this inquiry was taken when Rt Hon Stephen Dorrell MP was in the Chair. Mr Dorrell was elected as Chair by the House on 9 July 2010 and resigned as Chair on 4 June 2014. The Committee wishes to place on the record its thanks to Mr Dorrell for his work with the Committee throughout this inquiry.

The challenge for health and care services from long-term conditions

4. The effective management of long-term conditions on the population of England is widely acknowledged to be one of the greatest challenges facing the NHS in the early 21st century. A service which, on current expenditure plans, is unlikely to receive more than the most minimal real-terms increases in its budget until at least 2016 is expected to meet the healthcare needs of a population which is, on average, living longer and requiring greater support. Advances in the care and treatment of many conditions have had the happy effect of ensuring that a greater proportion of the population is able to enjoy a longer and more active life. But such care and treatment require greater expenditure on staff, pharmaceuticals and equipment over a longer period, and consume increasing resources.

5. The Department of Health defines a long-term condition as “a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies”.4 The Department estimated in 2012 that over 15 million of the population of England had been diagnosed with at least one long-term condition.5 On current trends, that figure was projected to increase by a further 20% to around 18 million by 2025. The proportion of NHS services accounted for by people with long-term conditions is substantial: 55% of GP appointments, 68% of outpatient and A&E appointments and 77% of inpatient bed days. It is estimated that 70% of total expenditure on health and care in England is associated with care for the 30% of the population with long-term conditions.

3 Details of the evidence sessions are given on page 84
4 Department of Health, Long Term Conditions Compendium of Information, 3rd edition, May 2012, p 3. The 2nd edition of the Compendium (2008, p 10) defined long-term conditions as “those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies. The life of a person with a LTC is forever altered – there is no return to ‘normal’.”
5 Ev 74, para 1
6. Citing research by The King’s Fund, the Department estimates the average cost per year of treatment for a person with a single long-term condition in the health and social care system is £1000. For a person with two long-term conditions the cost is £3000; for those with three the estimated cost is £8000.6 Without improvement in both the rate of prevention of long-term conditions and the management of those with such conditions, the Department estimates that by 2016 the cost pressures on the NHS will reach an additional £4 billion per annum compared to the baseline of 2010.7

7. Further complications come from the increasing prevalence of comorbidities, or concurrent diagnoses of more than one long-term condition. In 2012 the Department projected that the number of those with more than one long-term condition would rise from 1.9 million in 2008 to 2.9 million in 2018, and that the increase in such comorbidities, taken together with the general cost pressures indicated above, would add £5 billion to the annual costs of the health and care system between 2011 and 2018.8

8. These basic figures led us to question whether health and care services in England are optimally structured to handle the present number of people in England with long-term conditions in a way which is effective both in providing the best care and treatment possible and ensuring the best use of public money. Nor do they provide any assurance that the system is well-placed to handle future levels of demand.

9. Leaders of the principal organisations in the health and care system have recognised the difficulties posed by trends in the incidence of long-term conditions. In July 2013 the NHS Call to Action noted that expenditure on people with long-term conditions accounted for “a disproportionate amount of NHS resources” and that people living at higher levels of deprivation were more likely to live with a debilitating condition, more likely to live with more than one condition, and likely to do so for more of their lives.9 The situation required a response from the system:

The NHS, working with local authorities and the new health and wellbeing boards, needs to be much better at providing a service that appropriately supports these patients’ needs and helps them to manage their own conditions. Better management of their own conditions by patients themselves will mean fewer hospital visits and lower costs to the NHS overall, and more community-based care, including care delivered in people’s homes.10

**Integrating health and care services**

10. In this report we examine two main and related issues: the principles which should underpin the clinical care of people with long-term conditions, and the way that the health and care system should be managed to support the delivery of such care.

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6 Ibid., paras 1-2
7 Ev 75, para 4
8 Long Term Conditions Compendium of Information, 3rd edition, p. 6
9 The NHS belongs to the people: a call to action, NHS England, July 2013, p. 8
10 Ibid.
11. The themes which the Committee has covered in its inquiry are in no sense new. They stem from a policy priority which the Committee has consistently championed over the course of this Parliament: that of greater integration across the healthcare system and across health and social care services. In our 2012 report on Social Care, we drew attention to the significant proportion of the population who are now the “typical” users of NHS and social care services: those with long-term and chronic conditions who need coordinated care packages to allow them to lead fulfilling lives.\(^{11}\) We found that “many older people, and those with disabilities and long-term conditions need to access different health, social care, housing and other services, often simultaneously.”\(^ {12}\) We also found that many services which should be joined up for the benefit of the service user instead sat in unconnected silos, kept apart in part by the fragmented nature of commissioning budgets, and we concluded then that there was a link between experiences of fragmented services and the multiplicity of funding streams and commissioners of services. We did not think that the reforms to commissioning structures proposed in the Health and Social Care Bill, now enacted, would simplify the process for commissioning health and care services in this regard.\(^ {13}\) Much of the evidence we received in the course of this inquiry indicated that for service users with long-term conditions commissioning remains fragmented and the delivery of care centred on the person can be frustratingly remote.

12. Our findings in 2012 have since been echoed in the 2013 report of the House of Lords Select Committee on Public Service and Demographic Change:

> We heard that a new model of care is needed, more focused on prevention, early diagnosis, intervention, and managing long-term conditions to prevent degeneration ... A remarkable shift in NHS services will be needed to deliver this new model of care. Older people with long-term conditions want good primary care, community care and social care, linked up around them regardless of clinical categories or structural splits between health care on one hand and social care on the other. They want good out-of-hours services, so that their conditions can be managed in their own homes and prevented from deteriorating, and to make it possible to minimise upsetting, disruptive and expensive episodes in hospital. This is not the system we have.\(^ {14}\)

While the Lords report focused on care for the ageing and elderly, in an era of substantial demographic change, the arguments apply to health and care services for all those with long-term conditions who rely on such services to support them in their daily lives.

13. It had been anticipated that a substantial proportion of the necessary change of health and care services described above would have come about during the period of the “Nicholson Challenge”, the five-year period during which the NHS has been expected to find up to £20 billion in efficiencies to meet the anticipated cost pressures on the service in an era of flat budgets and rising demand. Having tracked progress against the Nicholson

\(^{11}\) Health Committee, Fourteenth Report of Session 2010-12, Social Care, HC (2010-12) 1583, para 5

\(^{12}\) Ibid., para 10

\(^{13}\) Ibid., para 11

\(^{14}\) House of Lords Select Committee on Public Service and Demographic Change, First Report, Session 2012-13, Ready for Ageing?, HL (2012-13) 140, paras 198-199
Challenge in our annual reports on public expenditure on health and care services over the course of this Parliament, we have reached the broad conclusion that the scale of change contemplated is unlikely to materialise in the period before May 2015. Since a return to year-on-year increases in real-terms expenditure on the NHS from the public purse appears at present unlikely, and a reduction in the cost pressures seems equally unlikely, it seems to us probable that Nicholson-style restraints will have to continue in some form into the next Parliament and across a future spending round: indeed, NHS England has now indicated that the anticipated funding gap of £20 billion expected by 2015 is likely to widen to £30 billion by 2020/21. The incoming chief executive of NHS England, Simon Stevens, told us that this projection was based on the twin assumptions of flat NHS spending in real terms to 2020/21 and demographic projections of population growth and ageing over the same period: the question he posed to the NHS was “what is it going to take to make significant inroads there?”

14. Social care faces its own funding pressures. In May 2013 the Association of Directors of Adult Social Services (ADASS) estimated that by April 2014 local authority social care budgets would have been reduced by a total of £2.68 billion, or 20%, since the beginning of the present spending round. Budget reductions therefore comprise the greatest present pressure on social care, but demographic pressures are also mounting: ADASS and the Local Government Association told us that, on the basis of their 2013 budget survey, local authority adult social services departments had estimated that demographic pressures would lead to annual increases in demand of about 3%, equivalent to £400 million. This would stretch service delivery, resulting in fewer people receiving services, but at higher cost and intensity.

15. Challenging decisions on the future shape of health and care services remain to be addressed. It is unlikely that they can be evaded. Our report, therefore, considers the future shape of publicly-funded services for the care of people with long-term conditions in a context of continuing financial challenge for the NHS and for adult social care services.

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15 The NHS belongs to the people: a call to action, p. 15
16 Oral evidence taken on 29 April 2014, HC (2013-14) 1219, Q 48
18 Ev w57
2 Strategic direction of services for long-term conditions

The approach of the Department of Health and NHS England

16. The Department of Health told us that the Government is “committed to improving care for people with long-term conditions so that they are able to enjoy an independent, fulfilling life, and have the support needed to manage their health.” The Secretary of State is said to have identified this area as a particular priority for action. We examined how this commitment was being implemented.

Integration of health and care services

17. To support the development of integrated health and care services, including services for long-term conditions, the Department has now established an Integrated Care and Support Working Group including the Department of Health, NHS England, Monitor, Public Health England, the Association of Directors of Adult Social Services, the Association of Directors of Children’s Services and the Local Government Association. These national partners, working as the National Collaboration for Integrated Care and Support (NCICS), have co-produced a framework document on integration, published in May 2013. The Department claims that the framework “has a focus on improving outcomes and experiences for individuals, the challenges facing localities, the national offer of support, and how we will monitor progress.” The national partners are working “to enable and encourage localities to innovate and experiment in ways that will deliver integrated and joined-up care and support at pace and scale.”

18. The Secretary of State for Health and the Minister of State for Care and Support summed the issues up in their joint foreword to the framework document, entitled Integrated Care and Support: Our Shared Commitment:

People may be living for longer, but often they are living with several complex conditions that need constant care and attention, conditions like diabetes, asthma or heart disease. And this is not only about older people—children born with complex conditions are now living to adulthood, while those with learning disabilities and other groups have lifelong needs. All these people need continuous care and support, and the right systems and resource to enable that.

We need major change and we are determined to act. That means building a system of integrated care for every person in England. It means care and support built around the needs of the individual, their carers and family and that gets the most out of people’s lives.”

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19 Ibid.
20 Ibid.
22 Ibid, para 19
23 Ibid, para 20
of every penny we spend. If the illness is prevented, the condition properly managed, the fall avoided, not only is that better care for the individual but it also means less pressure on the system.

We need to create a culture of cooperation and coordination between health, social care, public health, other local services and the third sector. Working in silos is no longer acceptable. We have to end the institutional divide between physical and mental health, primary and secondary care, and health and social care. We must provide a seamless service focussed on the individual within their own home. A big part of this will be working to ensure that we avoid crises in people’s care which too often result in hospital admissions. This should always be regarded as a failure. If we can do better at preventing deterioration of health then we know that fewer people will end up in hospital. Instead they will receive the right care, when and where they need it.24

19. NCICS has set out an ambitious vision for the delivery of integrated care and support services:

Our shared vision is for integrated care and support to become the norm in the next five years. [...] We will judge ourselves successful if, in two years, all localities in England have adopted models of commissioning and delivering integrated care and support and if, five years from now, integrated care and support has become the norm with improving outcomes and more positive experiences of care and support reported by patients and people who use services.25

20. This work is initially being undertaken through 14 “integration pioneers”.26 NHS England has said that the purpose of the integration pioneers is to “act as exemplars to address local barriers to delivering integrated care and support locally, and [to] highlight national barriers that the national partners can work to address. They will support the rapid dissemination, promotion and uptake of lessons across the country and will be offered central support to breaking down these barriers by the national partners.”27

21. We note with interest the establishment of 14 pioneer sites which are intended to address existing barriers to the integration of health and care services and indicate where such barriers need to be broken down by work at national level. We plan to examine the work of these integration pioneers in greater detail in a separate inquiry.

22. We note that NCICS has set ambitious goals not only for the adoption of models to commission and deliver integrated care and support but also for the wholesale delivery of integrated care and support services and corresponding increases in positive outcomes. We welcome the commitment of the National Collaboration for Integrated Care and Support to ensuring that all localities in England have adopted models to commission

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24 Integrated Care and Support: our shared commitment, pp. 1-2
25 Ibid., p. 8
26 Ev 76, para 20. The 14 pioneer sites are: South Devon and Torbay; North West London; Worcestershire; Cornwall; Islington; Waltham Forest, East London and the City; Greenwich; Leeds; South Tyneside; Staffordshire; Southend; Cheshire; Barnsley; and Kent.
and deliver integrated care and support by mid-2015. We recommend that the Department of Health monitor progress towards the achievement of this objective and publish by July 2015 its assessment of the extent to which each locality in England has adopted models to commission and deliver integrated care and support, together with its assessment of the strengths and weaknesses of different models and approaches in particular contexts.

23. As we discuss below, an integrated approach to health and care services is vital to the delivery of effective services to people with long-term conditions, and there will clearly be substantial overlap between the objectives of the Department of Health, NHS England and other national partners in ensuring that people with long-term conditions receive better care on a more integrated basis.

**Long-term conditions and The Mandate**


25. In respect of long-term conditions, the Government has set four objectives for NHS England in the period to March 2015:

   i. “to make measurable progress towards making the NHS among the best in Europe at supporting people with ongoing health problems to live healthily and independently, with much better control over the care they receive”28

   ii. “to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment”29

   iii. “to achieve a significant increase in the use of technology to help people manage their health and care”30, and

   iv. “to make measurable progress towards [making the diagnosis, treatment and care of people with dementia in England among the best in Europe] by March 2015, in particular ensuring timely diagnosis and the best available treatment for everyone who needs it, including support for their carers”.31

The Department told us that these were specific objectives that NHS England “must meet”.32 We note, however, that objectives ii and iii are expressed as aspirations, not as indicators which can be measured.

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29 Ibid., para 2.6

30 Ibid., para 2.7

31 Ibid. para 2.13

32 Ev 75
26. Dr Martin McShane, NHS England’s Director for improving the quality of life for people with long term conditions, explained that the development of an outcomes framework which measured progress against The Mandate’s objectives was “a work in progress”, and that it represented a shift in the focus of assessment: while a recent National Audit Office study had identified shortcomings in care processes, for example, other research had demonstrated that “benchmarked against the rest of Europe”, the NHS in England had delivered “the best outcomes for people with diabetes.” He went on to explain that

> [P]rocess is really important, but for too long we have completely disconnected it from purpose. We have not understood what the outcomes we are trying to deliver are and the measures of progress we are making. That is a huge step forward and we are probably the first country in the world to make that step.

“A whole range” of new analytical measures were now being developed, some around the annual GP Patient Survey measure of quality of life, aimed at understanding the factors which correlate with improved quality of life for people with long term conditions: “we are now starting to tease out what the measures are that we can put in place that show that doing this improves someone’s health and care.”

27. Professor Alan Silman, of Arthritis Research UK, indicated to us the advantages of this approach for some types of condition and the difficulties in adapting it to others. The outcomes-based approach might be an advantage when planning and evaluating treatment for conditions such as diabetes or high blood pressure, where the biomedical indicators of the condition were strong and relatively easily measured, but it was more difficult to set objectives and establish the desired outcomes for care planning in relation to chronic musculoskeletal conditions:

> The problem for implementing care planning for many other long-term conditions is actually understanding what it is we want to change, what it is that constitutes quality of care for patients. Then you throw into the mix, for example, the complexity that with many of these conditions people have chronic pain, fatigue and depression. What is it that we want to achieve? What are the goals that we are working towards with our patients, so that they understand the aim of their care plan? [...] There are no easy answers to [those questions], but I think they are fundamentally important for patients.

**Progress against The Mandate’s objectives**

28. Dr McShane indicated where he considered that progress had been made against three of the four objectives set for NHS England in The Mandate. On personalisation of treatment, he drew to the Committee’s attention the NHS England active presentation *Transforming Participation in Health and Care*, published in September 2013, which he
indicated was a resource to give people “authority to inform and influence their care.” He told us that NHS England was “working assiduously” on measures to track improvements in quality of treatment for patients with dementia, that the number of people who received a timely diagnosis had “vastly increased” over the past two to three years, and that all four components necessary to successful management of dementia conditions—the person, the professional, the carer and the community—were being included in policy development. The Minister of State for Health and Care Services, Norman Lamb MP, added that progress had been made on setting a specific objective for dementia diagnosis: consultation with clinical commissioning groups (CCGs) had led to the development of a “clear, measurable objective” that by 2015 two-thirds of people with dementia would receive a diagnosis.

The full set of progress indicators given to NHS England in The Mandate are set out in Figure 1. Figures for each indicator are collated by the Health and Social Care Information Centre (HSCIC) as part of the regular NHS Outcomes Framework data series. The time series for these data sets varies: some draw on established indicators, while other indicators have been newly introduced and one has not yet been established. Data for indicators 2, 2.1 and 2.4 (health-related quality of life for people with long-term conditions, the proportion of people feeling supported to manage their condition and the health-related quality of life for carers) were published for the first time only in September 2013, with a further release in February 2014. Indicator 2.6.ii, measuring the effectiveness of post-diagnosis care in sustaining independence and improving quality of life, is still in development: it is estimated that the first data will be released in 2016/17. For four of the nine outcome indicators, therefore, there are little or no data against which progress can be measured.

We note the claims made by the Department of Health and NHS England for progress against the objectives set out in the Mandate. We are nevertheless not persuaded that the claims made to us represent substantive progress against the measurable objectives given to NHS England, such as they are. The publication of a resource to assist service users in personalising their services is not in itself evidence of progress in their experience of care or improvement in their quality of life.

The intention in the Mandate and the NHS Outcomes Framework to establish measures to indicate progress in the enhancement of quality of life for people with long-term conditions is welcome. We nevertheless note that a number of these indicators are still in development or have been introduced so recently that they cannot demonstrate in any meaningful sense what progress may have been made by the NHS in increasing the quality of life for people with long-term conditions by March 2015. We recommend that in its response to this report the Department of Health should quantify the “measurable progress” it expects NHS England to have achieved against clearly specified baseline measures for all relevant Mandate objectives for long-term

38 Q237
39 Q238
Managing the care of people with long-term conditions. NHS England should similarly set out in response to this report the progress it has made against each objective against the same baseline measures together with its estimate of likely further progress by March 2015. Where such indicators and baselines are not yet available the Department should be transparent about the extent to which measurable objectives can be said to exist and consider how those objectives should be developed and modified.
Figure 1: Progress indicators for NHS England relating to Domain 2 of The Mandate (Enhancing quality of life for people with long-term conditions)

Enhancing quality of life for people with long-term conditions: Key areas where progress will be expected (Part two of the NHS Outcomes Framework)

Overarching indicator

2 Health-related quality of life for people with long-term conditions

Improvement areas:

*Ensuring people feel supported to manage their condition*

2.1 Proportion of people feeling supported to manage their condition

*Improving functional ability in people with long-term conditions*

2.2 Employment of people with long-term conditions

*Reducing time spent in hospital by people with long-term conditions*

2.3.i Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults) (Chronic ambulatory care sensitive conditions are those where the right treatment and support in the community can help prevent people needing to be admitted to hospital.)

2.3.ii Unplanned hospitalisation for asthma, diabetes and epilepsy in under 18s

*Enhancing quality of life for carers*

2.4 Health-related quality of life for carers

*Enhancing quality of life for people with mental illness*

2.5 Employment of people with mental illness

*Enhancing quality of life for people with dementia*

2.6.i Estimated diagnosis rate for people with dementia

2.6.ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life
The National Strategy for Long Term Conditions

32. In May 2012 the Department of Health issued a consultation paper on a government-wide national strategy for long-term conditions, which it aimed to publish by the end of 2012. Following the passage of the Health and Social Care Act 2012, responsibility for the provision of services for long-term conditions passed to NHS England. The Department subsequently abandoned its plans for a government-wide national strategy and transferred the work to NHS England, which has responsibility for “enhancing the quality of life for people with long-term conditions” under its mandate from the Secretary of State. As the Minister of State told us, “all of the information that had been gathered as part of the process building up to the [national] strategy [for long-term conditions] has been passed to NHS England. None of that is lost, but it does more sensibly sit under the responsibility of NHS England to map out the way forward.”

33. Martin McShane described the approach NHS England has taken to long-term conditions policy following the transfer of responsibility from the Department:

When I came into this job I discovered there were three different teams in the Department of Health addressing long-term conditions. We have set up the five [Mandate] domains and we have created cross-cutting programmes across each of the domains to support improving quality of care for people across the whole context, as I have described. If you like, my team is very small but my resources are very large. So I work in a cross-cutting way with all the other directorates in NHS England—patients and information, finance, commissioning development and operations—to make sure we have a clarity of purpose, a clarity of direction and we are focused on making those system changes.

34. He appeared clear that the former approach to national strategic planning was now redundant:

We already have published a number of documents. On the NHS England website there is the narrative around quality. We have published the narratives for each of the domains and have already started to publish some of the tools. But the traditional “Let’s publish one strategy which says how we are going to deliver long-term condition management” is not our approach. It is about how we move the whole system to ensure that people with long-term conditions get high-quality care as well as delivering changes to premature mortality and hospital care.

35. We received a number of submissions implicitly critical of the decision to abandon plans for a national strategy for long-term conditions. The British Heart Foundation wanted to ensure that the change in approach resulted in “tangible improvements for people with long-term conditions”, and stressed that the development of the new approach must be cross-governmental. Sanofi Diabetes understood the desire of NHS England to drive change locally, but called for national leadership to guide changes in approach to specific conditions. Dr Sue Roberts, Chair of Year of Care Partnerships, an NHS-based organisation promoting the use of care planning in long-term conditions care, indicated

42 Q231
43 Ev w67
that the main components of a national strategy for long-term conditions were now the responsibility of different parts of NHS England and Public Health England, and that commissioning arrangements for services to manage long-term conditions were similarly fragmented locally.\textsuperscript{44}

**NHS England’s plan to 2018/19**

36. The planning framework for NHS commissioners issued by NHS England in December 2013 entitlement the outcomes-based approach adopted in The Mandate.\textsuperscript{45} It sets out NHS England’s ambition to deliver “transformational change” for the health and care system in the five years to 2018/19. The planning document envisages “a significant shift in activity and resource from the hospital sector to the community”, and requires CCGs commissioning services in 2014/15 to make “significant progress” towards an overall target of reducing hospital emergency activity by 15% by 2018/19. Martin McShane reminded us of the significance of the planning document and the planning process in driving change in the NHS over the next five years.\textsuperscript{46}

37. The ambition which NHS England has outlined for 2018/19 is for a health and care service with six principal characteristics, all of which are relevant to service users with long-term conditions:

- Including citizens in all aspects of service design and change, and empowering patients fully in their care
- Provision of wider primary care at scale
- Modern integrated care models
- Access to urgent and emergency care of the highest quality
- Greater productivity from elective care
- Specialised services concentrated in centres of excellence

38. CCGs are required to take the lead in developing plans to implement such changes in their communities, working with local authorities and other stakeholders, and securing local agreement to their plans through health and wellbeing boards. While NHS England will not be prescriptive about how objectives are to be achieved, and will not set specific targets for individual CCGs, it will provide assurance that all plans are “sufficiently robust”. Final plans were required to be submitted by June 2014, though the incoming chief executive of NHS England, Simon Stevens, recently told the Committee that “a bit more time would probably help with that process”.\textsuperscript{47} The assurance process is designed to ensure that “both NHS England and CCGs are mutually accountable for delivering [...] improvements.” NHS England will monitor the delivery of plans, and where it has...
identified concerns about delivery it will agree or otherwise ensure “improvement actions”, using its statutory powers where necessary. 48

Planning for the future of services for long-term conditions

39. We note the disappointment in several quarters that the Department of Health has not pursued its national strategy for the management of long-term conditions. The objectives of the Department are now not being implemented through a strategy devised at the centre, but through a series of objectives which NHS England is expected to fulfil. NHS England appears to be addressing these objectives through a matrix organisational structure, seeking cooperation and communication across the organisation in order to achieve objectives, with substantial delegation of responsibilities to CCGs. The NHS England plan for 2014/15 to 2018/19 includes objectives in several areas relevant to the management of long-term conditions but does not specifically address their management.

40. We recognise that NHS England does not wish to take a prescriptive approach to the development of a national strategy for long-term conditions. There is clearly considerable overlap between the delivery of integrated health and care services and the delivery of improvements in the management of long-term conditions. We are nevertheless concerned that national policies on the commissioning and management of health and care services for 15 million people with long-term conditions are being developed without the benefit of a clear and coherent indication of how NHS England plans to meet the Government’s policy objectives in this area set out in The Mandate. On the evidence before us we find it difficult to perceive clearly how changes in services for the management of long-term conditions are being commissioned, structured, delivered or monitored.

41. We note that the original plan to develop a national strategy for long-term conditions was explicitly cross-government in its perspective and involved participants from 12 Government departments. 49 This attempt to develop a joined-up, government-wide approach to the management of long-term conditions has been dropped following the transfer of policy responsibility from the Department of Health to NHS England. The Department and NHS England should clarify how cross-departmental working is to be continued in the absence of a cross-Government strategy.

42. We are concerned that the growth in demand arising from long-term conditions and associated patterns of co-morbidity has not been matched by the urgency with which the Department of Health and NHS England have developed their strategic responses. This finding is of particular concern since the long-term conditions agenda lay at the heart of the Nicholson Challenge to achieve transformative change in the delivery of health and care services. We recommend that in its response to this report NHS England set out clearly:

48 Everyone Counts, p. 40

49 The 12 departments which participated in the cross-Government group established to develop the strategy were the Department of Health, the Department for Work and Pensions, the Department for Communities and Local Government, the Department for Education, the Home Office, the Ministry of Justice, the Department for Environment, Food and Rural Affairs, the Cabinet Office, the Department for Transport, the Department for Culture, Media and Sport, the Department for Energy and Climate Change and the Department for Business, Innovation and Skills.
• the changes it considers necessary to better support people with long-term conditions;
• the strategic objectives such changes are meant to fulfil;
• the plan it has devised for achieving such changes;
• the steps to be taken to engage other relevant Government departments in the delivery of such changes, and
• the milestones it has set for delivery.

43. The Secretary of State should publish, as part of his response to this report, a statement of the changes the Government would wish to see incorporated into the next refresh of the Mandate in respect of long-term conditions, including a statement of the urgency he attaches to their delivery.

44. We further recommend that NHS England report to the House by October 2014 at the latest on the outcome of its 2014 planning round, setting out in detail its assessment of the aggregate effect on the health economy of England and of each NHS England area of the local plans made by each clinical commissioning group.
3 Clinical care for people with long-term conditions

Treating the person, not the condition

45. The Department’s definition of a long-term condition is “a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies”.50 The definition on the face of it provides a satisfactory means of categorising a class of conditions which are not curable but are not of themselves terminal. Those diagnosed with such conditions are likely to need support or intervention from health and care services to varying degrees in order to carry on a reasonably fulfilling life.

46. Though we did not receive any evidence to suggest that this definition was inadequate, we received a representation which challenged the way in which the categorisation was presently applied. Macmillan Cancer Research told us that cancer, which did not appear to fall within the Department’s definition of long-term conditions, should be considered a long-term condition by virtue of the long-term physical and emotional effects on those who had undergone and were recovering from the disease and its treatment: it had been estimated that between 20 and 25% of those treated for cancer were currently experiencing a consequence of cancer and its treatment which had an adverse impact on the quality of their life.51

47. The Department’s definition does not appear to cover conditions which significantly affect quality of life and for which there is little immediate prospect of recovery. The Royal College of General Practitioners suggested that a working definition was bound to be subjective:

As with many concepts in healthcare, there are likely to be many different interpretations of what constitutes a long-term condition. Ultimately, the best means of defining what is and isn’t a long-term condition, and making decisions about care requirements, is as part of a conversation between an individual and their doctor (usually a GP).

For example, those who have used tranquillisers and sleeping tablets following medical advice and prescription, and have as a consequence developed an involuntary dependency which severely affects their quality of life, might be considered to have developed a long-term condition requiring support or intervention from publicly-funded health and care services.

Multimorbidities and long-term conditions

48. Added to challenges of definition and recognition is the increasing issue of patients presenting with more than one long-term condition, a difficulty exacerbated by the
susceptibility of those diagnosed with such multimorbidities to develop mental health conditions requiring treatment alongside the physical ones.

49. The Department of Health and NHS England in their memorandum recognised the prevalence of multimorbidities and the consequent challenge to the present model of provision of health and care services:

Patients should not be seen as diagnoses or collections of conditions but as people living with these conditions. Increasingly people have co-morbidities, requiring input from a number of different health and care professionals; the health and care system needs to be geared up to support the whole person, considering their needs within an holistic context. This approach requires support from a wide range of stakeholders as it is a fundamental shift in emphasis from a disease focussed to a person centred system.52

Clinical decision-making is more difficult in people with multi-morbidity because clinicians and patients often struggle to balance the benefits and risks of multiple recommended treatments (the use of polypharmacy in people with long-term conditions brings accordant risk of medication errors and resulting injury or death), and also because patient preference rightly influences the application of clinical and economic evidence. The majority of people with one LTC have more than one, and individual levels of disability may vary irrespective of the number of co-morbidities identified (and the severity of illness). Recognising this variation in need is key to the delivery of personalised care.53

50. A common theme in the evidence we received was the lack of coordination in the health and care system experienced by people with more than one condition, a difficulty multiplied by the development of further comorbidities. As the British Heart Foundation (BHF) put it:

People with long-term conditions, such as heart disease, often have numerous, confusing and uncoordinated interactions with the health system and social care systems. Typical problems include dealing with a range of different healthcare professionals who do not have access to existing medical records or other information, poorly scheduled appointments and a lack of clarity about who to contact for advice and support.54

The BHF provided in its evidence two “webs of care” based on the experience of two service users with several morbidities, indicating how they have interacted with different services related to their care. The two diagrams, reproduced at Figures 2 and 3 below, illustrate “the complexity of different services that patients are required to navigate.”55

51. Professor Nigel Mathers, Vice-Chair of the Royal College of General Practitioners, identified the issue of multimorbidity as one which needed to be addressed as a priority:

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52 Ev 77
53 Ibid.
54 Ev w10
55 Ibid. The “webs of care” are reproduced at Ev w 13-15.
“all the NICE guidelines, all the pathways, are designed for people allegedly with only one condition, but most people have multiple conditions.”56 Dr Peter Fisher, of the Royal London Hospital for Integrated Medicine, suggested that the “single-disease framework”, where medical professionals specialised in the treatment of one condition, had been successful in eliminating several diseases, but was less successful in the management of people with more than one condition. He observed that once single conditions were treated “we are left with a large residue of interlinked, complex, multiple diseases where you need to treat the person, not the disease.” Professor George Lewith, of the University of Southampton, put this in context: “we have hospitals that are designed to cure specific conditions and they are full of old people with multimorbidity on polypharmacy.”57
Figure 2: Care pathway of “Patient A”
Figure 3: Care pathway of “Patient B”
52. In their joint memorandum, Dr Fisher and Professor Lewith argued that NHS was “weak” in the treatment of multimorbidity, which they considered to be highly prevalent. They stated that NHS secondary care services were often specialised and provided for little holistic overview of the patient. Multimorbidity, they argued, was frequently compounded by polypharmacy—the prescription of multiple medications—which was in turn frequently associated with adverse drug reactions. They stated that 50% of UK care home residents took six or more drugs daily, with an attendant high risk of adverse drug reaction. There was a risk that the fragmentation of clinical care for patients with multimorbidities through the delivery of separate specialist services might result in lack of awareness of drugs prescribed by different doctors.58

53. Recent research connected with the development of an integration project in South Somerset has attempted to quantify the extent of chronic conditions—many of which are long-term conditions—and comorbidities in the local population. In a dataset recording the health characteristics of 114,872 residents, the population was found to have on average 4 recognised conditions each, of which on average one was a chronic condition. Just over half the population (58,360, or 50.7%) had no chronic conditions; 14,056 (12.2%) had two and 13,009 (11.3%) had three or more. 49 separate chronic conditions were identified in the population: almost 16% of the population had a diagnosis of hypertension, and 10% had asthma. Many of the conditions identified were experienced by less than 1% of the population.59 The dataset indicates 7,605 unique combinations of chronic conditions among the population, and indicates the prevalence of multimorbidities. Of the 1,294 diagnosed with a mental health condition, for example, 1,052 (81.3%) had at least one other chronic condition. 693 (82.5%) of the 840 individuals with adult rheumatoid arthritis had at least one other chronic condition.60 The study found that for those with asthma and diabetes, hospital costs accounted for the largest proportion of costs, while costs for those with dementia occurred mostly in social care, mental health care and community care settings. For the population as a whole, the costs of health and social care were driven more by an individual's morbidity profile than by their age.61

54. Dr Peter Aitken, Chair of the Faculty of Liaison Psychiatry at the Royal College of Psychiatrists, described the difficulties facing the clinician trying to manage the care for a patient with multiple morbidities, and indicated how an approach to planning the care of those with multimorbidities worked:

I will give you an example of a multidisciplinary meeting happening in a general hospital setting, which is what I do day in, day out. Our patient will have multiple things wrong with them and we will be having a discussion: "What is it you want to be able to do? Let us bring in our experts from cancer care, diabetes or from heart disease, and let us have a conversation, because this is pretty tricky.”

58 Ev 83-84
60 Ibid., p. 7
61 Ibid., p.ii
We have an evidence base for these disease states but we do not have a particularly secure evidence base for what happens when these things occur together. Each of these disease states might be treated with medicine according to NICE guidance, and there might be particular therapeutic approaches that each would choose to take, but when they all occur together in the one individual there will be some trades. The care planning meeting is the trading discussion where the risks of one course of action versus another are traded out. That is why the expertise is essential. This is not protocolised care. This is the grey area with protocolised care, where you have to make a judgment. If I give you this medication, it is going to prolong the heart rhythm in a way that puts you at risk of a heart attack or dropping dead; or, if I do this, it is more likely to increase your risk of stroke.

It is finding that balance and then agreeing that this is the way forward to help you get to where you need to be. The communication with the general practitioner then becomes absolutely pivotal. We have done that piece of work and used up that time. How do you then communicate the essence of that to the absolutely busy primary care physician and their team, so that they can support that work going forward?  

55. Dr Karen Lowton, of King’s College London, indicated that advances in the treatment of certain childhood conditions formerly considered terminal had led to the emergence of “new” ageing populations (NAPs), defined as “those born with serious health conditions who did not previously survive to adulthood and those developing previously life-limiting conditions in early or mid-life who are now more likely to reach mid- to late-adult life”:

Successful early intervention, ongoing treatment, and ageing processes for those with previously lifelimiting conditions, has resulted in complex conditions, co-morbidities, and LTCs of NAPs. One prominent example of this phenomenon is highly active antiretroviral therapy (HAART) for those with HIV infection.

These populations included adults with cystic fibrosis, congenital heart disease, childhood liver disease, cerebral palsy, human immunodeficiency virus, and Down’s syndrome. Dr Lowton indicated that as they aged they also began to experience many of the long-term conditions found among the older population, but at a much earlier age: people with rare childhood diseases were now more likely to experience both their underlying rare condition and acquired long-term conditions as they grew older.

Our view

56. We concur with the Department of Health’s view that patients should not be seen as diagnoses or collections of conditions but as people living with these conditions. It nevertheless seems to us that the Department’s own definition of a long-term condition may undermine attempts to introduce a whole-person approach to the management of long-term conditions.

62 Q106
63 Ev 96
64 Ibid.
57. We note the evidence we have received on the state of the evidence base for polypharmacy. It should be a matter of some concern that patients with multiple morbidities are being prescribed several medications to manage their conditions, in many cases without a secure understanding of how these medicines may interact. The inappropriate prescription of multiple medications, or the prescription of multiple medications which do not achieve the desired effect, has been defined as “problematic polypharmacy” in a recent research paper by The King’s Fund. The evidence base for polypharmacy could be strengthened by the routine inclusion of patients with polypharmacy and multiple morbidities in clinical trials. We recommend that in revising its current clinical guidelines and developing further guidelines the National Institute for Health and Care Excellence should routinely take into account the incidence of multiple morbidities and the attendant risks of polypharmacy.

58. The definition of long-term conditions which the Department of Health has chosen to use is a perfectly serviceable categorisation of medical conditions by reference to their effect on the quality of life of the person with the condition. The evidence we have received nevertheless suggests that it does not adequately capture the complexity of care required by many people with one or more conditions who have no immediate prospect of recovery and require support from perhaps many different sources in managing their health and care. The increasing proportion of people with more than one physical or mental health condition complicates the treatment landscape and requires a move away from the single-disease model which the Department’s definition seems to represent. Advances in the treatment of many conditions have had the relatively happy effect of turning them from terminal conditions into long-term conditions, but has also increased the complexity of the support required from the health and care system to help those with long-term conditions live productive and fulfilling lives. This objective is now recognised in the outcomes which the Secretary of State requires from the health and care system’s support for those with long-term conditions. We consider that the working definition of a long-term condition used by the Department should follow suit.

59. The objective of the health and care system in treating people with long-term conditions should be to improve the quality of life of the person. At a time when increasing numbers of people requiring support and treatment from the system have multiple conditions combining physical health, mental health, social care and other support requirements, it seems anachronistic that the Department’s definition of long-term conditions appears to emphasise a single-disease approach to treatment. We recommend that the Department revise its working definition of long-term conditions to emphasise the policy objective of treating the person, not the condition, and of treating the person with multiple conditions as a whole.

Present arrangements for management of long-term conditions

60. The fragmented nature of the health and social care system supporting people with long-term conditions is well known, but is worth describing again here. Professor Alan Maynard summed it up as follows:

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65 M. Duerden, T. Avery, R Payne, Polypharmacy and medicines optimisation: making it safe and sound, The King’s Fund, December 2013
Health and social care production is fragmented into the silos of primary care, acute care (now commissioned by two organisations, specialist care by NHS England, and non-specialist acute care by CCGs), social care (provided by local authorities (LAs), CCGs and the voluntary sector) and public health (also provided by LAs and CCGs). These silos are insulated by incentives which support the resources, power and income of providers rather than enhancing collaboration and exploitation of economies of scale to advantage the patient and the taxpayer.66

We examine below aspects of the functioning of the present system about which concerns were raised in evidence. Given the substantial number of people with diabetes, both diagnosed and undiagnosed, and the proportion of the healthcare budget spent on diabetes services, we were keen to examine in particular the provision of health and care services for diabetics. We summarise below the evidence we received about present arrangements for managing diabetes care, much of which illustrates broader concerns about the overall structure and functioning of the present system.

**Long-term conditions and NHS payment and incentive structures**

61. We heard that the present operation of payment and incentive frameworks for healthcare could act to disadvantage those diagnosed with particular conditions where the clinical requirements of care for the condition were not adequately recognised. Dr Sue Roberts told us that in the context of general practice highly common musculoskeletal conditions were not properly recognised within the incentive structure of the Quality and Outcomes Framework (QOF) for general practice: “[they] are not really QOF conditions and get lost.”67 The National Ankylosing Spondylitis Society contended that ankylosing spondylitis and many other musculoskeletal disorders fell within the Department’s definition of long-term conditions but had historically not been treated as such by primary care trusts.68 Arthritis Research UK acknowledged that rheumatoid arthritis as a condition had been introduced to the QOF for the first time in 2013-14, and that as a consequence GPs would be incentivised to ensure that patients had an annual face-to-face review: such a review might “provide an important opportunity to systematically integrate care planning conversations for people with rheumatoid arthritis.”69

62. Dr Martin McShane, of NHS England, admitted that present structural incentives in the health and care system did not necessarily ensure the best care for people with long-term conditions:

> In part, some of the incentives and financial incentives in the system, which are brilliant for planned care, just don’t work for long-term condition management. Competition and choice is great for planned care, but long-term conditions demand integrated care and that requires a new dynamic.70

66 Ev 99

67 Q26

68 Ev w89

69 Ev 103

70 Q275
Managing the care of people with long–term conditions

Long-term conditions in community care

63. We received considerable evidence indicating deficiencies in services to support those with long-term conditions in community settings. One submission, from the MND Association, representing those with motor neurone disease, catalogued the inadequacy of neurological support services available in many areas:

The problems reported by people with MND in respect of their support at home are myriad. A lack of care plans, integrated care or specialist nurses may be the issue; alternatively, respite care may not be available, placing huge burdens on regular carers; community support workers (nurses or social workers) may not be trained in helping people to manage non-invasive ventilation (NIV) or a gastrostomy (PEG, PIG or RIG); a stay in hospital to fit a PEG, for instance, might be prolonged by the absence of a social care package to allow the person to be discharged safely; specialised equipment for mobility, communication and environmental control may be provided or modified far too slowly, leaving the individual at risk, for instance, of falls. Provision of all of these things is hugely variable across England, although the low prevalence of MND and the highly localised nature of provision makes quantifying the impact of any individual one of these very hard.71

64. The MND Association argued that with appropriate support, including home modifications and respite care, people with MND could “usually be cared for most appropriately in the home”.72 They noted that although annual expenditure on neurological services had increased by 37% in real terms between 2006/07 and 2009/10 (from £2.1bn to £2.9bn), a National Audit Office study had shown that unplanned admissions of people with MND to hospital had been rising at above the rate of increase for the NHS as a whole (31% from 2004/05 to 2009/10 compared to 20% for all unplanned admissions): this was seen as evidence of the deficiencies in community services to support those with MND at home. They argued that the costs associated with such increases could be saved by “more effective investment in caring for people with MND in the home.”73

65. Several other submissions to the inquiry pointed out that rates of hospital admission for treatment of certain long-term conditions were increasing, and suggested that with appropriate prior support in the community such admissions would be unnecessary.

Managing the care of people with diabetes

66. The National Audit Office has estimated that in 2009-10 there were 3.1 million people aged 16 years and older with type 1 or type 2 diabetes in England, of whom 2.34 million were diagnosed and 760,000 were undiagnosed. It estimated that NHS spending on diabetes services in that year was at least £3.9 billion, or around 4% of the NHS budget.74

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71 Ev w53
72 Ev w53
73 Ibid.
74 National Audit Office, The management of adult diabetes services in the NHS, HC (2012-13) 21, para 1. 10% of those in the UK with diabetes have Type 1 diabetes, where the body cannot produce any insulin. It is not preventable, and is treated by daily doses of insulin. In Type 2 diabetes, the body does not produce enough insulin or the insulin produced does not work properly. It can be treated through a healthy diet and increased physical activity, though tablets and/or insulin may also be required.
Other estimates have put the total NHS expenditure on the condition as high as £10 billion annually, or roughly 10% of NHS England’s annual budget for commissioning services: indirect societal and productivity costs have been estimated at a further £13.9 billion.\(^75\)

**The mix of service responsibilities for diabetes care**

67. The prevailing orthodoxy about the service mix required for those with long-term conditions appears to favour a transfer of services from acute care to primary and community care. ADASS and the Local Government Association told us that there are “strong and widely acknowledged arguments for disinvesting from acute services and reinvesting into community settings.”\(^76\) The experience of provision of diabetes services suggests that in fact the optimal service mix requires participation from all care settings but within a different balance of provision.

68. The evidence we received indicated that the mix of services for diabetes care in England was not structured to provide the best and most effective care to all people with diabetes. The Association of British Clinical Diabetologists (ABCD) argued that routine diabetes care in the UK in general was principally delivered through practice nurses in primary care GP practices. ABCD considered this arrangement “inappropriate” for a number of reasons, chief among which were the perceived lack of specialist training for practice nurses in diabetes care and the fact that practices tended to work in isolation.\(^77\) ABCD attributed the decline in diabetes treatment in the acute sector to a number of factors, including the willingness of specialist teams to work outside hospital settings, the introduction of a Payment by Results tariff which required payment for referrals to specialist care, and the development of a structure under the Quality and Outcomes Framework which incentivised the treatment of diabetes in primary care.

69. Diabetes UK stressed to us that people with diabetes needed their care to be commissioned through integrated pathways covering primary, community and secondary care services. Access to specialist secondary care was vital, and it was recommended that those with type 1 diabetes (i.e. those who produce no insulin) should have their support coordinated from secondary care.\(^78\) ABCD suggested that routine diabetes care in the secondary or hospital sector was now less common than it had been before the 1990s.\(^79\) The result of this shift in services was an effective limitation on the number of diabetes patients treated in the acute sector: ABCD indicated that between 10 and 30% of such patients were now treated in hospital, and referrals for treatment tended to occur later in the disease process, when complications less amenable to treatment may have developed.

70. Diabetes UK also indicated that while access to specialist secondary care was necessary, primary and community care services should also receive greater skills in diabetes treatment and focus on the coordination of care, strategies to prevent diabetes developing,

\(^{75}\) Ev 105 (Diabetes UK), citing Hex et al. “Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs”, *Diabetic Medicine*, vol. 29 issue 7 (July 2010), pp 855-862

\(^{76}\) Ev w54

\(^{77}\) Ev w68-70

\(^{78}\) Ev 106

\(^{79}\) Ev w68-70
structuring management for those with chronic conditions, educating those with diabetes and planning care to support those with diabetes to manage their own condition. Secondary care services should improve the specialist treatment offered to inpatients in order to reduce the length of stay in acute hospitals. ABCD argued for “a considerable expansion” of staffing in primary care to allow adequate care planning for diabetes patients, and for the designing and commissioning of interfaces between diabetes specialist teams in secondary care and those in primary care treating diabetes patients: such collaborations were made more difficult by “the hardening of the organisational and financial barriers in the modern NHS”.81

71. Baroness Young of Old Scone, Chief Executive of Diabetes UK, described to us her view of how primary care should operate to put the diabetes patient at the centre of any annual care planning meeting with a GP. She envisaged that prior to any care planning meeting the patient should be provided with information about the results of any relevant tests carried out, indicating, for instance, levels of cholesterol, blood sugar and blood pressure. At the annual care planning meeting—a consultation rather longer than the standard GP consultation slot—the GP and the patient would discuss the information provided by the tests, any issues raised by the patient and any observations made by the GP, in order to draw up a care plan for the coming year. These arrangements had been trialled in the “Year of Care” pilots which we discuss at greater length below. Baroness Young told us that

The pilots demonstrated that by doing [the care planning consultation], at the same cost, even though the up-front process was more expensive because it took longer, you could reduce the number of visits to the GP that the patient had as they felt more confident about their care because there was a care plan in place and the practice nurse was able to take that forward, and also [. . .] it would—it could reduce the number of patients being propelled into crisis where they then have to go for secondary care.82

Diabetes services in primary and community care

72. Diabetes UK indicated where primary and community care services should be strengthened to reduce the need for hospital admissions. Public awareness campaigns and full implementation of NHS Health Checks could lead to earlier diagnosis and reduce the number of those diagnosed with diabetes who have already developed complications. NICE guidelines recommend structured education for those with diabetes to assist them in managing their condition, though a 2012 Diabetes UK survey had found that nearly one third of those asked had never been offered structured education, and in some primary care trusts no-one had attended structured education courses.83
73. Diabetes UK noted that an estimated 95% of diabetes care was self-management.\textsuperscript{84} Baroness Young told us that it was difficult to estimate how many people were receiving structured education in self-management, but it was clear that many people were receiving no help at all in the day-to-day management of their condition. She cited evidence that expenditure on education and self-management for those with type 1 diabetes would break even after four years and then begin to deliver cost savings. While Diabetes UK had not yet found a means of providing self-management education to those with type 2 diabetes in a way which produced savings, all studies had found such education to be cost-effective.\textsuperscript{85}

74. The National Institute of Health and Care Excellence (NICE) recommends that all those with diabetes have a programme of nine tests annually to ensure that their condition is being controlled. The checks are designed to give early warning of avoidable diabetic complications. Diabetes UK reports that only one third of adults with type 1 diabetes and half of those with type 2 diabetes are receiving all the recommended annual tests in primary care or community care: they also report wide variations in the proportion of people in geographical areas who receive all checks, from as little as 14% in some places up to 71% in others.\textsuperscript{86} Diabetes UK recommends that the checks are made available to all people with diabetes through annual care planning reviews, and that the results of such checks are used to ensure effective treatment and support self-management, ideally through an integrated care pathway.\textsuperscript{87} MSD-UK pointed out that action should be taken on the results of all checks to ensure that people’s long-term condition and risk-factors were being managed effectively: for example, although 90% of people with diabetes were receiving an annual test for glycated haemoglobin levels (HbA1c, a measure of blood sugar) and cholesterol, only 60% of those tested were achieving target levels of glycated haemoglobin and only 40% were achieving target cholesterol levels.\textsuperscript{88} MSD-UK considered that quality measures and outcome indicators throughout the system, such as CCG outcome indicators, should be designed to reflect effective management of long-term conditions.

75. The Society of Chiropodists and Podiatrists stressed that every diabetes care pathway should include services to prevent and manage foot disease in people with diabetes: foot complications accounted for more hospital admissions than any other diabetes complication, and 80% of such amputations were preventable.\textsuperscript{89} The Society indicated that the variation in rates of foot amputation arising from diabetes complications varied tenfold across commissioning organisations in England, from 0.3 per thousand to 3.5 per thousand, and that this variation had been correlated to the structure of available specialist services.

\textsuperscript{84} Ibid. 
\textsuperscript{85} Q80 
\textsuperscript{86} Ev 106, para 2.5 
\textsuperscript{87} Ev 106, para 2.6 
\textsuperscript{88} Ev w51 
\textsuperscript{89} Ev w86
Keeping diabetes patients out of secondary and social care

76. Baroness Young thought that three principal elements of the health and care system “really helped” to reduce hospital admissions, namely good GPs and practice nurses, the availability of specialist advice (over the phone or in person) from doctors and nurses to those in primary or community care, and the availability of skills to assist patients in managing their own conditions.90 Furthermore, she was concerned that health systems for the treatment of diabetes should be joined up, to address the needs of people with diabetes long before they had any social care needs: she recommended an integration of health systems to ensure early diagnosis and proper risk assessment of people with diabetes, and the fulfilment each year of the programme of recommended checks, to prevent those with diabetes from getting to the point where they might need social care.91

Diabetes specialist nurses

77. Baroness Young stressed the importance of diabetes specialist nurses in both secondary and primary care. In secondary care, a specialist diabetes inpatient nurse is important in ensuring that patients receive good care and prompt discharges. In community and primary care settings, a diabetes specialist nurse assists other healthcare professionals as much as patients: a specialist nurse will train and support GPs and practice nurses as well as providing advice and support to diabetes patients, often over the phone. Such nurses were considered important to an integrated service, not least because they could give support and advice which would prevent the need for expensive secondary interventions.92 Diabetes UK was concerned at the apparent downgrading of the role of diabetes specialist nurses, in common with other nurse specialisms, and also had concerns at the number of unfilled vacancies for diabetes specialist nurses. Baroness Young advocates the development of a standard accreditation process for diabetes specialist nurse training.93

Diabetes and multiple morbidities

78. ABCD told us that patients with diabetes commonly had multiple morbidities, including ischaemic heart disease, heart failure, kidney failure, peripheral vascular disease, advanced eye disease and complications leading to foot or leg amputations. Although diabetes specialists still tended to have a commitment to generalism, rather than specialising in a single organ system, the present structure of the healthcare system constrained their work patterns.94 While GPs were overwhelmingly generalist, specialist care was organ- or system- specific, resulting in patients with multimorbidities receiving referrals out from the GP to individual specialists with little coordination of care. As a result the care pathway for a patient with multimorbidities “resembles a cricket batsman’s stroke pattern rather than a smooth continuum”, and should be made simpler from the point of view of the patient: the patient with diabetes and comorbidities would prefer to
have conditions treated through a single point of reference. This would require a change in NHS structures to integrate care and provide teams operating between primary care, social services and secondary care.

79. According to ABCD, the NHS is not “optimally structured” to treat patients with multiple morbidities in the community: GPs had undertaken this role but now found it more difficult because of increasing complexities in treatment and increasing pressures on primary care. Complex conditions should ideally be managed by a team of healthcare professionals working within an organisation which can bridge all current functions being provided in primary, secondary and community care: ABCD recommended that for diabetes such a team should include a diabetes consultant and should be connected with social care services, services to treat the comorbidities and acute care services in the event that conditions required complex investigation in hospital.

Our view

80. The evidence we have taken on managing the care of people with diabetes as a long-term condition has highlighted a number of issues common to the treatment of many long-term conditions. The optimal mix of services for treatment of diabetes patients requires a rebalancing of provision across care settings, with commissioning pathways running in an integrated way through primary, community and secondary care and with access to specialist secondary care services where necessary. People with diabetes should receive more effective support in self-management, while earlier intervention and support from primary and community care services can reduce the incidence of complications from diabetes and reduce the demand for acute and specialist services. In many cases this support can best be delivered through specialist nurses, whose expertise is key to the effective operation of diabetes services in both primary and secondary care. The evidence the Committee has taken on diabetes services demonstrates the need for a general rebalancing of commissioning and care pathways for long-term conditions. These should provide treatment which is integrated across primary, community, secondary and social care settings. We recognise the benefits to the patient and to the health and care system of robust support for self-management of long-term conditions.

81. We view with concern reports of apparent downgrading of the role of, and reductions in the numbers of, specialist nurses. Their expertise is vital in supporting an integrated system of care for diabetes, from self-management through to acute and specialist services.

Delivering integrated care centred on the person

82. The Department and NHS England set out in their memorandum their policy on promoting person-centred care for people with long-term conditions:

The NHS will promote and support:

- The use of evidence based assessment and holistic care planning across multi-disciplinary teams;
• Proactive identification of people at risk, or with additional LTCs, to encourage improved management;

• The deployment of staff skilled in motivational interviewing, shared decision making and the promotion of effective self-care, and the use of technology where appropriate such as telehealth and telecare;

• Integrated teams that work effectively together without the constraints of professional or organisational boundaries;

• The use of advanced care planning as a tool to reduce avoidable admissions and to enable more people to die at home.

NHS England will support the piloting of personalised, participative care planning, and learning from these pilots will be shared with CCGs and will contribute to the evidence base regarding the management of people living with multi-morbidities.

83. Don Redding of National Voices, the body which represents some 130 charities working for service users, explained to us the narrative, developed by National Voices and others and adopted by all national leaders of health and care systems, which defined integrated care as being about co-ordinated care centred on the person.95 He observed that the “realisation and understanding” of the need for coordinated care built around the person was “penetrating quite rapidly” round the health and care system, though he feared that while services were being joined up and coordinated, the restructuring risked losing sight of the service user:

[...S]ystem leaders own the pieces on the board—the services, the professionals, the budgets and so on—and they feel that if they can configure them a different way around the person it will be better. [...]ervice users, people who are trying to self-manage or trying to live with disabilities or chronic conditions [...] are saying that [this approach] falls short because it does not understand that this is about “me being able to take some control, set the goals and determine the direction of care and support that I receive”.96

**Person-centred care: the Year of Care approach**

84. Dr Sue Roberts, chair of the Year of Care Partnerships, described to us a delivery system intended to bring together current expertise and experience of care for people with long-term conditions into a “practical, reproducible and transferable approach to providing better services and better support for people and their families who live day to day with these conditions.”97 The proposed system had been designed around personalised care planning and integrated care services, and relied upon a change in the culture of long-term conditions care to drive changes in the system for delivering long-term conditions care.98 It offered “a starting point for a ‘new deal’ for people with LTCs built on a new

95 Q117
96 Ibid.
97 Ev 85
98 Ibid.
relationship between the individual and the healthcare professional and better use of primary and community care resources.”

85. The delivery system had been developed from the Year of Care pilot programmes sponsored by the Department of Health which ran from 2007 to 2010. They had trialled new approaches for long-term conditions care in three communities, using diabetes as an exemplar. Dr Roberts claimed that

The approach puts people with LTCs firmly in the driving seat of their care and supports them to self-manage. It transforms what is often ‘tick box’ care encouraged by the QOF system into a constructive and meaningful dialogue between the healthcare professional and the person with diabetes.

The delivery system had been designed to adapt to the circumstances of people with other long-term conditions. Its main features were:

- A collaborative care planning consultation between the individual and the health professional on all the individual’s health issues, involving shared decision-making and support for the individual to identify goals, actions and needs for information.
- “Social prescribing” services to direct individuals to the local services they needed to support the goals and actions identified; these services might include telehealth services.
- The coordination or integration of any additional clinical and social care support required from multidisciplinary teams.

The House of Care model

86. Dr Roberts explained that the delivery system—a “new way of working”—could not operate “within the current constraints of time, clinic organisation and workforce design.” The concept of a “House of Care” had been developed to represent the issues to be addressed by those who wanted to adopt the new methods of working with people with long-term conditions. The House of Care—in effect a series of checklists indicating the requirements for successful delivery—is ‘built’ around the care required for the individual. Four components are required for the model to operate: informed and empowered patients and carers, healthcare professionals committed to working in partnership, the commissioning of appropriate services and the operation of the organisational and clinical processes necessary for successful treatment.

87. The model, if adequately implemented, should lead to care planning principles which are embedded in local practice and sustainable. Dr Roberts explained that a training
programme developed to educate health and care professionals in “building the house” was intended to develop the new skills required and to challenge attitudes towards care for people with long-term conditions. In essence, it enabled the tenets of personalised care planning to be inculcated in health and care professionals in a way which could be transferred to other health communities and used to treat those with other single or multiple long-term conditions.  

Figure 4: The House of Care approach to providing health and care services to manage long-term conditions

Source: The House of Care: Planning services at national, local, and personal levels for people with long-term conditions, NHS England, February 2014

105 Ibid.
88. Liz McAnulty, a trustee of The Patients Association, recognised the usefulness of the conceptual framework of the “house of care” and thought that the idea was good: she nevertheless reminded us that models of person-centred care had been devised before which had not necessarily delivered what was expected. She acknowledged that some patients were reporting improvements in care from more integrated services in certain areas, but reminded us that the challenge of implementation lay in system leadership: “the leaders who pull it all together”.\textsuperscript{106} She gave practical examples of the change required in health and care services to make them genuinely patient-centred: services opening in evenings or at weekends to enable more people to use them; easier procedures for securing an appointment with a GP, and consultations lasting longer than the standard 10 minutes, during which patients with multiple conditions would be able to discuss all the conditions they wished with their GP.\textsuperscript{107}

89. Don Redding stressed that the “foundation” of the House of Care approach was the commissioning of services required to support the care of individuals with long-term conditions, the mix of which would vary from individual to individual:

\[...P\]eople are going to need to put in place, as a result of [a] care planning conversation, a menu of things that range from the specialists, who know their specialist bits of care [...] through to what happens with their home care, for instance, and what happens with the allied professionals who are working with them [...] If somebody’s own goal is [...] “I want to be more active and I want to be out in the community more, because I have lost that”, then you need places to [...] refer them to which are nothing to do with medical knowledge necessarily but which are community support.\textsuperscript{108}

The commissioners need to be able to commission not just the integrated diabetes pathway but a menu of support that enables people to achieve the goals that they would set for themselves which are around not just health but well-being.\textsuperscript{109}

**Care planning: general principles and specific conditions**

90. While Baroness Young of Diabetes UK supported the concept of care planning, she reminded us that the “house of care” approach had originally been developed to demonstrate the changes in primary care required in order to be able to undertake care planning for diabetes successfully and on a cost-neutral basis.\textsuperscript{110} Now that the “house of care” was being applied to care planning for people with other single conditions, and those with multimorbidities, she was concerned that the design of a generic approach should not override the specific care requirements of particular conditions:

If a patient has multiple morbidities, planning for their particular care means that account has to be taken of their multiple morbidities. The one anxiety we have about

\textsuperscript{106} Q122  
\textsuperscript{107} Q123  
\textsuperscript{108} Q124  
\textsuperscript{109} ibid.  
\textsuperscript{110} Q97
the whole comorbidities debate at the moment is what I call grey goo. If you are not careful, you work at such a level of abstraction of principles, because that is the only thing that is in common between different conditions, that you end up losing the very specific focus on the distinct things that individual conditions need. In the case of people with diabetes, it is very much education for self-management, the 15 essential care measures that they need to have delivered every year and access to specialist care at the point that it is required.\(^\text{111}\)

We need to be very clear about what are the things that are generic and span all the conditions and the particular things that individual conditions require. That makes it quite difficult in terms of the leadership of the whole process. The general practitioner and the practice nurse are going to be very important, but where does specialist input come from? How do we make sure in that process that there is enough specialist input, and also that the individual GP and practice nurse are well enough trained in a range of conditions to be able to do that planning exercise effectively, and then the subsequent implementation in support of it? I do not think we are yet at the bottom of that, of being able to understand what the art of the possible is in terms of the balance between generic skills and specialist skills. That, in my view, is what needs to be sorted.\(^\text{112}\)

91. Dr Peter Aitken explained the requirements for successful care planning for people with single conditions and multimorbidities alike:

There are two critical ingredients to it. One is having the specialist resource available to input in a genuine multi-professional way. The multidisciplinary team has to be real; it cannot be all the same kind of practitioner at the same sort of level, which is often part of the constraint of budget. It has to be people with expertise genuinely working together to help the person make sense of what they are trying to do.

The second key ingredient is time. Effective care planning takes an hour plus. It is not something that the GP can achieve in an eight-minute consultation in a surgery. When we are resourcing for mental health and for care planning around long-term conditions, my plea would be, “We need a currency that values time.” That time needs to be costed, to be understood—and it may need to be protected, because what happens under the pressure of constrained resource is that you get skill diminishing, grade deflation and a reduction in time. People will say, “We think that you can do this with lower-grade staff, and we think that you can do it in 20 minutes.” Without a robust dataset to say, “No, it needs to be 89 minutes, because that is the level of conversation that delivers the outcome benefit that we seek”—until we have data that can defend time—we are all going to find it rather difficult to defend the multidisciplinary environment and the skill mix required to do it properly.\(^\text{113}\)

92. Professor Alan Silman, of Arthritis Research UK, and Baroness Young disagreed on the scope of care planning for people with multimorbidities. Professor Silman suggested that a

\(^{111}\) Ibid.\(^{112}\) Q98\(^{113}\) Q99
care plan for the patient “in the multi-morbid environment” could take account of all their conditions, including any psychological and psychiatric conditions, while accepting that some conditions could not be addressed adequately through care planning. Baroness Young thought that many patients would have a “primary anxiety” which would govern how they wished their conditions to be managed: in effect, they would determine their own priorities for treatment. Care planning would only be effective, she argued, if GPs and others in primary care had the skills to deal with specific conditions:

What remains to be seen is how effectively we can skill up primary care to be able to deal with the comparatively fine grain of several primary conditions, because care planning will be no good to man or beast if it does not deal with the specifics of your diabetes, if you have diabetes, no matter how well or poorly looked after it is.114

Our view

93. Throughout this inquiry we have been struck by the mismatch between the needs of the 15 million service users with one or more long-term conditions and the design of a health and care system set up principally to treat and cure episodes of ill health. Planning care around the person with a long-term condition or conditions, rather than expecting the service user to fit in with organisational structures often designed around the management of a single episode of care, appears to be a rational response to the changing needs of the population. The purpose of a health and care system designed to manage the care of people with long-term conditions must be to deliver interventions which are as effective as possible in sustaining and prolonging the quality of life of the service user. Moreover, such interventions are unlikely to be restricted to those within the remit of health and social services. We wholeheartedly endorse the principle that systems for the management of long-term conditions must be designed to be responsive to the service user’s needs and priorities for their own wellbeing.

94. The increasing prevalence of long-term conditions, and the prevalence and complexity of co-morbidities in physical and mental health, mean that personalised approaches to care and support must rapidly become the norm in the health and care system if effective care and support is to be delivered. In its plan for the NHS to 2018/19, NHS England has set an objective of “including citizens in all aspects of service design and change, and empowering patients fully in their care”. We consider that in order to meet its objective of empowering patients fully in their care, NHS England should promote the introduction of individual care planning for service users with long-term conditions. NHS England should adopt and adapt the principles underpinning the House of Care approach as necessary and should seek to eliminate barriers to effective integrated working. The House of Care model and its associated delivery system provide a sound conceptual framework to analyse and determine an individual’s care needs. However, care must be taken to ensure that the wishes and requirements of the service user are not subordinated to rigid and inflexible care planning protocols.

114 Q102
Personalisation and patient involvement

95. The Department of Health in its memorandum indicated the benefits of the personal health budget in the provision of health and care services tailored to the needs of the individual:

Personal health budgets are another way of giving people more control over how their long-term health needs are met. They build on personalised care planning, knowing how much money is available to meet agreed health outcomes, and enables people to meet their needs in ways that work for the individual. They allow people to take a holistic, whole-life approach to planning, and facilitate integration across health and social care (personal budgets have been available for much longer in social care).

Personal health budgets are new to the NHS and early implementation is focused on people receiving NHS Continuing Healthcare (the majority of who will have at least one long-term condition), who will have a right to ask for one by April 2014. CCGs will be able to offer them more widely on a voluntary basis to other patients who could benefit.115

96. The Patients Association indicated that greater involvement of patients in determining their care would be welcome:

Patient care is about two sets of expertise: the medical expertise of the doctor to propose treatments, diagnose and identify problems, and the patient’s own expertise in how they feel, what they need to make them feel better and the support they need to remain healthy. Combining these two viewpoints to come to a solution which is not only clinically appropriate but also right for the patient are the core principles of shared decision making. It is also not unheard of for patients with long-term conditions to have more significant knowledge about their condition than their doctor.116

97. Don Redding, of National Voices, described broad support for the personalisation of health budgets, giving patients some control over the services they wished to receive to manage their condition. He described the present level of support for personalisation as “a key moment”:

There is no doubt that there is an appetite for the roll-out of personal health budgets and for that to keep pace and momentum [. . .] Most [of the bids to be designated as integration pioneers] are setting ambitions around that because they understand it to be part of the personalisation that needs to be supported. I know of people who were very sceptical of personal health budgets who finished up being very impressed by the pilots and their evaluation [...] . At the sort of leading edge of some of that practice locally, there will also be some push for people to be able to join their budgets up, and to be able to act together as commissioners of their care where they think they may want similar things. I definitely think it is going to be a fast-
increasing part of the landscape. I get a little wary sometimes when I hear people say quite baldly that they feel that that in itself solves the integration question, because then the person will be able to integrate their care. They will not. The care and support that they need will extend far beyond what the personal health budget will cover. However, it can make a crucial difference, I think, to people’s sense of self-efficacy […] the sense that you can take some control of your circumstances. Just getting that, even in baby steps, is very important for people with multiple long-term conditions.¹¹⁷

98. The Royal College of General Practitioners told us that “personal health budgets potentially offer the opportunity to meet individuals’ health and social care needs in a more integrated way, but pose various practical challenges and risks.”¹¹⁸ The NHS Confederation suggested that

If people are to manage long-term conditions more effectively then care will need to be personalised around people’s individual needs. Personal health budgets could be one way of doing this. Our work shows that take-up of personal health budgets should be driven by genuine demand from patients rather than quotas, learning the lessons from the continuing rollout of personal budgets in social care. Good advice and support for patients will be essential.¹¹⁹

Patient choice and personalisation in the provision of treatment

99. An important element of the systematic and cultural shift towards greater personalisation of care is the change in the relationship between the service user and the health professional. Dr Sue Roberts described this as a move away from the “professional gift” model, where health professionals diagnose conditions, determine treatments and administer them, towards a more collaborative approach, where the service user—often with greater knowledge of his or her condition or conditions than the health professional—could engage in a constructive discussion about the care and treatments available and what might or might not work in managing the condition.¹²⁰

100. ADASS and the Local Government Association drew attention to a range of health and social care services operating under the Think Local Act Personal umbrella, services which supported their users to determine “their needs and priorities, based on the outcomes they want to achieve and arranging the support that they require and how it is provided.”¹²¹ They gave the example of greater personalisation of services in end of life care, arguing that social services departments had the best access to local intelligence which could inform the design and delivery of improvements in end of life care and the development of holistic approaches which could focus on the needs and wishes of the individual.

¹¹⁷ Q131
¹¹⁸ Ev 125
¹¹⁹ Ev w200, para 3.7
¹²⁰ Q55
¹²¹ Ev w55
101. We took evidence on the use of complementary and alternative medicine (CAM) in the management of long-term conditions from Dr Peter Fisher of the Royal London Hospital for Integrated Medicine and Professor George Lewith of the University of Southampton. Professor Lewith indicated that CAM was often requested and used by those with long-term and complex conditions:

We get powerful evidence that says that many people use complementary medicine to empower and enable themselves to self-manage, from cancer through to complex, difficult-to-diagnose-and-treat conditions like fibromyalgia and many of the long-term conditions like arthritis and diabetes. In all these chronic conditions, without fail, we get very high use of CAM. If you ask the patients why they are using CAM, they talk about different kinds of consultations, consultation environments and empowerment processes and that is something that we really need to take notice of if our new NHS is genuinely […] to take on the process of having the patients at the centre of it because that has been a long-term political promise that has not always been fulfilled.122

Professor Lewith explained how acupuncture—a CAM intervention—could assist in the management of musculoskeletal conditions, by addressing the pain caused by the condition and providing the environment in which it could be treated more readily:

There is good evidence that good acupuncture will take away pain in a variety of different conditions. If you start moving an osteoarthritic knee because it is less painful, you will get repair and reconstruction. So conditions which you may think are chronic are probably remediable to movement. If you have a positive consultation environment, an encouraging process, a treatment that is pretty safe compared to non-steroidal [anti-inflammatory medication] and you have a process of encouragement happening with diminished pain, you will get some degree of actual repair and you will get an improvement in quality of life.123

“Whole-person” approaches to treatment, such as those adopted by CAM practitioners, could improve outcomes when used in conventional medicine:

[B]eing nice to people and approaching them as whole people has a big effect on their symptoms. [The whole-person approach] could be delivered within regular medicine […] We need to learn the lessons from complementary medicine and deliver them better conventionally, but you are not going to get GPs who are working 14 hours a day within the current health system, and who are all pretty disillusioned, to have increased compassion.124

102. We do not propose to evaluate here the evidence for the efficacy or otherwise of specific complementary and alternative medicine approaches to the treatment of long-term conditions. Nevertheless, we note that greater involvement of service users in discussions and decisions about treatment of their long-term conditions will inevitably increase the demand for commissioning of complementary and alternative treatments
by patients who feel that they have gained benefit from them in managing their conditions or who believe these treatments will be effective. The test for commissioners and health and care professionals will be how to evaluate and measure the effectiveness of such interventions appropriately, and to determine whether they will deliver improved outcomes in terms of better quality of life.

**Information management and patient data**

103. The Mandate to NHS England set the following priorities for “a significant increase in the use of technology to help people manage their health and care”, to be achieved by March 2015:

- “everyone who wishes will be able to get online access to their own health records held by their GP. The Board should promote the implementation of electronic records in all health and care settings and should work with relevant organisations to set national information standards to support integration;
- “clear plans will be in place to enable secure linking of these electronic health and care records wherever they are held, so there is a complete record as possible of the care someone receives;
- “clear plans will be in place for those records to be able to follow individuals, with their consent, to any part of the NHS or social care system;
- “everyone will be able to book GP appointments and order repeat prescriptions online;
- “everyone will be able to have secure electronic communication with their GP practice, with the option of e-consultations becoming much more widely available;
- “significant progress will be made towards three million people with long-term conditions being able to benefit from telehealth and telecare by 2017; supporting them to manage and monitor their condition at home, and reducing the need for avoidable visits to their GP practice and hospital.”

104. The Department of Health suggested to us that patient-accessible records would allow “greater personalisation of treatment plans and for patients better to understand their treatment and have a say in how their care is personalised.” The Department has since confirmed that by March 2015 GP practices will be required to provide people with access to their own care records online, or to have published plans for how they plan to do so. From April 2014 the General Medical Services contract (the “GP contract”) is to be changed “to make clear the need for general practice to securely share records with other services, where patients are content for them to do so.”

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126 Ev 80, para 59

127 Transforming Primary Care: safe, proactive, personalised care for those who need it most, Department of Health and NHS England, April 2014, p. 25

128 Ibid., p. 40
Committee in November 2013, Martin McShane of NHS England estimated that at that date electronic summary care records had been deployed across 60% of GP practices in England.\textsuperscript{129} He indicated that continuity of care for those with long-term conditions required “informational continuity”:

> We are now seeing with mobile technology the development of apps, which means that people can take their information with them. There was an 80-year-old taken to A and E recently who handed over her iPad and said, “All my medical records are here. Would you like to use them?”, which rather stunned the assessing clinician, but they did find it useful.\textsuperscript{130}

105. Accenture told us that “a key challenge for professionals working across the health and care sector is access to patient information. This is particularly important for vulnerable patients with multiple chronic conditions. Electronic Medical Record systems should be compatible across health providers, from acute to community, in order to ensure patients receive the right treatment at the right time—avoiding unnecessary hospital admissions and lengthy stays resulting from a lack of awareness of a patient’s medical history.”\textsuperscript{131} NHS England has now announced that it is to work with the British Medical Association General Practitioners Committee on enabling access to GP patient records from other care settings and making referrals electronically from April 2015 or having plans in place to do so. The Department of Health and NHS England also want all ambulance services, NHS 111 services and A&E departments to be able to access GP patient records.\textsuperscript{132}

106. The Pharmaceutical Services Negotiating Committee (PSNC) argued that patient “gatekeeping” of records was key to an integration of pharmacy into the rest of the health service “so that those being managed by community pharmacies could choose to make their information accessible to those pharmacies would ensure that pharmacies were aware of any other care being given to patients, and any potential health problems, and tailor their care to better meet their needs.”\textsuperscript{133} Alistair Buxton of the PSNC explained why the establishment of infrastructure and protocols to enable pharmacists to work with medical records held by a GP was necessary:

> One of the practical issues in bringing more care into primary care [...] is information flows and the fact that they do not generally, particularly between secondary care and primary caring, flow in an elegant, electronic and efficient manner [...] between ourselves and general practice and other primary care practitioners and community providers with general practice. Working in a pharmacy, if I have an issue I need to raise with a patient’s GP, with their consent, I would wish to review their record as appropriate to ensure I am not posing a question that perhaps the GP has already dealt with. But, assuming there is a legitimate reason to send some information through, I do not want to create more

\textsuperscript{129} Q302
\textsuperscript{130} Q275
\textsuperscript{131} Ev w194, para 5.3
\textsuperscript{132} Transforming Primary Care, p. 41
\textsuperscript{133} Ev 94, para 25
work for my GP colleagues. At the moment, I may create admin work of copying and pasting data into the patient’s records and our IT systems just do not work well.134

107. Baroness Young told us that the NHS in Scotland had introduced an integrated diabetes information service accessible by patients, GPs and those in secondary care, but it had not been designed as a fully-integrated patient-accessible record. Asked whether she supported the principle of patient access to their entire online record, and patient control over who else could access it, she struck a cautionary note, reminding us that not all service users would be inclined to make use of the advantages of electronic medical records controlled by the patient, even if they were available:

[One] thing that we need to be conscious of—particularly in diabetes, where there is strong correlation between type 2 diabetes and social deprivation and ethnicity—is that part of the problem is how you get patients to engage with their condition at all. The idea that somehow they are going to fall over themselves to access their records or to be the main repository of their records is quite a challenge in that environment.135

Our view

108. Better information management, electronic record sharing and patient control are features which have the potential to improve the management of long-term conditions immensely, by enabling greater integration of information and empowering patients to manage their own condition or conditions. While policymakers envisage the benefits of better-informed, better-engaged “digital patients” with a more active role in self-management of a long-term condition it is important that the health and care system also supports those who are for whatever reason unable or unwilling to participate in self-management of their conditions. We recognise the considerable benefits to patients and the health and care system of greater use of electronic records, better information sharing and more supported self-management. The NHS is nevertheless designed as a universal service and its benefits must be accessible to all. Advances which will benefit the engaged, informed and technologically-literate patient must not be pursued to the disadvantage of those who are vulnerable or unable to access new opportunities for better care.

Education, training and workforce planning

109. In their memorandum to this inquiry, the Department of Health, NHS England and Health Education England had this to say about the training, retraining and education of medical professionals to deal with new ways of managing long-term conditions:

Health Education England is responsible for ensuring that the health sector has the right numbers of appropriately educated and trained staff to treat and care for the growing numbers of patients with LTCs in order to deliver high quality services. This

134 QQ218-219
135 Q110
will be reflected in the approaches to workforce planning as well as workforce development, education and training adopted by Health Education England.136

110. In its submission, the NHS Confederation called for “multi-professional training” to be the norm in preparing for new ways of managing long-term conditions:

Make multi-professional training the norm. In order to develop a flexible workforce, training that enables working across and with different sectors is essential. Staff needs the right sort of skills to provide different types of care to patients during the same appointment. It will be important for Health Education England to provide national leadership in this regard.137

111. Dr Karen Lowton pointed out the relative lack of specialist knowledge in medical professionals now required to deal with “new ageing populations” presenting with conditions or combinations of conditions not generally experienced:

Health services have been developed around professional clinical career structures. For many NAPs, for example those with coronary heart disease, both specialist and generalist cardiology input are required as this ‘new’ population of adults no longer fit within the traditional service divisions which split adult and paediatric cardiology’. Most adult services for NAPs are based exclusively within secondary care, where multi-disciplinary teams have been developed to enable holistic care. Commonly, models are hierarchical, in a tertiary or specialist centre, with shared or outreach care delivered at district general hospitals, few receive care at local hospitals alone. One exception to secondary care provision is cerebral palsy, where adults, largely an outpatient population, give hospital neurologists little exposure to this group in their training. Furthermore, many community-based clinicians, especially general practitioners (GPs), would not expect to see more than one patient with, for example, cystic fibrosis during their career. When they do, there is a risk of their attributing any new symptom to the underlying condition, with patients acknowledging that a ‘specialist’ patient may not always help educate their GP about their condition through their preference to contact specialist services.138

112. The RCGP made the following statement about workforce planning and training:

Continuing to move care out of hospitals and into the community has significant implications for the primary care workforce. The Centre for Workforce Intelligence has highlighted that the GP workforce is not growing quickly enough to meet predicted increases in demand. The CfWI has recommended a 17% increase in recruitment into GP speciality training, which will necessitate a reduction in recruitment into training in hospital-based specialties. We need a robust long-term approach to workforce planning, led by Health Education England, to ensure that patients with long-term conditions are supported by an adequate GP workforce.

136 Ev 75, para 8
137 Ev w200
138 Ev 97, para 13
As the needs of patients change — and as the rise of multiple morbidities continues to lead to increases in the complexity of care — we also need to ensure that GP training reflects this. The RCGP’s proposals for extending the length of GP training from 3 (currently the shortest of any medical specialty) to 4 years are in the process of being considered by the Government, with a decision by health Ministers across all four nations of the UK expected in late 2013. Extending and enhancing GP training will mean that GPs of the future are better equipped to provide care and support to those with long-term conditions.  

113. Dr Sue Roberts suggested that the cultural change required to embed this new model throughout the NHS was considerable: a survey of GP attitudes had indicated that “sixty percent of GPs do not endorse people being independent decision makers, still seeing their role as ‘doing to’ rather than ‘doing with’. These attitudes can be challenged and changed by quality assured training with positive outcomes for all. Links with the Royal Colleges and Health Education England provide an avenue to review training capacity.”

114. Dr Martin McShane, a general practitioner by training, described his view of the cultural changes required to deliver better care for people with long-term conditions throughout the health and care system:

It is about professional collaboration. Continuity always requires that and management continuity, which we have talked about, but also relational continuity. This is where the named doctor comes in, getting back to knowing who I can trust and turn to when I have problems with the care that is being delivered for me in the way that we have had so clearly articulated is not happening in places.

I also think that relational continuity is about relational continuity between professionals. When I was a GP, there was a coterie of incredibly useful specialists—not all of them doctors, some of them nurses—whom I would contact when I wanted help in managing the patients I was looking after in the community. It is about that team-working. [...] The biggest transformation is at the personal level. That is why we are working with the Royal College of General Practitioners, NESTA, the Health Foundation and others, to create a narrative and an understanding of how we support professionals and change the culture right at the coalface. I know I did not behave that way in the past and it is a big ask. So we are working with Health Education England on how we change the training and the skills that professionals have coming up for the future challenges, not the past.

115. We note with concern the shortfall in the primary care workforce projected by the Centre for Workforce Intelligence. We recommend that Health Education England set out clearly how they plan to address this projected shortfall.

116. If care planning, integrated services, multidisciplinary working and supported self-management of long-term conditions are to become common practice across the health and care system, the requirement for structural and cultural change at all levels
will be extremely challenging. Medical professionals in all disciplines who are treating those with long-term conditions will in many cases have to adapt their ways of working with patients and with those from other disciplines.

117. We recommend that Health Education England, in response to this report, sets out its strategy for the adaptation of the present medical workforce, and the training of the future workforce, to the delivery of a model of integrated care centred on the person. Such training should also encourage those specialising in one discipline to develop an understanding of the functioning and the capability of other healthcare disciplines and therapies.
4 Managing the system to deliver better care for long-term conditions

Why change the present mix of services?

118. We noted above the broad consensus that a national health service designed to provide acute services to treat single episodes of care is now increasingly required to provide complex treatment to people with long-term conditions. There is a prevailing view about the direction of travel required which, put broadly, holds that better-quality care, at better value to the health and care system, can only be delivered to people with long-term conditions if health and social care services are more integrated, and if there is greater emphasis on preventative services, early interventions and community-based services rather than acute services.142

119. We sought evidence on the scope for a variation in the present mix of health and care services, and received substantial corroboration of this view. The Department of Health and NHS England suggested that effective treatment of long-term conditions could take place outside hospitals: early diagnosis could reduce emergency attendances at A&E departments and emergency admissions to acute hospitals, and care management for those with long-term conditions which was properly coordinated and integrated could reduce the use of acute services.143 The Nuffield Trust pointed out that any transfer of services from the acute sector would require effective community health services and good-quality primary care.144

Changing the service mix: managing ambulatory care-sensitive conditions

120. One proposal for change to the service mix involves the treatment of chronic ambulatory care-sensitive conditions (CACSCs). The Department of Health told us that of the additional £4 billion of annual cost pressure on the NHS expected by 2016, the majority was attributable to a continued inappropriate and unplanned use of expensive acute hospital services, and indicated that NHS England would “need to work with partners to shift spend to support more primary and community based care and prevention.”145 It considered that many attendances at A&E departments and emergency admissions to hospital could be avoided by better management of “those with conditions sensitive to ambulatory care”.146 The mandate to NHS England includes a specific measure designed to ensure that more such conditions are normally treated outside hospital: indicator 2.3.i of The Mandate tracks the rate of unplanned hospitalisation for chronic ambulatory care sensitive conditions in adults.

142 Q2
143 Ev 75
144 Ev 127, para 2.1
145 Ev 75, para 4; Ev 74
146 Ev 75, para 11
121. The Department defines chronic ambulatory care-sensitive conditions (CACSCs) as “those where the right treatment and support in the community can help prevent people needing to be admitted to hospital.”147 The Nuffield Trust defined them as “clinical conditions for which the risk of emergency admission can be reduced by timely and effective ambulatory care, meaning mainly primary care, community and social services, and outpatient care.”148 As such the conditions are defined by whether they are considered treatable by primary and community health and care services, and measuring rates of unplanned hospital admissions for CACSCs can therefore indicate the adequacy of local community and primary care services in providing routine management for such conditions.149

122. Nuffield Trust research has indicated a steady increase in annual rates of emergency admissions for CACSCs between 2001 and 2011, even when figures are adjusted to take account of demographic change.150 A number of reasons are suggested for the overall increase, including changes in hospital admission procedures and changes in the underlying prevalence of the disease. A further reason given is the perceived lack of alternatives to inpatient care for such conditions: social care may be inadequate or community-based alternatives to hospital treatment lacking. In this area, however, reliable evidence on the impact of local and national health policies on the quality and cost of community services was lacking and required “much more comprehensive, independent and transparent analysis”.152

123. Data collated by The King’s Fund from Hospital Episode Statistics for 2009/10 indicated that all ACSCs (i.e. chronic, acute and vaccine-preventable) accounted for one in every six emergency hospital admissions in that period, and cost commissioners £1.42 billion.153 Of the chronic ACSCs, chronic obstructive pulmonary disease (10%), asthma (10%), angina (9%), congestive heart failure (7%) and diabetes complications (6%) accounted for 42% of emergency admissions for all ACSCs.154 These conditions between them accounted for 41% (or £582 million) of the overall tariff cost to commissioners of such admissions.155 Costs were amplified in older age groups, an occurrence explained by the likely greater incidence of co-morbidities and complex conditions in such age groups. Measures proposed to reduce the incidence of such admissions in the short to medium

147 The Mandate, p. 13
148 Ev 128, para 2.1
149 The most frequently used subset of ambulatory care-sensitive conditions used in the NHS in England contains 19 conditions, divided into three categories thus: Vaccine preventable: influenza and pneumonia; other vaccine preventable conditions; Chronic: asthma; congestive heart failure; diabetes complications; chronic obstructive pulmonary disease; angina; iron-deficiency anaemia; hypertension; nutritional deficiencies; Acute: dehydration and gastroenteritis; pyelonephritis; perforated or bleeding ulcer; cellulitis; pelvic inflammatory disease; ear, nose and throat infections; dental conditions; convulsions and epilepsy; gangrene. Tian et al, Emergency hospital admissions for ambulatory care sensitive conditions: identifying the potential for reductions, The King’s Fund, April 2012, citing Purdy et al, “Ambulatory care sensitive conditions: terminology and disease coding need to be more specific to aid policy makers and clinicians”, Public Health, vol. 123, issue 2, pp 169-173, February 2009.
150 Ev 128, para 2.3
151 Ibid, para 2.5
152 Ibid., para 2.6
153 Tian et al, op. cit., p.1
154 Ibid., p. 4
155 Ibid., p. 6
term included better management of ACSCs in primary care, and CCGs were encouraged to examine the admissions data of their constituent practices to understand where variations in admissions were occurring and why.\(^{156}\)

124. Judith Smith explained why the treatment of such conditions was in particular focus:

\[\text{[W]hy is it [that policymakers] want to make the shift? If it is around quality and outcomes, we are probably on a reasonable track, but given the financial context in which the health service is working—one that looks like it is going to remain austere for at least another decade—the cost-effectiveness aspect is becoming even more important.}\(^{157}\)

When pressed on the rationale for advocating a reduction in hospital admissions for such conditions, she stressed that effective interventions were assessed by both their quality and their cost-effectiveness.\(^{158}\)

125. Dr Sue Roberts suggested that a focus on the reasons for treatment in secondary rather than primary care was rather missing the point:

\[\text{[...] I think the reason that we are in the situation that we are now is because we are just looking at one part of the system—the obvious one—in fact, where we are up against it at the moment—which is emergency admissions to acute hospitals. By only concentrating on those, in a sense, and only accepting that we are going to do two things to people—"Shall we do them there or there?"—we miss the point of how we should be managing the whole population [...] and move from, "We are going to treat and do things to you," to "We are going to involve you much more throughout your whole life in how this is going to happen."}\(^{159}\)

Martin McShane, of NHS England, appeared to concur:

\[\text{We have to try and create a system that looks at a system, not just its different components. We have had a system that has focused very much on hospitals and we have had this mantra about moving care out of the hospital. I do not think it is about moving care out of the hospital. It is about creating the right care in the community so that people do not need to go into hospital. That is the agenda we are facing and which we need to tackle. To do that requires a huge cultural change, which is the biggest change.}\(^{160}\)

**Our view**

126. Ensuring that more patients with chronic ambulatory care-sensitive conditions are treated in primary care or in community settings, rather than in acute hospitals, may yet prove to be an important component of the Government’s plan for management of long-

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\(^{156}\) Ibid., p. 11  
\(^{157}\) Q41  
\(^{158}\) Q42  
\(^{159}\) Q43  
\(^{160}\) Q232
Managing the care of people with long-term conditions

term conditions in the health and care system, not to mention a strategy for reducing the
costs of the acute sector. We nevertheless consider that it is an error to regard a greater
volume of treatment of CACSCs in the community as a worthwhile outcome in itself: what
matters is whether such treatment results in better outcomes for the patient.

127. In its Mandate to NHS England the Government identifies the level of unplanned
hospitalisation for CACSCs as an indicator for progress in the overall improvement area of
reducing time spent in hospital by people with long-term conditions. We are not
convinced that this is the most appropriate indicator to select, though we recognise that it
may be the only one readily available. In our view, the focus of changes to the health
and care system in management of long-term conditions ought to be on the provision of
personalised services which treat the whole person, enable active self-management and
mitigate the adverse effects of the condition to enable the person to have as active a life
for as long as possible. If that objective is pursued, then it ought to follow that unplanned
admissions to hospital will reduce: but the reduction in admissions to acute care should be
the happy consequential outcome of a system which manages the care of people with long-
term conditions better, not the yardstick against which progress is measured.

128. We doubt whether necessary change in health and care provision for the long term
will be achieved through measures which merely address the symptoms of poor
management of many chronic ambulatory care-sensitive conditions, namely excess
unplanned admissions to acute providers. The priority for the Department of Health
and NHS England should be to address the underlying structure of services and
incentives which send so many patients with CACSCs to acute care in the first place.

Long-term conditions in primary and community care

129. The NHS Confederation told us of the “widespread agreement” that, where clinically
appropriate, increasing the care given to people with long-term conditions in the home
and in the community was the “right approach” and provided more effective support. A
2012 survey of Confederation members indicated that 63% believed that a move of services
from acute care was a priority. The Confederation also reported a Department of Health
survey of members of the public in 2012 which found that 66% of those polled agreed that
moving services into the community could raise standards.161

130. Many witnesses provided evidence of the effectiveness of local changes in service mix
in the treatment of long-term conditions. The NHS Confederation and the Nuffield Trust
both highlighted the example of the North West London Integrated Care Pilot, launched in
June 2011, which piloted a multidisciplinary approach to the coordination of care for a
population of 550,000 people, with a focus on integrating care for people older than 75
years and people with diabetes. In both cases the populations were experiencing variations
in the provision of care and a high level of avoidable admissions, and in both cases the
outcomes were readily measurable.162

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161 Ev w201, para 4.4
162 Ev w201
131. In North West London the pilot involved over 100 general practices, two acute care trusts, five primary care trusts, two mental health care trusts, three community health trusts, five local authorities and two voluntary sector organisations with a specific focus on the conditions in focus. Clinicians across the participating organisations worked together in multi-disciplinary groups to assess the relative health risks to the populations under consideration (“risk-stratification”), to develop shared protocols for treatment, to develop care plans for patients and hold case conferences for patients with particularly complex needs or problems, and to identify the care available and the gaps in provision. The pilot was funded with £7 million from the London Strategic Health Authority, using funds which would otherwise have been spent on payments to acute trusts under the 30% tariff payable on excess emergency readmissions.

132. The overall aim of the pilot was to deliver integrated services to the whole population, focusing effort on the 20% of the population identified as being responsible for 80% of the cost of health and care services. The NHS Confederation reported that some benefits from the pilot had been identified early on, though others would be realised over a period of between five and 10 years. Based on the impact to May 2013, the pilot “hopes” to reduce emergency admissions for people over 75 with diabetes by 10%. Better patient experience of coordinated care across providers has also been reported.

133. The Confederation also drew attention to the results of a smaller-scale initiative in Hammersmith and Fulham, where a community-based team had been set up to improve care for those with chronic obstructive pulmonary disease (COPD). This community services provided rehabilitation services, community clinics, specialist support for primary care, support for patients following discharge from hospital and support for self-management of the condition. The benefits attributed to the programme included a saving of £170,000 in the cost of first and follow-up appointments, a reduction in hospital admissions for COPD by 19% and a reduction in readmissions by 66%.

134. Dr Judith Smith, of the Nuffield Trust, suggested that most patients—including those with long-term conditions—would rather be treated closer to, or in, their homes in preference to inpatient or outpatient treatment in hospital. Professor Alan Maynard was not so certain: for some episodes of care in the course of management of certain long-term conditions, treatment in an acute hospital would clearly be the most appropriate course of action. We received a submission from the Pemphigus Vulgaris Network expressing great concern at any proposal which might result in treatment for this serious skin condition being provided outside specialised secondary care settings. Baroness Young, of Diabetes UK, also expressed reservations about a wholesale transfer of all diabetes services to the primary or community sector.
135. While the prevailing assumption may be that people with long-term conditions would welcome treatment being provided through community or primary care as close to home as possible, this approach should not be taken for granted in the design of systems to support the management of long-term conditions. Many conditions will continue to require treatment to be provided being provided in specialised secondary care settings.

136. Alan Maynard challenged the present policy assertion that care for long-term conditions could be better provided in the community via integrated pathways of care, in ways which offered better quality, improved outcomes and potential savings in cost. He argued that in “practically all public and private health care systems” the incentives and fragmented systems of care delivery tended to weaken commissioners, with the result that in many cases the policy ideal—transfer of care for long-term conditions from the acute sector to community care—would not be achievable: community care would come to complement, rather than replace, acute services. Without the power to demand reductions in hospital capacity and the money to pay GPs to increase the care they provided, commissioners would have little power to influence the prevailing pathway from the GP to secondary care.170

137. There is evidence to indicate that poorly-planned changes to service mix have not in the past had the desired effect. The British Association of Dermatologists (BAD) reported that some dermatology outpatients services had been decommissioned, to be replaced by community-based services which provided care closer to home for dermatology patients. However, the expected improvements in service provision had not been realised and there had been increased referrals to both community and acute services. BAD feared that changes in commissioning arrangements and the introduction of commissioning from “any qualified provider” had resulted in the “fracturing” of care pathways. This had meant that there was no net reduction in the cost of treatment when compared to acute care: in fact overall costs increased because patients were often “lost” in referrals from their GP to a community care service. BAD was also concerned that primary care services were “buckling” under current levels of demand.171

The evidence for benefits

138. We have received a great deal of evidence of the benefits of a change in the mix of services for long-term conditions, which we describe elsewhere in this report, and we have heard a number of persuasive arguments from common sense. We nevertheless note that on the existing evidence the clinical case for change is rather stronger than the economic case. The NHS Confederation told us that a shift of care from acute services into the community and into the home “will improve the quality of care provided to patients with long-term conditions and has the potential to save money.”172

139. Dr Peter Aitken, of the Royal College of Psychiatrists, painted an attractive picture of integrated services in operation:

170 Ev 99
171 Ev w191, para 3.4
172 Ev w201 [emphasis added]
For us it is the most natural thing in the world to create an integrated system [. . . ] [W]here you see mature commissioning working well—the Torbay system is a good example of that—you have staff that are co-located, the skills are in the same building and they can gather around the person in real time; seven steps of interagency referral can become perhaps two telephone calls and a conversation over coffee. It works.173

140. Professor Alan Maynard took a more sceptical view of the potential benefits of large-scale service change:

[W]e have not got a robust evidence base that says, “Does it work? Does it maintain the quality and length of my life at a reasonable cost?”—its cost-effectiveness. We do not have that evidence base. Therefore, there are many fashions like, “Community care is good.” What is community care? We have to break it down and look at different groups and different interventions. But, even when you do that, you still have the problem of evidence, and it is poor.174

He expressed some scepticism over the evidence for the effectiveness of the House of Care model:

Here we have an obviously well-intentioned and nicely designed intervention. There are lots of them about. This one is very attractive, but it has to be accepted that it is a pilot and you really need to do a proper evaluation. The timing of how far you go with pilots before you do evaluation is important. Our problem is that we have lots of ingenious doctors—there are a couple of ways always thinking of new things to do, how to change A and E, how to change community care, how to do neighbourhood care teams. It is always happening. But I stand there and say, “I demand evidence. Get used to thinking critically, please. Evaluate.”175

141. Professor Maynard pointed out the challenge for commissioners seeking to improve outcomes for people with long-term conditions who are considering changes to the mix of services being commissioned:

[I]f you look at the cost-effectiveness evidence, it is very poor and patchy. If you look at the effectiveness evidence, it is simply very poor. Therefore, for a lot of the espousal of community care and argument to improve the way in which services are co-ordinated to [people] with long-term care problems, it is really very poor. In a CCG, you are faced with the problem of how to invest resources. You look for evidence, and it is not there. Essentially, everyone else in the NHS is doing the same thing, looking for evidence, not having it, and so you experiment. The tradition in the NHS for the last 40 years has been to experiment but not to evaluate. Therefore, we do not have that information. [...] So there are a lot of prejudices and views here, but we do not have that firm evidence base on which to proceed.176

173 Q85
174 Q38
175 Q20
176 QQ2, 3
142. Dr Judith Smith of the Nuffield Trust concurred on the adequacy of the evaluation of previous experiments with shifts to community care:

[W]e lack good, long-term robust studies of the overall effect of those experiments. Far too often, they are expected to report too soon and are asked to look at measures such as cost and activity. The majority of those studies that we have carried out at the Nuffield Trust tend to have very disappointing results because we are often expected to report very early in the process. Also, we find that those interventions have often been quite poorly designed and there has not been careful thought given to the outcomes that are expected.177

She noted that the evidence for benefits in terms of patient experience and outcomes was stronger than the evidence for economic benefits.178 Although there was evidence that integrated care structures in places such as Torbay had reduced the demand on acute services, it was difficult to attribute the reduction in demand on acute services specifically to the change in service mix.179 She suggested that a study of at least five years was necessary to demonstrate genuine benefits to patient outcomes and demand on services:

Our sense often is that there is a tendency within NHS management to be, first of all, perhaps overly optimistic at the start and set what turn out to be unrealistic objectives, but also to want results very quickly to prove progress at a point at which it is just not realistic. We know from a much wider body of evidence about bringing about large-scale change in healthcare that it can take several years to get new systems and ways of working up and running before you then start to see changes happen in terms of services and patient outcomes.180

143. Dr Sue Roberts was not surprised at the lack of evidence for benefits, suggesting that the methods of evaluating changes in service mix did not appreciate the scope of the change contemplated:

The totality of international evidence about long-term conditions says that this is a complex intervention. It can be reduced to three components. Basically, it is improving structure and becoming more proactive, which is probably the necessary but not sufficient element, and the other two that make it sufficient are involving people in their own care and a partnership approach between these two. So we endlessly design better research around one or other component and it is not going to work because this is complex. We are not going to get results and see the benefit of it because we have to look at the totality. I am all in favour of [the proposition] that we fundamentally need more research—massively more research—in these experiments, but the experiments have to be the whole-system experiments that are going to make a change, not small parts of it where we are not going to see a difference.181

177 Q4
178 Ibid.
179 Q5
180 Q6
181 Q8
144. Dr Peter Aitken called for frequent evaluation of new interventions to manage long-term conditions:

Rigour and evaluation is going to be the key that unlocks what we do next, so I would go back to my plea that, when we set up these models, these social experiments, we make sure that we put in the evaluative research programmes around them that deliver quick learning. We are not looking for three years from now. We want to learn as we go, but we want the journey measured, please, so that we can decide after six months, “That is not the way to go. We need to turn that way,” or, “This looks like a purposeful line of inquiry. Let us have some more of that, please.”

145. Dr Karen Lowton of King’s College London raised a related issue of the design of future models of care for young people with one or more rare and complex conditions. They were increasingly ageing successfully, because of medical advances and changed in social attitudes, but there was no evidence base to indicate how services for such people should be configured to give optimal care:

Most people are treated in specialist units that cannot be moved into the community because you need a concentration of expert care and specialist equipment, but we do not know how their care can be integrated within the community so that they are supported to self-manage often very difficult complex conditions. Also, clinicians caring for them often do not know what is going to happen next because many of these cohorts are the oldest; there is no cohort ahead of them. One of the problems is: how do you manage evidence-based medicine and how do you commission if you do not know what is going to happen next with these particular patients?

Our view

146. During the course of this inquiry we have not received any evidence to indicate conclusively that a large-scale change in the mix of health and care services for long-term conditions—in essence, a shift from the acute sector to the community sector—will achieve either the improvements to the physical and psychological well-being of people with long-term conditions or the benefits to the health and social care budget that some have claimed. There is nevertheless sufficient evidence to indicate that a change in service mix may well deliver outcomes—such as support for better self-management, more responsive care from community-based services, and less reliance on referrals to the acute sector—which will benefit people with long-term conditions.

147. As Dr Sue Roberts pointed out to us, that the absence of evidence does not necessarily mean that such a change would not be effective. The experience of integrated care trusts in England, and vertically-integrated care organisations overseas, suggests that such a change may well be effective. Yet to commissioners and providers who are under financial strain and facing demands to do more with less, the risks of undertaking substantial
changes in the service mix without reasonable assurances that such changes will deliver better outcomes and greater value for money may not be an attractive prospect.

148. As our witnesses indicated, the gathering of empirical evidence on the effectiveness of change can be hampered by short-term approaches to modelling interventions and evaluating outcomes. There is a clear financial incentive to prioritise the benefits which can be achieved tomorrow from quick fixes over the merits of investment in, and sustained support for, more difficult but ultimately beneficial changes which guarantee fewer rewards in the short term. In the light of the current demographic and financial pressures facing the health and care system, many may argue that system change cannot await the outcome of lengthy trials and detailed evaluations. To that argument we respond that while the results of demonstration projects and pioneers can win acceptance for the principle of change, they cannot substitute for a coherent change programme based on sound analysis. Pilot projects may demonstrate whether concepts are feasible and new ways of working can achieve benefits, but they are not primarily designed as trials.

149. Robust evidence on the long-term clinical effectiveness and cost-effectiveness of large-scale changes to the mix of services for long-term conditions is lacking. We consider that such evidence is vital to making the case for, and informing the design of, any form of sustainable service change which is to command widespread support. We therefore recommend that NHS England commission sufficiently rigorous studies of the effectiveness of services for people with long-term conditions which are delivered through integrated models of care, and that the outcomes for health and for cost-effectiveness across all settings are regularly and rigorously evaluated.

Commissioning services for the care of people with long-term conditions

150. There is no unified structure in England for the commissioning of services for the treatment of long-term conditions.

- Most acute care services and primary care services in community settings are commissioned by clinical commissioning groups, having regard to priorities set by local authority health and wellbeing boards.

- Primary care services delivered through GPs are de facto commissioned by NHS England within the framework of the National Health Service (General Medical Services Contracts) Regulations 2004\(^\text{185}\), as amended, and under the directions collectively known as the NHS Primary Medical Services Directions, negotiated annually between NHS Employers and the General Practitioners Committee of the British Medical Association.

- Specialised services for long-term conditions are commissioned directly by NHS England.

We received evidence to suggest that commissioning responsibilities for certain conditions were not wholly clear and were dependent on the publication of detailed commissioning

\(^{185}\) SI 2004/291
plans for specialised services by NHS England. The MND Association was concerned that the scope of service specifications for long-term neurological conditions had not been developed by NHS England in May 2013, and that there was a consequent risk that services which NHS England subsequently decided not to support through specialised commissioning would not have been included in local CCG commissioning arrangements.186

151. In addition, local authorities will provide or commission social care services to support those with long-term conditions eligible for such support. ADASS told us that they were working with The King’s Fund to produce guidance for health and wellbeing boards in integration such activity: they suggested that it was necessary for local authorities to engage with health service commissioners and providers across all local settings in order to ensure that resources were effectively pooled to facilitate the commissioning and design of new services “with a clear understanding of the sheared improvement agenda”.187 ADASS stressed that integrated services for the support of people with long-term conditions “must be designed from the bottom up, designed around integrated health and care personal support plans and the pathways of people through a local health and care system.”188

152. The Department of Health indicated that the NHS would support effective local commissioning for long-term conditions by:

i. “Working with Monitor to develop currencies and prices that support improved outcomes for people with long-term conditions;

ii. Establishing successful networks and partnerships with the third sector, social care and user organisations;

iii. Supporting CCGs and other partners at local Health and Well Being Boards (HWB) to address the prevention of LTCs in partnership with Local Authorities and local community action.”189

153. The Department also indicated that NHS England would work to spread best practice, and gave an example from the Wirral where an admissions prevention service had been commissioned to reduce GP referrals to hospital for urgent care and admission rates to residential care from acute care. The benefits of the service, as reported by the Department, were “improved service user assessment”, where providers agreed goals and outcomes; a shift to supporting people at home; and better value for money from better use of existing partnership resources.190 The partners in the National Collaboration for Integrated Care and Support would be encouraging local commissioners “to innovate and experiment in ways that will deliver integrated and joined-up care and support at pace and scale”, not least through the 14 “integration pioneers”. The NHS would use “policy and commissioning levers to support management continuity” and would “build [. . .] on the

186 Ev w52
187 Ev w55
188 Ibid.
189 Ev 76, para 22
190 Ev 77, para 24
GP practice to support relational continuity.” The approach would be supported by the publication of NICE quality standards for long-term conditions.

154. The NHS Confederation stressed to us that a “collaborative, whole-system approach” was needed to support people to manage long-term conditions: “CCGs cannot do this alone. They need to be supported at system level to work with local authority commissioners and NHS England.”

Arthritis Care suggested that assistance to commissioners must be based on “a good understanding of the realities” of commissioning services for long-term conditions, but that commissioners themselves ought to examine how they could improve condition-specific services: “the services for each condition needs to be looked at to see how it can improve, offer better value for money, and integrate better with other services.”

**Practical support for commissioners**

155. In our call for evidence we asked for examples of practical support given to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions. For some conditions—for instance diabetes,193 epilepsy,194 dermatological conditions195 and rheumatic conditions196—it appears that there is a wealth of third-party guidance and support available for commissioners who wish to improve the design and delivery of local services. Charities supporting those with neurological conditions have established Neurological Commissioning Support (NCS) to work with commissioners to map neurology services, identify and analyse service gaps and help in the development of appropriate services.197 The British Society for Rheumatology (BSR), Arthritis Care and the National Rheumatoid Arthritis Service have, with Department of Health funding, formed the Rheumatology Commissioning Support Alliance “to support commissioners and develop tools to demonstrate how better services for patients and better value for the NHS can both result from a more service user-centred approach,” while the BSR itself has released a “commissioning toolkit” for providers “to help rheumatology professionals develop their knowledge and skills to design effective services and make the most of commissioning opportunities.”

156. In other cases the support available for commissioners appears patchy or non-existent. The Royal College of Physicians of Edinburgh, for example, recommended that while CCGs were “in their infancy” there should be strong primary and secondary clinician involvement in commissioning decisions at area and CCG level and the availability of “significant resources” to facilitate the development of integrated services for long-term

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191 Ev w202, para 4.7
192 Ev w1 and w2
193 Ev 107, para 3.2
194 Ev w122, para 28
195 Ev w188, para 14
196 Ibid.
197 Ev w125
198 Ev w188, para 15
conditions care. The Anti-Coagulation Self-Monitoring Alliance (ACSMA) proposed a number of practical measures to support commissioners, including “identifying the prevalence and incidence of people requiring anticoagulation services in a local health economy; a national patient experience survey of people using anticoagulation services; incentives and payments directed more towards prevention of ill-health; and engaging with patients and service users in service design.” We draw from this proposal the inference that such support for commissioners of such services does not presently exist on any significant scale.

157. The DAFNE programme, a collaboration of 75 diabetes services from NHS Trusts and Health Boards across the UK and the Republic of Ireland, believed that commissioners often did not fully understand the difference in treatment needs and education requirements between type 1 and type 2 diabetes, and thought it “counterproductive” to expect commissioners to “reinvent the wheel” when commissioning services for type 1 diabetes when a national programme of support and education—such as that provided by DAFNE—was available.

158. National Voices, the coalition of health and social care charities, reminded the Committee that the Health and Social Care Act 2012 had introduced common duties on NHS England and CCGs to promote the involvement of each patient in decisions related to the prevention, diagnosis, care and treatment of their conditions. They advocated the creation of a coalition of third sector organisations, experts and think tanks “to gather momentum around the House of Care approach and to challenge commissioners to develop and implement it”. The Health Foundation told us that in their view commissioners lacked “an understanding of person-centred care and ‘how to get it’”; some commissioners recognised the role of supported self-management for long-term conditions in reducing pressure on services, but overall commissioners showed a “mixed” understanding of effective self-management support, and some were “unsure” about how to commission it.

159. The British Society for Rheumatology pointed out that practices in the collection of data to inform commissioning and treatment had not evolved to take account of changes in treatment options for rheumatology: for instance, because of advances in medication, patients with rheumatic disease were now largely treated in ambulatory settings rather than in acute wards. BSR considered that commissioners had little to inform their service specifications, and there was insufficient public health epidemiology data on rheumatic conditions—of which there are over 200—to inform Joint Strategic Needs Assessments. Parkinson’s UK was concerned that NHS commissioning outcomes frameworks lacked specific indicators and outcomes for neurological conditions, with the possible consequence that commissioners would focus on targets set by NHS England and pay less...
attention to addressing indicators and outcomes which were cross-cutting and where benefits were more difficult to demonstrate.205

160. The Nuffield Trust summarised the outcome of a research project observing commissioning practice in three sites thought to be at the forefront of commissioning best practice—Calderdale, Somerset and the Wirral—from November 2010 to January 2012.206 The study focused on commissioning for diabetes services in all three sites, and for dementia in Calderdale and the Wirral and stroke in Somerset. The study demonstrated the intensive nature of commissioning work in the implementation and support of change, and indicated a degree of collaborative working between providers and commissioners. Commissioners were observed to shy away from challenging providers and decommissioning services, preferring to consult on service improvements and develop existing relationships. The Trust thought that in the new commissioning environment commissioners might have to make more difficult decisions on the future of services and be prepared to “cut and run” rather than continue consultative processes when they believed local services had to be changed. Commissioning in the new environment was likely to be “a lonely role” if done well, as commissioner proposals for service change would threaten existing professional and provider interests and could prove unpopular in the community. The Trust proposed a comprehensive set of the support services commissioners would need to take on their new role effectively:

Commissioners will need intelligence from commissioning support units to challenge providers on quality and value for money, and where necessary, use procurement to let contracts for services for their populations. This should include high-quality public health and needs assessment advice, sophisticated and real-time data about services, accurate comparisons with national benchmarks, efficient payment and invoicing systems, support for modelling and planning future care. In addition, commissioners will need support in undertaking public consultation, accessing and analysing patient and public experience data, providing local system leadership, and handling procurement within a cultural context of collaboration.207

161. The Nuffield Trust also indicated how some local areas had sought to overcome barriers to integration of services. In addition to the North West London Integrated Care Pilot discussed above, a collaboration of NHS organisations serving a population of 215,000 people in Trafford had collaborated to redesign care pathways, share data, identify patients at risk of unplanned hospitalisation and test approaches to implement and evaluate integrated care. In both North West London and Trafford the Trust observed that the drivers for integrated working had arisen locally rather than under central direction: whatever the outcome of the 14 integration pioneers being promoted by the Department of Health and NHS England, other local examples of innovation were bound to emerge in response to funding pressures and should be evaluated and supported.208

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205 Ev w127, para 9.5
206 Ev 129-130
207 Ev 130
208 Ev 129, para 3.5
162. The Trust identified one possible factor which could inhibit moves to commission more coordinated community-based services: the competition and choice regime, the scope for regulatory action and the operation of procurement law could inhibit commissioners in planning service redesign and innovation. They also considered that the burden of proof on commissioners wishing to redesign services would be substantial, as the benefits of any service redesign which theoretically reduced competition and patient choice would have to be demonstrably "significant, quantifiable and evidence-based". The Trust thought this would be a high bar to meet, particularly given the time required for full evaluation of the benefits of large-scale integrated care projects.209

Changes in primary care commissioning: the Proactive Care Programme

163. In April 2014 the Department of Health and NHS England announced changes to the GP contract which potentially presage a broader shift in the way that primary care services delivered through the GP surgery are commissioned. The Proactive Care Programme is intended to provide greater integration and personalisation in the care and support of those over 75 and those with the most complex health and care needs. GPs will be expected to identify at least two per cent of the population on their practice list with complex needs who will benefit the most from more integrated approaches to the management of their care.210

164. The Department of Health expects over 800,000 people to be eligible for the programme. Those enrolled on the programme by their GP practice are promised the following:

- A personalised care and support plan
- A named GP who will oversee the care and support provided and be accountable for it
- A care coordinator who will provide advice on the planning and provision of health and care services
- Telephone consultations with the GP surgery
- Follow-up care after any discharge from hospital treatment

165. The programme depends on substantial multidisciplinary working, engaging community nurses, community pharmacy, allied health professionals, social workers care assistants, volunteers and others to deliver care. The impact of the programme is to be measured and evaluated locally and nationally, with the aim of providing similarly personalised care planning services through general practice to more of the population.

209 Ibid., para 3.6
210 Transforming Primary Care, p. 17
Our view

166. To be effective and sustainable, any reshaping and integration of services for people with long-term conditions must be designed and implemented at local level with the participation and support of leaders of the local health and care systems and active collaboration with the local Health and Wellbeing Board. Models promulgated from the centre are unlikely to work without substantial local adaptation and acceptance.

167. Support and guidance for those commissioning services for long-term conditions appears to be unevenly distributed. Charities and other third sector organisations supporting those with some of the more common conditions or groups of conditions can provide substantial guidance and advice to commissioners on how to plan the provision of services for those with long-term conditions in the local area: but this advice and support is not uniform across all conditions. The NICE quality standards which should inform commissioning decisions are welcome, where they exist, but the provision of such standards is not yet comprehensive. We recommend that NHS England review the condition-specific guidance, quality standards and support available to commissioners from the NHS, from NICE and from third parties with a view to identifying and filling gaps in the support available to commissioners.

168. Guidance from the Department of Health and NHS England will be vital in assisting commissioners to shape the changes in services for long-term conditions, but the centre must not prescribe solutions which local health economies are better placed to determine. The contribution of each Health and Wellbeing Board to the determination of commissioning priorities for long-term conditions across each local area will be significant: Boards have a vital contribution to make to the development of the broadest appropriate range of services across the area they serve, taking into account the demand for patient choice. Similarly, commissioners must be flexible and innovative in identifying the providers to deliver the mix of services which will best achieve the objectives for management of long-term conditions in their area.

169. We recommend that commissioners should engage providers and the public as fully as possible in discussions about objectives for health and wellbeing outcomes in their local area and how they might be best be achieved. Commissioners should also explicitly relate payment to outcomes achieved. Local Healthwatch organisations have a role to play in examining how commissioning priorities have been delivered.

A payment system which supports effective commissioning for outcomes

170. Underpinning all commissioning decisions in the NHS is a payment system which governs how funding flows from commissioners to providers of NHS care. The design of this system is of course hugely influential in determining how all healthcare is funded and provided across the NHS, and is consequently key to any redesign of NHS systems to increase effective management of long-term conditions. As we pointed out in our report on our 2012 accountability hearing with Monitor, “The setting of the tariff [for NHS payments] is of great significance to the NHS because of its implications both for short term cash flows in the system, and for longer term incentives for service design. [...] The
long-term framework of the tariff will have an immediate effect on service design and the integration of service provision.”211

**Issues with the present system**

171. Several witnesses identified the prevalence of the present Payment by Results (PbR) tariff for acute care as a major barrier to the commissioning and development of new approaches to the treatment of long-term conditions integrated around treatment of the person. We have ourselves argued that the current tariff arrangements often create perverse incentives for providers and inhibit necessary service change.212 Dr Nigel Mathers of the Royal College of General Practitioners told us that that reform of PbR was urgently required to incentivise the management and treatment of long-term conditions outside acute care.213 The NHS Confederation suggested that the NHS should be developing payment systems that incentivised prevention, early intervention, early supported discharge and more integrated working.214

172. Professor Alan Maynard, speaking from experience as a chair of a clinical commissioning group, doubted whether, under present structures, any progress could be made in reducing the number of long-term condition service users treated in acute settings while the tariff continued to benefit hospitals treating patients with long-term conditions:

> [T]he difficulty as you try and develop community initiatives, and hopefully evaluate them, how do you take resources out of the providers? So if you put diabetes care into the community, the risk is that the resources are still going to stay in the hospital. They have this hopper of bodies that they can treat, and they pull down the hopper and get payment by results. The incentive system maintains the income of the hospital, which is a bit frustrating when you are trying to economise and improve quality. The risk is that you do your community stuff and improve the quality, but you are not really doing much in terms of saving resources because, basically, [CCGs] are price takers. So if you are a CCG, we cannot fix the price, which is a bit strange.215

173. Martin McShane, of NHS England, recognised the need to establish a new and comprehensive tariff structure for the management of long-term conditions care:

> [T]he evidence from elsewhere is that you need to set that [tariff] across the whole system, linking the hospital, the community services and the general practice. There needs to be a proportionate risk for all those players. You cannot do it on an episodic, fragmented basis.216

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213 Q207
214 Ev w200, para 4.2
215 Q31
216 Q276
The Minister of State told us that “the overwhelming need to change from a system that incentivises activity is clear to everyone.”  

174. We observe that the development of the “new and comprehensive tariff” envisaged by NHS England will need to take multiple factors into account: a comprehensive model will, for example, need to facilitate shifts in the balance of investment in services, including decommissioning services no longer considered appropriate, while also providing funding for local authority and other functions as well as NHS expenditure.

**Developing a Year of Care tariff**

175. The Department of Health’s QIPP (Quality, Innovation, Productivity and Prevention) programme, which was established to drive forward quality improvements in NHS care at the same time as making the efficiency savings required by the Nicholson Challenge, included a workstream designed to support local implementation of the Year of Care Funding Model for people with long-term conditions. The funding model published by the Department described a potential new way of funding care for long-term conditions, developed to support health and social care providers to integrate care “in a more successful and sustainable way by better aligning the funding flows and incentives with peoples’ needs.”

176. Following the closure of the Department of Health’s QIPP workstreams in March 2013 and their transfer to NHS England, the programme has been taken up under the umbrella of the National Collaboration for Integrated Care and Support. The model under test is an annual risk-adjusted capitation budget based on levels of need. NHS England now believes that this model has the potential to change the payment system for up to 20 to 25% of the total health and social care budget in England, while providing better incentives to providers to improve the efficiency and effectiveness of services for patients. Seven ‘early implementer’ sites, comprising commissioners and providers, have been working since July 2012 towards implementation of the payment model: “shadow-testing” of the Year of Care currency is expected in 2014/15, with full implementation in 2015/16.

177. Martin McShane, of NHS England, told us that the programme was “discovering some quite exciting information.” According to NHS England the achievements of the programme to date include the development of a whole-population analysis approach which can support the development of a national funding framework on the Year of Care model, guidance on collecting the evidence required to demonstrate the effectiveness of earlier discharges from acute care, and the provision of an initial estimate of local per-patient tariffs which might be applied to reimburse providers depending on the health and social care needs of the population cohort addressed. NHS England envisages eventually

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217 Q282
218 QIPP Long Term Conditions: Supporting the local implementation of the Year of Care funding model for people with long-term conditions, Department of Health, April 2012
219 Ibid., p. 6
220 Ev 131
221 The ‘early implementer’ sites are Leeds; Southend; Kent; North Staffordshire and Stoke on Trent; West Hampshire; Barking, Havering and Redbridge, and Kirklees
222 Q276
applying the Year of Care funding model to other groups of service users who receive services delivered through more than one provider.

178. The development of a funding model which supports a ‘year of care’ approach to payment for the treatment of long-term conditions, rather than an approach to funding based on episodes of care, is welcome. We look to NHS England and the Department of Health to collaborate with Monitor in refining, developing and implementing this approach to funding for long-term conditions, based on an evaluation of the experience of the model in the early implementer sites.

**Long-term reform of NHS payment systems**

179. The Health and Social Care Act 2012 gives NHS England and Monitor joint responsibility for the payment system for NHS funded care, starting with the financial year 2014/15. In May 2013 both organisations issued a joint discussion paper examining the future of the NHS payment system. They indicated that for 2014/15 the list for nationally-mandated services and their prices—the National Tariff—would remain very close to the tariff agreed for 2013/14, since both commissioners and providers required a payment system to be predictable: some local experimentation would be authorised in order to support redesign of services and to develop a programme for research and development. The formal consultation notice on the 2014/15 tariff was issued in October 2013, and the tariff itself was issued in December 2013. Consultation on the design of the 2015/16 tariff began in February 2014.

180. NHS England and Monitor have indicated their plan to move towards “a single coherent system governing the payment of NHS services”. The objective they have jointly set is to design an “overarching payment system” which will enable prices to be set at a national level and varied at local level, and which will “be appropriate for all aspects of health care”. They indicate that a review of the operation of the present Payment by Results (PbR) system is necessary, although PbR had supported provider choice and had encouraged hospitals to keep down unit costs, evidence from commissioners and providers, supported by a number of recent reports, had indicated that the present system “does not always promote the best service design for patients”. NHS England and Monitor note that “there are few types of care in which paying for activities is sufficient to encourage the best patient outcomes”, and that a new payment system could be used to promote better integration of coordinated person-centred care both within the health sector and across health and social care.

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223 How can the NHS payment system do more for patients? A discussion paper, Monitor and NHS England, 13 May 2013
224 Ibid., p. 3
226 How Monitor and NHS England are working to make the payment system do more for patients from 2015/16, Monitor and NHS England, February 2014
227 How can the NHS payment system do more for patients?, p. 8
228 Ibid.
229 Ibid., p. 9
230 Ibid.
outcomes, rather than processes, would evidently influence the behaviour of providers and commissioners alike:

Paying for patient outcomes, if possible, can challenge a provider to decide how best to achieve those outcomes, alone or with partners. Designing the payment system to account for links between health care, social care, public health, housing, education and employment could stimulate more innovative ways to improve outcomes for local people.\(^{231}\)

181. The Minister of State suggested that the process of tariff reform would be facilitated and encouraged by imaginative use of existing flexibilities in the tariff system, especially by the integrated care pioneers:

We are saying to [the pioneers], “If you want to redesign your payment systems, your incentives, so that your acute hospital has a stake in keeping people out of hospital, go ahead and do it, and we will encourage and facilitate you doing that.” That then provides the learning for the rest of the system. As I understand it, there is work going on between NHS England and Monitor to redesign a national tariff approach, but there is this encouragement, not just passive acceptance, for areas to get on and experiment now, developing their own variations on that theme, using the Year of Care that has been developed.\(^{232}\)

Dr McShane described the encouragement to experiment, taken together with the guidance from NHS England to CCGs on planning services for the period to 2018/19, as “a tipping point” for tariff change.\(^ {233}\)

182. In our report on the 2013 accountability hearing with Monitor, we repeated our view that Monitor should attach a higher priority to its work on tariff reform, and further recommended that Monitor and NHS England “should initiate a formal joint process for a prioritised review of the NHS tariff arrangements with the objective of identifying and eliminating perverse incentives and introducing new tariff structures which incentivise necessary service change.”\(^ {234}\)

183. Monitor’s proposed linkage of payment systems to outcomes, rather than processes, will be highly significant if implemented. Mechanisms designed to promote a different balance of services and care will, for example, have to take into account the funding of links between health care, social care, public health, housing, education and employment. This will require a more joined up approach to the management of long-term conditions within government than presently appears to be the case.

184. Monitor has indicated that a final version of the joint long-term strategy on reform of the payment system will be published in the summer of 2014. We recommend that this strategy explicitly include processes to identify and eliminate perverse incentives in the present payment structure and to develop systems which

\(^{231}\) Ibid, p. 11
\(^{232}\) Q282
\(^{233}\) Q276
\(^{234}\) 2013 accountability hearing with Monitor, para 52
incentivise models of care centred upon all the needs of the service user. We further recommend that Monitor and NHS England evaluate the results of any tariff flexibilities used in the 14 integration pioneer sites, as well as the general flexibilities introduced in the 2014/15 tariff, and that the interim and final findings of the evaluation should be published.235

The 2014/15 tariff and parity of esteem for mental health services

185. We note that the guidance to commissioners on the application of the 2014/15 tariff indicates that they should apply a 1.8% reduction in payments for non-acute providers and a 1.5% reduction for acute providers. The disparity between the reductions in payment has caused considerable concern, particularly in view of its likely effect on services for those with long-term conditions which are provided through mental health trusts: concerns have been raised with the Committee in the course of its inquiry into children’s and adolescent mental health services and CAHMS. The Minister of State has indicated that he considers the decision by NHS England to cut the tariff for mental health and community providers in a different way from acute providers to be “flawed”, and we agree.236 The Minister has said that there is scope for CCGs and NHS England commissioners to agree with providers “to vary prices at a local level where there is a specific and legitimate reason to do so”, 237 and has stated that

This Government expects commissioners to demonstrate parity of esteem—equality for mental health—when agreeing financial settlements with mental health providers and we believe it is unacceptable to disadvantage mental health when allocating local funds.238

186. We find it difficult to understand how parity of esteem between physical and mental health services can be established, let alone maintained, when Monitor and NHS England have introduced a pricing structure for 2014/15 which has the explicit effect of reducing expenditure for mental health services at a greater rate than expenditure on acute services to treat physical conditions. We agree with the Minister of State that the differential pricing structure is flawed: in our view, it risks a disproportionate reduction in funding to mental health services. Monitor and NHS England must set out in their response to this report what steps they plan to take to support parity of esteem, both through the present tariff system and their proposals for tariff reform.

The effects of system change

187. Many of the arguments made to us advocating a change in management of long-term conditions in the health and care system have suggested that the provision of more personalised and integrated models of care outside the acute sector represents a “win-win” outcome: a move away from an unsustainable treatment model leads not only to better

235 The locations of each integration pioneer site are listed as a footnote to paragraph 20.
238 Ibid.
outcomes for patients but also a more effective use of public money in the NHS and in social care.

188. It is nevertheless worth reflecting on some of the implications of the substantial changes to the present model of provision which have been mooted. The Minister of State indicated that the ambition of achieving integrated health and care services by 2017 had been given “quite a turbo charge” by the introduction of the Better Care Fund and the initial pooling of health and social care budgets which the fund promoted: as a consequence “by 2015 the whole country will be starting to see a significant change. It does not all happen overnight, but there will be significant changes happening by then.”

The scale and pace of change

189. Dr Sue Roberts suggested that the delivery system for long-term condition management associated with the House of Care model would deliver “a tailored, personalised package of care and support for each of the 15 million people with one or more LTCs.” This is a laudable objective for the provision of better care, but it seems improbable to us, on the evidence we have seen, that the prerequisites for the wholesale move to this model—sufficient health professionals trained in care planning and person-centred condition management, a tariff system which prices and allocates resource effectively, and the infrastructure in primary and community care to support an effective care planning approach—are yet available in any NHS England area or region, let alone nationally.

190. CCG plans for commissioning services the five years to 2018/19, which were due to be submitted to NHS England by June 2014, may indicate the extent to which CCGs have foreseen demand for care planning and have begun to commission community services to support those with long-term conditions. But it is only at the point at which NHS England assesses and collates the CCG plans that the scale of the “significant” change predicted by the Minister, and the likely pace of change, will become apparent.

Will the change reduce costs?

191. As we have discussed above, there is evidence for cost savings from the redesign of services for people with long-term conditions in areas where such approaches have been trialled, though the robustness of some of the evidence for cost-effectiveness has been challenged and cost-effectiveness gains from large-scale reorganisations of services can by no means be guaranteed.

192. Funding for the implementation costs of some pilots have been found from anticipated efficiencies elsewhere: we referred above to the allocation of £7 million to the North West London Integrated Care Pilot from commissioner funding which would otherwise have been spent on payments for readmissions to acute providers under the marginal tariff. Clinical commissioning groups are required to hold back 2% of their allocation each year for non-recurrent expenditure, and the Department of Health has

239 Q246
240 Ev 86 and Q19
indicated that such funds could be used on changes in service mix and the redesign of services.

193. There is nevertheless no guarantee that changes to service design will in the short term be cost-neutral or even result in savings. Redesigning services should not be done on the cheap, but in an era of little or no growth in the health and care budget, expenditure on service redesign is likely in the short term to have to be met by spending reductions or efficiencies elsewhere.

The effect on the acute sector

194. Care planning for long-term conditions management in primary and community care is intended to have the effect of reducing the number of unplanned admissions to acute care services, which by common consent are recognised to be expensive, thereby freeing resource in the acute sector and reducing overall expenditure on long-term conditions. It follows that any substantial changes to the service mix which reduce the activity and the income of district general hospitals generated from treating inpatient and outpatient cases with long-term conditions is bound to have an effect on the acute sector. We note that in the more general context of integrating health and care services, one of the six conditions established for access to the Better Care Fund is “agreement on the consequential impact of changes in the acute sector”: local areas are required to identify what the impact of integrating services will be on each provider, and will be required to assure NHS England that there has been engagement with patients, service users and the public on such changes, as well as “plans for political buy-in”.

195. Put bluntly, a transfer of services for long-term conditions from acute to community and primary care may well under existing tariff arrangements lead to a substantial drop in provider income. While providers may be able to mitigate the effects of reduced tariff income by reducing the services provided for which there is less demand, the effect of such reductions may well lead to a reassessment of the services offered and consequent pressure to reconfigure acute providers. Merely shrinking a hospital’s services in line with reduced demand is in itself unlikely to guarantee the sustainability of the provider: fixed overheads, such as minimum staff and equipment costs and (in some cases) ongoing payments for the construction of new facilities limit a provider’s room for manoeuvre.

196. We asked the Minister whether the Department had made any estimate of the number of beds which might be released from the acute sector following any large-scale transition of long-term conditions care to the primary and community sectors. While he had not seen any estimate which may have been made, he was clear that the drivers behind the integration of services should lead to changes in acute provider capacity:

I want the incentives in the whole system to be aligned—and they are not at the moment. You have an acute hospital that is incentivised to do more, and that is not aligned with what people in community care are trying to do for their patients. We have to change that fundamentally.241

241 Q294
I do not have a figure in my mind [for acute bed usage] that in a new world it would be, but I do recognise that when you go and see Kaiser Permanente you see a much lower bed utilisation in hospital because they are keeping people healthier, and that is ultimately what our objective surely should be.242

197. In our recent report on Public expenditure on health and social care we concluded that “advocating service integration without recognising that the consequence of integration is reconfiguration of acute services is simply dishonest”, a conclusion which we are happy to repeat here. We observed that the argument for reconfiguration, leading to reduced emphasis on acute services, was supported by considerations of clinical quality as well as economic pressures, and noted that the present health and care system placed insufficient emphasis on identifying early symptoms and supporting normal life, with the result that it provided reactive acute care to patients whose condition should never have been allowed to become acute. The benefit of including Health and Wellbeing Boards in the commissioning decisions about health and care, with a single overview for a given community, should be to engage the local professional and lay communities in a greater understanding of the care quality issues which underlie the case for service reconfiguration, as well as the economic issues involved.243

198. We note with approval that a requirement of participation in the Better Care Fund is for local NHS areas to engage with patients, service users and the public on proposals for new integrated services and the consequences for acute service provision. Such engagement should be frank and comprehensive and should make the case for improvements in clinical outcomes and care quality.

199. Without an agreed package for change, and a corresponding commitment to implementation, any large-scale attempt to vary the mix of services for people with long-term conditions is unlikely to succeed. We recommend that NHS England, as part of its five-year planning round, undertakes modelling of the effect of commissioner plans on the acute sector by 2018/19. The likely scenarios for each NHS England area should be referred to the relevant Health and Wellbeing Boards for scrutiny and debate.

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242 Q299

243 Health Committee, Public expenditure on health and social care, Seventh Report of Session 2013-14, HC (2013-14) 793, para 70
Conclusions and recommendations

Strategic direction of services for long-term conditions

1. We note with interest the establishment of 14 pioneer sites which are intended to address existing barriers to the integration of health and care services and indicate where such barriers need to be broken down by work at national level. We plan to examine the work of these integration pioneers in greater detail in a separate inquiry. (Paragraph 21)

2. We welcome the commitment of the National Collaboration for Integrated Care and Support to ensuring that all localities in England have adopted models to commission and deliver integrated care and support by mid-2015. We recommend that the Department of Health monitor progress towards the achievement of this objective and publish by July 2015 its assessment of the extent to which each locality in England has adopted models to commission and deliver integrated care and support, together with its assessment of the strengths and weaknesses of different models and approaches in particular contexts. (Paragraph 22)

3. We note the claims made by the Department of Health and NHS England for progress against the objectives set out in the Mandate. We are nevertheless not persuaded that the claims made to us represent substantive progress against the measurable objectives given to NHS England such as they are. The publication of a resource to assist service users in personalising their services is not in itself evidence of progress in their experience of care or improvement in their quality of life. (Paragraph 30)

4. The intention in the Mandate and the NHS Outcomes Framework to establish measures to indicate progress in the enhancement of quality of life for people with long-term conditions is welcome. We nevertheless note that a number of these indicators are still in development or have been introduced so recently that they cannot demonstrate in any meaningful sense what progress may have been made by the NHS in increasing the quality of life for people with long-term conditions by March 2015. We recommend that in its response to this report the Department of Health should quantify the “measurable progress” it expects NHS England to have achieved against clearly specified baseline measures for all relevant Mandate objectives for long-term conditions. NHS England should similarly set out in response to this report the progress it has made against each objective against the same baseline measures together with its estimate of likely further progress by March 2015. Where such indicators and baselines are not yet available the Department should be transparent about the extent to which measurable objectives can be said to exist and consider how those objectives should be developed and modified. (Paragraph 31)

5. We note that the original plan to develop a national strategy for long term conditions was explicitly cross-government in its perspective and involved participants from 12 Government departments. This attempt to develop a joined-up, government-wide approach to the management of long-term conditions has been dropped following
the transfer of policy responsibility from the Department of Health to NHS England. The Department and NHS England should clarify how cross-departmental working is to be continued in the absence of a cross-Government strategy. (Paragraph 41)

6. We are concerned that the growth in demand arising from long-term conditions and associated patterns of co-morbidity has not been matched by the urgency with which the Department of Health and NHS England have developed their strategic responses. This finding is of particular concern since the long-term conditions agenda lay at the heart of the Nicholson Challenge to achieve transformative change in the delivery of health and care services. We recommend that in its response to this report NHS England set out clearly:

- the changes it considers necessary to better support people with long-term conditions;
- the strategic objectives such changes are meant to fulfil;
- the plan it has devised for achieving such changes;
- the steps to be taken to engage other relevant Government departments in the delivery of such changes, and
- the milestones it has set for delivery. (Paragraph 42)

7. The Secretary of State should publish, as part of his response to this report, a statement of the changes the Government would wish to see incorporated into the next refresh of the Mandate in respect of long-term conditions, including a statement of the urgency he attaches to their delivery. (Paragraph 43)

8. We further recommend that NHS England report to the House by October 2014 at the latest on the outcome of its 2014 planning round, setting out in detail its assessment of the aggregate effect on the health economy of England and of each NHS England area of the local plans made by each clinical commissioning group. (Paragraph 44)

Clinical care for people with long-term conditions

9. We recommend that in revising its present clinical guidelines and developing further guidelines the National Institute for Health and Care Excellence should routinely take into account the incidence of multiple morbidities and the attendant risks of polypharmacy. (Paragraph 57)

10. The objective of the health and care system in treating people with long-term conditions should be to improve the quality of life of the person. At a time when increasing numbers of people requiring support and treatment from the system have multiple conditions combining physical health, mental health, social care and other support requirements, it seems anachronistic that the Department’s definition of long-term conditions appears to emphasise a single-disease approach to treatment. We recommend that the Department revise its working definition of long-term conditions to emphasise the policy objective of treating the person, not the
condition, and of treating the person with multiple conditions as a whole. (Paragraph 59)

11. The evidence the Committee has taken on diabetes services demonstrates the need for a general rebalancing of commissioning and care pathways for long-term conditions. These should provide treatment which is integrated across primary, community, secondary and social care settings. We recognise the benefits to the patient and to the health and care system of robust support for self-management of long-term conditions. (Paragraph 80)

12. We view with concern reports of apparent downgrading of the role of, and reductions in the numbers of, specialist nurses. Their expertise is vital in supporting an integrated system of care for diabetes, from self-management through to acute and specialist services. (Paragraph 81)

13. The purpose of a health and care system designed to manage the care of people with long-term conditions must be to deliver interventions which are as effective as possible in sustaining and prolonging the quality of life of the service user. Moreover, such interventions are unlikely to be restricted to those within the remit of health and social services. We wholeheartedly endorse the principle that systems for the management of long-term conditions must be designed to be responsive to the service user’s needs and priorities for their own wellbeing. (Paragraph 93)

14. We consider that in order to meet its objective of empowering patients fully in their care, NHS England should promote the introduction of individual care planning for service users with long-term conditions. NHS England should adopt and adapt the principles underpinning the House of Care approach as necessary and should seek to eliminate barriers to effective integrated working. The House of Care model and its associated delivery system provide a sound conceptual framework to analyse and determine an individual’s care needs. However, care must be taken to ensure that the wishes and requirements of the service user are not subordinated to rigid and inflexible care planning protocols. (Paragraph 94)

15. We note that greater involvement of service users in discussions and decisions about treatment of their long-term conditions will inevitably increase the demand for commissioning of complementary and alternative treatments by patients who feel that they have gained benefit from them in managing their conditions or who believe these treatments will be effective. The test for commissioners and health and care professionals will be how to evaluate and measure the effectiveness of such interventions appropriately, and to determine whether they will deliver improved outcomes in terms of better quality of life. (Paragraph 102)

16. We recognise the considerable benefits to patients and the health and care system of greater use of electronic records, better information sharing and more supported self-management. The NHS is nevertheless designed as a universal service and its benefits must be accessible to all. Advances which will benefit the engaged, informed and technologically-literate patient must not be pursued to the disadvantage of those who are vulnerable or unable to access new opportunities for better care. (Paragraph 108)
17. We note with concern the shortfall in the primary care workforce projected by the Centre for Workforce Intelligence. We recommend that Health Education England set out clearly how they plan to address this projected shortfall. (Paragraph 115)

18. If care planning, integrated services, multidisciplinary working and supported self-management of long-term conditions are to become common practice across the health and care system, the requirement for structural and cultural change at all levels will be extremely challenging. Medical professionals in all disciplines who are treating those with long-term conditions will in many cases have to adapt their ways of working with patients and with those from other disciplines. (Paragraph 116)

19. We recommend that Health Education England, in response to this report, sets out its strategy for the adaptation of the present medical workforce, and the training of the future workforce, to the delivery of a model of integrated care centred on the person. Such training should also encourage those specialising in one discipline to develop an understanding of the functioning and the capability of other healthcare disciplines and therapies. (Paragraph 117)

Managing the system to deliver better care for long-term conditions

20. We doubt whether necessary change in health and care provision for the long term will be achieved through measures which merely address the symptoms of poor management of many chronic ambulatory care-sensitive conditions, namely excess unplanned admissions to acute providers. The priority for the Department of Health and NHS England should be to address the underlying structure of services and incentives which send so many patients with CACSCs to acute care in the first place. (Paragraph 128)

21. While the prevailing assumption may be that people with long-term conditions would welcome treatment being provided through community or primary care as close to home as possible, this approach should not be taken for granted in the design of systems to support the management of long-term conditions. Many conditions will continue to require treatment to be provided being provided in specialised secondary care settings. (Paragraph 135)

22. Robust evidence on the long-term clinical effectiveness and cost-effectiveness of large-scale changes to the mix of services for long-term conditions is lacking. We consider that such evidence is vital to making the case for, and informing the design of, any form of sustainable service change which is to command widespread support. We therefore recommend that NHS England commission sufficiently rigorous studies of the effectiveness of services for people with long-term conditions which are delivered through integrated models of care, and that the outcomes for health and for cost-effectiveness across all settings are regularly and rigorously evaluated. (Paragraph 149)

23. We recommend that NHS England review the condition-specific guidance, quality standards and support available to commissioners from the NHS, from NICE and from third parties with a view to identifying and filling gaps in the support available to commissioners. (Paragraph 167)
24. Guidance from the Department of Health and NHS England will be vital in assisting commissioners to shape the change in services for long-term conditions, but the centre must not prescribe solutions which local health economies are better placed to determine. The contribution of each Health and Wellbeing Board to the determination of commissioning priorities for long-term conditions across each local area will be significant: Boards have a vital contribution to make to the development of the broadest appropriate range of services across the area they serve, taking into account the demand for patient choice. Similarly, commissioners must be flexible and innovative in identifying the providers to deliver the mix of services which will best achieve the objectives for management of long-term conditions in their area. (Paragraph 168)

25. We recommend that commissioners should engage providers and the public as fully as possible in discussions about objectives for health and wellbeing outcomes in their local area and how they might be best be achieved. Commissioners should also explicitly relate payment to outcomes achieved. Local Healthwatch organisations have a role to play in examining how commissioning priorities have been delivered. (Paragraph 169)

26. The development of a funding model which supports a ‘year of care’ approach to payment for the treatment of long-term conditions, rather than an approach to funding based on episodes of care, is welcome. We look to NHS England and the Department of Health to collaborate with Monitor in refining, developing and implementing this approach to funding for long-term conditions, based on an evaluation of the experience of the model in the early implementer sites. (Paragraph 178)

27. Monitor has indicated that a final version of the joint long-term strategy on reform of the payment system will be published in the summer of 2014. We recommend that this strategy explicitly include processes to identify and eliminate perverse incentives in the present payment structure and to develop systems which incentivise models of care centred upon all the needs of the service user. We further recommend that Monitor and NHS England evaluate the results of any tariff flexibilities used in the 14 integration pioneer sites, as well as the general flexibilities introduced in the 2014/15 tariff, and that the interim and final findings of the evaluation should be published. (Paragraph 184)

28. We find it difficult to understand how parity of esteem between physical and mental health services can be established, let alone maintained, when Monitor and NHS England have introduced a pricing structure for 2014/15 which has the explicit effect of reducing expenditure for mental health services at a greater rate than expenditure on acute services to treat physical conditions. We agree with the Minister of State that the differential pricing structure is flawed: in our view, it risks a disproportionate reduction in funding to mental health services. Monitor and NHS England must set out in their response to this report what steps they plan to take to support parity of esteem, both through the present tariff system and their proposals for tariff reform. (Paragraph 186)
29. We note with approval that a requirement of participation in the Better Care Fund is for local NHS areas to engage with patients, service users and the public on proposals for new integrated services and the consequences for acute service provision. Such engagement should be frank and comprehensive and should make the case for improvements in clinical outcomes and care quality. (Paragraph 198)

30. Without an agreed package for change, and a corresponding commitment to implementation, any large-scale attempt to vary the mix of services for people with long-term conditions is unlikely to succeed. We recommend that NHS England, as part of its five-year planning round, undertakes modelling of the effect of commissioner plans on the acute sector by 2018/19. The likely scenarios for each NHS England area should be referred to the relevant Health and Wellbeing Boards for scrutiny and debate. (Paragraph 199)
Formal Minutes

Wednesday 18 June 2014

Members present:

Rosie Cooper  David Tredinnick
Barbara Keeley  Valerie Vaz
Grahame M. Morris  Dr Sarah Wollaston
Virendra Sharma

Mr Stephen Dorrell having resigned as Chair, Mr David Tredinnick took the chair for the meeting, pursuant to the order of the Committee of 10 June 2014.

Draft Report (Managing the care of people with long-term conditions), proposed by the Chair, brought up and read.

Ordered, That the draft Report be read a second time paragraph by paragraph.

Paragraphs 1 to 199 read and agreed to.

Summary agreed to.

Resolved, That the Report be the Second Report of the Committee to the House.

Ordered, That the Chair make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

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[Adjourned till Tuesday 24 June at 2pm]
Witnesses

Tuesday 18 June 2013

Dr Karen Lowton, Senior Lecturer in Ageing and Health, Institute of Gerontology, King’s College London, Professor Alan Maynard OBE, Professor of Health Economics, Department of Health Sciences, University of York, Dr Sue Roberts CBE, Chair, Year of Care Partnerships, and Dr Judith Smith, Head of Policy, Nuffield Trust

Wednesday 16 October 2013

Professor Alan Silman, Medical Director and Director of Policy and Health Promotion, Arthritis Research UK, Baroness Young of Old Scone, Chief Executive, Diabetes UK, and Dr Peter Aitken, Chair of the Faculty of Liaison Psychiatry, Royal College of Psychiatrists

Don Redding, Director of Policy, National Voices, and Liz McAnulty, Trustee, The Patients Association

Tuesday 29 October 2013

Dr Peter Fisher, Clinical Director and Director of Research, Royal London Hospital for Integrated Medicine, and Professor George Lewith, Professor of Health Research, University of Southampton

Professor Nigel Mathers, Vice Chair of Council, Royal College of General Practitioners, Alastair Buxton, Head of NHS Services, Pharmaceutical Services Negotiating Committee, Emily Holzhausen, Director of Policy and Public Affairs, Carers UK, and Victoria Matthews, Assistant Long Term Conditions Adviser, Royal College of Nursing

Tuesday 12 November 2013

Norman Lamb MP, Minister of State for Care and Support, Department of Health, and Martin McShane, Director, Improving the quality of life for people with long-term conditions, NHS England
List of printed written evidence

1. Department of Health supplementary       Ev 80
2. NHS England supplementary        Ev 81
3. Dr Peter Fisher, Royal London Hospital for Integrated Medicine and Professor George Lewith, University of Southampton Ev 82
4. Dr Sue Roberts                    Ev 85
5. Pharmaceutical Services Negotiating Committee       Ev 92
6. Dr Karen Lowton, King’s College London       Ev 94
7. Professor Alan Maynard       Ev 98
8. Arthritis Research UK         Ev 100
9. Diabetes UK                    Ev 104
10. Patients Association          Ev 108
11. Royal College of Nursing      Ev 112
12. The Royal College of Psychiatrists       Ev 116
13. National Voices                Ev 120
14. The Royal College of General Practitioners       Ev 123
15. Nuffield Trust                 Ev 127

List of additional written evidence

(published in Volume II on the Committee’s website www.parliament.uk/healthcom)

1. Arthritis Care                           Ev w1
2. British Acupuncture Council            Ev w4
3. The Royal College of Radiologists       Ev w5
4. Together for Short Lives               Ev w5
5. British Heart Foundation               Ev w8
6. Chartered Society of Physiotherapy     Ev w16
7. Nichola Ebbern                          Ev w20
8. Lymhoeema Support Network              Ev w20
9. Prostate Cancer UK                     Ev w23
10. ME Association                         Ev w24
11. Celesio UK and Lloydspharmacy          Ev w28
12. Pemphigus Vulgaris Network             Ev w31
13. Action Duchenne                        Ev w32
14. Centre for Mental Health               Ev w36
15. YoungMinds                              Ev w38
16. The College of Optometrists            Ev w41
17. reMEmber (The Chronic Fatigue Society) Ev w44
18. The Nottingham Traumatic Brain Injury Service Ev w45
19. Dwayne Johnson                         Ev w47
20. Joint Epilepsy Council                 Ev w47
21. MSD-UK Ltd                              Ev w49
Managing the care of people with long-term conditions

22 MND Association
23 Association of Directors of Adult Services and the Local Government Association
24 Urology User Group Coalition
25 Mrs Christine Talbot
26 Doreen
27 Care Quality Commission
28 Genzyme Therapeutics Ltd
29 UK Centre for Tobacco Control Studies
30 British Lymphology Society
31 Sanofi Diabetes
32 Association of British Clinical Diabetologists
33 Crohn’s and Colitis UK
34 Scope
35 Julie Hinks
36 Royal National Institute of Blind People
37 Action for M.E.
38 Baxter Healthcare
39 British Association for Counselling and Psychotherapy
40 Society of Chiropodists and Podiatrists
41 National Ankylosing Spondylitis Society (NASS)
42 British Association and College of Occupational Therapists
43 Royal College of Physicians of Edinburgh
44 Sue Ryder
45 Vertex Pharmaceuticals UK
46 Astellas Pharma Ltd
47 Macmillan Cancer Support
48 Alliance Boots
49 Novo Nordisk
50 National Housing Federation
51 Epilepsy Action
52 Parkinson’s UK
53 British Specialist Nutrition Association
54 Terrence Higgins Trust
55 Urology Trade Association
56 Multiple Sclerosis Trust
57 Optical Confederation
58 Coloplast
59 The Society of Homeopaths
60 The Work Foundation
61 Napp Pharmaceutical Group
62 British Pain Society and the RCGP Clinical Champion for Chronic Pain
63 AntiCoagulation Self-Monitoring Alliance
64 Roche Diagnostics UK
65 Janssen
List of unprinted evidence

The following written evidence has been reported to the House, but to save printing costs has not been printed and copies have been placed in the House of Commons Library, where they may be inspected by Members. Other copies are in the Parliamentary Archives (www.parliament.uk/archives) and are available to the public for inspection. Requests for inspection should be addressed to the Parliamentary Archives, Houses of Parliament, London SW1A 0PW (tel. 020 7219 3074; email archives@parliament.uk). Opening hours are from 9.30 am to 5.00 pm on Mondays to Fridays.

John Smith Solicitors
Ask & Prosper
List of Reports from the Committee during the current Parliament

All publications from the Committee are available on the Committee’s website at www.parliament.uk/healthcom.
The reference number of the Government’s response to each Report is printed in brackets after the HC printing number.

Session 2014–15

First Report 2014 Accountability hearing with the Health and Care Professions Council HC 339

Session 2013–14

First Special Report 2012 accountability hearing with the Care Quality Commission: Government and Care Quality Commission Responses to the Committee’s Seventh Report of Session 2012–13 HC 154
Second Special Report 2012 accountability hearing with Monitor: Government and Monitor Responses to the Committee’s Tenth Report of Session 2012–13 HC 172
Third Special Report 2012 accountability hearing with the Nursing and Midwifery Council: Government and Nursing and Midwifery Council Responses to the Committee’s Ninth Report of Session 2012–13 HC 581
First Report Post-legislative scrutiny of the Mental Health Act 2007 HC 584 (Cm 8735)
Second Report Urgent and emergency services HC 171 (Cm 8708)
Third Report After Francis: making a difference HC 657
Fourth Report Appointment of the Chair of Monitor HC 744
Fifth Report 2013 accountability hearing with the Nursing and Midwifery Council HC 699 (HC 1200)
Sixth Report 2013 accountability hearing with the Care Quality Commission HC 761 (HC 1218)
Seventh Report Public expenditure on health and social care HC 793
Eighth Report Public Health England HC 840
Ninth Report 2013 accountability hearing with Monitor HC 841
Tenth Report 2013 accountability hearing with the General Medical Council HC 897

Session 2012–13

First Report Education, training and workforce planning HC 6-I (Cm 8435)
Second Report PIP breast implants: web forum on patient experiences HC 435
Third Report Government’s Alcohol Strategy HC 132 (Cm 8439)
Fourth Report 2012 accountability hearing with the General Medical Council HC 566 (Cm 8520)
| Fifth Report | Appointment of the Chair of the Care Quality Commission | HC 807 |
| Sixth Report | Appointment of the Chair of the National Institute for Health and Care Excellence | HC 831 |
| Seventh Report | 2012 accountability hearing with the Care Quality Commission | HC 592 |
| Eighth Report | National Institute for Health and Clinical Excellence | HC 782 |
| Ninth Report | 2012 accountability hearing with the Nursing and Midwifery Council | HC 639 |
| Tenth Report | 2012 accountability hearing with Monitor | HC 652 |
| Eleventh Report | Public expenditure on health and care services | HC 651 (Cm 8624) |

**Session 2010–12**

| First Report | Appointment of the Chair of the Care Quality Commission | HC 461-I |
| Second Report | Public Expenditure | HC 512 (Cm 8007) |
| Third Report | Commissioning | HC 513 (Cm 8009) |
| Fourth Report | Revalidation of Doctors | HC 557 (Cm 8028) |
| Fifth Report | Revalidation of Doctors: General Medical Council’s Response to the Committee’s Fourth Report of Session 2010–11 | HC 1033 |
| Sixth Report | Complaints and Litigation | HC 786 (Cm 8180) |
| Seventh Report | Annual accountability hearing with the Nursing and Midwifery Council | HC 1428 (HC 1699) |
| Eighth Report | Annual accountability hearing with the General Medical Council | HC 1429 (HC 1699) |
| Ninth Report | Annual accountability hearing with the Care Quality Commission | HC 1430 (HC 1699) |
| Tenth Report | Annual accountability hearing with Monitor | HC 1431 (HC 1699) |
| Eleventh Report | Appointment of the Chair of the NHS Commissioning Board | HC 1562-I |
| Twelfth Report | Public Health | HC 1048-I (Cm 8290) |
| Thirteenth Report | Public Expenditure | HC 1499 (Cm 8283) |
| Fourteenth Report | Social Care | HC 1583-I (Cm 8380) |
| Fifteenth Report | Annual accountability hearings: responses and further issues | HC 1699 |
| Sixteenth Report | PIP Breast implants and regulation of cosmetic interventions | HC 1816 (Cm 8351) |
Oral evidence

Taken before the Health Committee
on Tuesday 18 June 2013

Members present:
Mr Stephen Dorrell (Chair)
Andrew George
Grahame M. Morris
Mr Virendra Sharma

Examination of Witnesses

Witnesses: Dr Karen Lowton, Senior Lecturer in Ageing and Health, Institute of Gerontology, King’s College London, Professor Alan Maynard OBE, Professor of Health Economics, Department of Health Sciences, University of York, Dr Sue Roberts CBE, Chair, Year of Care Partnerships, and Dr Judith Smith, Head of Policy, Nuffield Trust, gave evidence.

Q1 Chair: Good morning. Thank you for joining us. We are slightly sparsely attended this morning. A couple of our colleagues, we believe, are coming and are expected during the course of the session. I apologise that we are a bit of a thin attendance. We have more witnesses than we have members of the Committee, at least as we start this morning. Could I ask you to open the session by introducing yourselves briefly and saying where you come from? Let us start with Dr Lowton.

Dr Lowton: Hello, my name is Dr Karen Lowton. I am a senior lecturer in ageing and health at the Institute of Gerontology at King’s College London.

Professor Maynard: I am Alan Maynard. I am an economist from the University of York. I have about 30 years involved in NHS management. I am currently chair of Vale of York CCG.

Dr Roberts: I am Dr Sue Roberts. I am currently chair of Year of Care Partnerships, which is an NHS organisation housed in Northumbria Healthcare Trust. I have been a consultant physician for 30 years and was national clinical director for diabetes up until 2008.

Dr Smith: Good morning. I am Dr Judith Smith. I am director of policy at the Nuffield Trust, which is an independent charitable health research foundation based here in London. I have been involved in health services, research into primary care, chronic conditions and commissioning for nearly 20 years.

Q2 Chair: Thank you very much. As you know, this is the first evidence session in an inquiry on management of long-term conditions that the Committee has launched. I would like to open the discussion by looking at the structure of services required to deliver effective care for people with long-term conditions. You will know that there is a very strong sense in the health and care community that, if we are to deliver better quality and more economic care to people with long-term conditions, we are only going to do that if there are more integrated services between health and social care and more emphasis on prevention, early intervention and community-based services rather than acute services. I start with that as a prevailing orthodoxy. I would like to begin, if I may—in particular, because Professor Maynard in his evidence to us has suggested the evidence base for this conclusion is not as strong as it might be by exploring the extent of that consensus. Firstly, is it an accurate characterisation of the consensus? Secondly, to what extent do you agree with it? Thirdly, is the agreement to be otherwise based on an opinion or evidence? Can I start with Professor Maynard?

Professor Maynard: Thank you. Being ancient, I find it quite fascinating to look at the history of this. A couple of our colleagues, we believe, are coming and are expected during the course of the session. I would like to begin, if I may—in particular, because Professor Maynard in his evidence to us has suggested the evidence base for this conclusion is not as strong as it might be by exploring the extent of that consensus. Firstly, is it an accurate characterisation of the consensus? Secondly, to what extent do you agree with it? Thirdly, is the agreement to be otherwise based on an opinion or evidence? Can I start with Professor Maynard?

Professor Maynard OBE: Good morning. Thank you. Being ancient, I find it quite fascinating to look at the history of this. In 1972, was to integrate all the services DHSS in 1972, was to integrate all the services together. Here we are, 40 years later, and we have still not integrated them. Therefore, one asks the question: what is the incentive structure that prevents the better merging and integration of these services? Of course, one then looks round for evidence. One wants evidence about the benefits to patients, and in many cases that is not well charted in the sense that ideally one would like randomised controlled trials, but there are few of those. If we do not have randomised controlled trials, we want quasi-experiments that tell us what the effects are. In many cases, we simply do not know whether various elements of community care work or do not work. But we also need information about cost. Being a boring economist, one just says one would like to see the cost of these new diabetes or COPD innovations, because if you decide to fund some sort of experiment you are committing resources and denying other patients care. Therefore, you have an obligation to look very carefully at the cost consequences of this. Briefly and in summary, Chairman, if you look at the effectiveness evidence, it is very poor and patchy. If you look at the cost-effectiveness evidence, in many cases it is simply absent. Therefore, for a lot of the espousal of community care and argument to improve the way in which services are co-ordinated to the likes of me, with long-term care problems, it is really very poor. In a CCG, you are faced with the problem of how to invest resources. You look for evidence, and it is not there. Essentially, everyone else in the NHS is...
It is a comment on both. We do not know what works in community care or is it a comment on more integrated health and community services?

Professor Maynard: It is a comment on both. We do not know what works in community care or quite how to integrate things. We run on a set of views that community care is good. But for instance it may well be that A and E is the best way of reducing admissions to hospitals. A RAND paper has just come out arguing that, if you look at integrated care, primary care does not have the capacity to do a very detailed work-up. Therefore, sending patients to A and E and getting them to go more to A and E is a good way of working them up and denying them hospital admissions. So there are a lot of prejudices and views here, but we do not have that firm evidence base on which to proceed.

Q3 Chair: Before throwing it to the other witnesses, can we be clear? Is that a comment on community care or is it a comment on more integrated health and community services?

Professor Maynard: It is a comment on both. We do not know what works in community care or quite how to integrate things. We run on a set of views that community care is good. But for instance it may well be that A and E is the best way of reducing admissions to hospitals. A RAND paper has just come out arguing that, if you look at integrated care, primary care does not have the capacity to do a very detailed work-up. Therefore, sending patients to A and E and getting them to go more to A and E is a good way of working them up and denying them hospital admissions. So there are a lot of prejudices and views here, but we do not have that firm evidence base on which to proceed.

Q4 Chair: There must be something there that other witnesses would like to comment on. Shall I start with Dr Smith and then move along?

Dr Smith: Thank you, yes. Looking back over a similar period of time to that which Professor Maynard has suggested, we have to bear in mind that a lot of care has changed. There is more care for people with chronic conditions than there takes place in, in particular, the primary care general practice setting that would not have happened 30 or 40 years ago. For example, I am sure Dr Roberts will have things to say about diabetes care in this respect. We also see that a significantly greater number of people are living longer with complex range, often, of long-term conditions, so the whole issue of co-ordination of care—what is often talked about as integration of care—is becoming ever more important. Of course we see admissions continuing to rise, including those that would seem to be amenable to good care in the community. That has led to many experiments—often quite small scale—of trying to shift that curve, that rise in admissions. I agree with Professor Maynard that we lack good, long-term robust studies of the overall effect of those experiments. Far too often, they are expected to report too soon and are asked to look at measures such as cost and activity. The majority of those studies that we have carried out at the Nuffield Trust tend to have very disappointing results because we are often expected to report very early in the process. Also, we find that those interventions have often been quite poorly designed and there has not been careful thought given to the outcomes that are expected. The one conclusion I would reach on a look at the evidence that we have is that it is stronger in terms of patient experience and outcomes in relation to having care that is outside of hospital—that is, in the community—but much weaker in terms of the economic evidence. So it partly begs the question as to why we want to shift care.

Q5 Chair: Can I push back? For example, when both McKinsey, whose name has already been mentioned, and also the people from Torbay—Dr Wollaston, a member of the Committee, sends her apologies this morning—say of the Torbay structure of services that it has reduced demand on the local acute hospital services, is that simply not right? That appears to be in conflict with the proposition that both you and Professor Maynard advance, that there is no evidence.

Dr Smith: There is evidence but there are issues about the strength of that evidence. When it comes to looking at changes in emergency admissions, an initial look at that evidence will often suggest a reduction, but, when there are matched controlled studies that happen to look at a population elsewhere that is equivalent—say, for the sake of argument—to Torbay, you will often find there has been a similar change in that population, which begs the question that there may be other factors that have led to that change. It is often very difficult to attribute a change in admissions to the specific intervention. As I say, one of the problems is that we do not study for a long enough period of time.

Q6 Chair: What should be long enough?

Dr Smith: In our work that we have been doing at the Nuffield Trust, we suggest that we need studies of at least five years. Our sense often is that there is a tendency within NHS management to be, first of all, perhaps overly optimistic at the start and set what turn out to be unrealistic objectives, but also to want results very quickly to prove progress at a point at which it is just not realistic. We know from a much wider body of evidence about bringing about large-scale change in healthcare that it can take several years to get new systems and ways of working up and running before you then start to see changes happen in terms of services and patient outcomes.

Q7 Chair: Can we bring in Dr Roberts and Dr Lowton?

Dr Roberts: Your summary at the beginning about what the consensus is was absolutely spot on. What is needed is to look within that consensus and unpack it a little bit, particularly where it comes from. It comes from the idea that long-term conditions are just the same as all the other conditions that can be cured and palliated over the years, but they are fundamentally different in terms of management. While technological and drug interventions are obviously part of the problem—that is why people are living longer—in fact the management of these conditions is in the hands of the individual; they make most of the decisions every day that are going to affect their outcome. We need to reframe or reconsider our thinking and build up what we do from the fundamental need of the patient. We need to think of integration, which is key to this but in a much wider way, of self-management with clinical care, integration of the person with the professional—all sorts of other modalities of integration—and form must follow function. So we are indeed going to need a number of the forms of integration that you have alluded to, but we have to be careful when we put
them in that they do in fact support what patients need and not traditional thinking.

Q8 Chair: But it is odd, is it not, given the strength of the professional and managerial view in support of the basic analysis you offer, that the research base— the evidence base for the proposition you advance—is regularly reported to be so weak?

Dr Roberts: I do not think it is a surprise at all in a sense. To go back, the first thing is that when there is no evidence it does not mean that it is not effective. It just means there is no evidence. People who resist change, for whatever reason, often use the lack of evidence as a reason to do so: “The problem is too pressing for us to rely on that.” The reason that I do not think it is a surprise is that all of us, I suspect, come from the same scientific sort of background, which is that you take an element and you reduce it to something you can experiment on because that is the easy way—to put it in a test tube and get results.

The totality of international evidence about long-term conditions says that this is a complex intervention. It can be reduced to three components. Basically, it is improving structure, becoming more proactive, which is probably the necessary but not sufficient element, and the other two that make it sufficient are involving people in their own care and a partnership approach between these two. So we endlessly design better research around one or other component and it is not going to work because this is complex. We are not going to get results and see the benefit of it because we have to look at the totality. I am in favour of what both of my colleagues have said, which is that we fundamentally need more research—massively more research—in these experiments, but the experiments have to be the whole-system experiments that are going to make a difference, not small parts of it where we are not going to see a difference.

Q9 Chair: Okay. I now come to Dr Lowton in a moment, but Professor Maynard was shaking his head vigorously when you said what you need is more research. I thought that is what you were after.

Professor Maynard: What I would like is better research. We still have the issue that we are pouring a considerable amount of public resources into research, but one then has to ask the question: why is it not producing answers to these questions? Over the last 10 years—and further back with Cochrane and goodness knows what—we have put a lot of money into research, yet we are still at a really rather primeval level with regard to evidence. We also have to be pretty critical about how research funding is done. If you look at, shall we say, Iain Chalmers and other people, they would argue, like I would argue, that it is a question not of more funding for research but of better research. We teach people how to do good research and then they do outrageous things, bias their results and generally drive mere academics up the wall. So the issue is not necessarily more in the sense of more money but rather much better-designed research articulated to answer these questions.

Q10 Chair: Do you disagree with that, Dr Roberts?

Dr Roberts: I think that the need is to have better interventions so that the appropriate research can be applied. What we do not have is the appropriate interventions. We have some suggestions.
and in any particular way. That is something that we should be really looking at seriously and looking at the incentives, things like consultant job plans, to enable specialist expertise to be much more widely available. But primary care should be the hub of this.

**Dr Smith:** British primary care has two really important factors that are often regarded internationally as being very special. They hold the key to some of this. The first one is that our general practices have a registered list, a population for whom they are responsible. The second is that general practice is supposed to have a role in co-ordinating people’s care wherever they go in the wider health system. In relation to the first one about the registered list, I do not think at the moment that general practice always has the time and capacity to make the most of that resource, of the registered list. In fact, the Nuffield Trust, together with the National Association of Primary Care, recently published a report called “Reclaiming a population health perspective”, arguing that general practice could use that registered list to be doing work much further upstream, to be looking at the demography, the epidemiology indeed, of that population and saying something like, “We have 2,000 smokers in our practice. What should we be doing about that?”, or, “We have 2,500 people whose body-mass index is above 30. What should we be doing?” So actually getting upstream, which is critical in terms of long-term conditions, much more could be done there. Certainly, there are innovative general practices and general practitioners who are doing think about how they could start to take more of a population health perspective with their teams.

On the second point about general practices as the co-ordinator of care in the wider system, again, there are practices that are starting to think about ways in which they could take that further. They are often doing that by operating perhaps on a scale, now starting to work in networks or federations of general practices. Because of that scale, they have the opportunity to perhaps contract for the sort of specialist expertise that Dr Roberts was talking about and have that much more directly available to them locally and design and put into practice some different approaches to care. As to those two factors about the population health role of general practice and the co-ordinating role, there is much we could learn from some innovative examples that are out there.

**Professor Maynard:** Yes. We have known that there is a relationship between GP and hospital admissions for about 20 years. I remember Clive Smeed, who was chief economic adviser to the Department of Health, arguing this point 20 years ago, and Jarman argues the same sort of thing. What we seem to have done is relatively deprive primary care as the demand has gone up. So there are some really major policy issues here, ie “You could quite easily advocate more funding for primary care,” but what are you going to cut to do that?

The other little point I would make is about hospitals. Hospitals can be dreary places—he said, as a patient—but they do benefit from economies of scale. That is a significant plus. If you take things out into the community and you have, shall we say, nurses going round in classic community care, rather than patients going to the diabetes nurse in the hospital, you may have differences in productivity, cost and effectiveness. So one should not necessarily dismiss hospitals as something that we need to reduce. It is rather like the mergers literature on hospitals. We seem to be merging hospitals, and we have again known since the time that the Chairman was Secretary of State—we were publishing things about it—that there is no evidence that hospital mergers reduce costs or improve quality, but we continue to do it. It is a sort of rhetoric—

**Chair:** If you make it smaller—

**Mr Sharma:** It is debatable.

**Professor Maynard:** I think the questions you are raising about primary care, where you put your resources, raise this issue of how you shift resources within a constant budget. That is the problem with this community care advocacy. The risk is that we will invest in community care and you will make the quality of my care more expensive but we will not shrink the hospitals and the total cost rises. So you have to ask the question: is community care a complement or a substitute? What time horizon is there for ensuring that they are substitutes?

**Q13 Graham M. Morris:** Can I ask a supplementary there of Professor Maynard with regard to the lack of evidence and what seems to be the established logic about it being cost-effective? What about the international evidence? As a Committee, we visited Sweden and looked at some of their investments in community-based services. I found it difficult to understand how integrated teams travelling relatively long distances, visiting patients in their own homes, would be more cost-effective than bringing them into a single centre where they are all housed in a multi-disciplinary group under one roof, but the evidence does seem to support that being a wise use of resources. It has had the consequential effect of reducing the number of hospitals, the number of beds in hospitals and improving outcomes, which seems remarkable, but that was their experience based on their evidence. Had you looked at that?

**Professor Maynard:** I know something about the Swedish system. I see what is argued about them. Some of my colleagues in my clinical commissioning group have been over in Sweden recently. I am sceptical because, again, the issue that Judith was talking about was: what is the design, what are the controls and what is the cost data? I am a mere economist and I am not interested in evidence-based medicine; I am interested in economics-based medicine because what is clinically effective may not be cost-effective and what is cost-effective isn’t always clinically effective. One has to get into these designs not just the effectiveness for improving my outcomes as a patient but also the costing implications and the shifting of resources.

**Q14 Chair:** You also have to get into the design, do you not, a sense of the value you are delivering for the cost, whether it is the objective clinical outcome or the patient’s experience on the outcome achieved as well: the patient’s view about the outcome?
Professor Maynard: Yes, but in the treatment I had I was distressed, set alone not satisfied, but they kept me alive and I was grateful. The issue I always end up thinking about is, “That was a pretty horrible process—that chemotherapy was not very nice—but at least it gave me the outcome I wanted”: that I could stagger through your door this morning.

Q15 Chair: So you are capable of working out that the personal cost, in terms of discomfort, was worth the benefit. But people with long-term conditions requiring them to travel to a remote hospital for a relatively less technical intervention than the one you personally experienced, where that same intervention could be delivered more conveniently to them, is something that is a cost without a benefit, is it not?

Professor Maynard: Yes. There are obvious trade-offs there about how you treat different conditions. If you have kidney disease, you are going to be looking at your creatinine, which needs a blood test, and you can have a telephone call with your renal physician. If you are looking at some form of cancer, you are looking at your paraprotein and whatever, and you could do a lot of that at distance. But, basically, if you are getting into complications, then clearly you want to be there. So it is horses for courses.

Dr Roberts: We are in danger of looking at long-term conditions as acute conditions that always need treatment and things being done to people. The international evidence that the redesign has been built on would suggest that we need to be doing things with people that help people live in their communities.

Those people who now have complications and have an acute episode on the basis of their long-term condition do use a lot of expensive resources, but they are very much smaller in terms of the total numbers of people we are dealing with. Unless we turn the tap off and prevent those complications coming and prevent those people from falling into complications, then clearly you want to be there. So it is horses for courses.

Dr Smith: That is absolutely right. Going back to my point about primary care and the potential for population health management there—which is absolutely building on what Sue was just saying—I agree that there are economies of scale in hospitals, and I want to add that I think there are economies of scale to be had in primary care practices working in a much more networked and federated manner, getting beyond, in a sense, small corner shops into something more organised and at scale, yet preserving the ability of people to access their local services.

To give one example of that and how we could extend things further, pharmacy is an area of primary care that already delivers some services to people with long-term conditions but could do much more in terms of both screening and helping people manage both use of medications and also in providing advice and support. That needs to be done thoughtfully in terms of a network, with sharing of information and records with general practice and so on. We could build up that base of support, advice and proactive work within the primary and community setting. We have many of the professional skills there but we are not always making the most of them.

Chair: I interrupted Virendra.

Q16 Mr Sharma: Do you want to answer?

Dr Lowton: I agree with Dr Smith on the idea of networks. We have cancer networks now that appear to work very effectively where you have specialist care in specialist tertiary units, and then throughout the network at primary level, at acute care level, you have people trained to know exactly what to do. So you could have specialist care in a specialist hospital and perhaps more routine chemotherapy delivered much more locally. There are many conditions, certainly within the new ageing population, that would benefit from not always going to tertiary care.

We have just been following up the first British recipients of childhood liver transplants who are nearly 30 years on and they still attend Addenbrooke’s hospital on a six-monthly or annual basis for a check-up. Many of those participants were saying how much they would rather have a consultation by Skype. To have to completely rely on tertiary care for an acute check-up is quite difficult when they are travelling from all over the country.

Chair: Thank you.

Q17 Mr Sharma: Dr Roberts, the Year of Care approach was trialled with diabetes patients. How adaptable is it to the treatment of other conditions? Also, what conditions would not be appropriate and has any assessment—although mentioned briefly—been made of the likely savings per patient from the Year of Care?

Dr Roberts: The Year of Care programme used diabetes as an exemplar, and diabetes is often used in long-term condition work because it affects every organ of the body—every organ has a bit of the NHS—so if you can get it right for diabetes you can get it right for other conditions. It was a feasibility study, so it did not make out that it was a randomised controlled trial. The purpose of it was to see if it was possible in UK situations, particularly in primary care, to work in new ways, ways that didn’t involve the person, with diabetes in this case, in really being supported to get the skills, knowledge and confidence they needed. So it was a feasibility trial: could we do all the things that the patients’ organisations had been listing that they would like to have done? We worked intensively with three very different populations, with primary care, to work out how to do it, and we successfully showed how to do it. We measured quite a few impacts of what we did. This was an uncontrolled trial so it was just what we observed there and it was extremely helpful in delivering the outcomes that the patients wanted. It improved experience and they perceived that they were getting more support for behaviour change. The thing that was astoundingly good was that it was a better way of working for staff. That was the thing that enabled this to embed and to carry on.

After that study—and we did very little economic cost working, measurement, for a variety of reasons—we
were able to show that, within primary care overall, it was cost neutral to make the changes that were required, but it was not a serious study at all. We then took the principles of it, which I have outlined in some of the papers that I have given you, produced a prototype and scaled it up to 12 other sites to show that it was transferable, reproducible, and solid. Then we took the principles and have transferred it to lung disease, COPD, to health checks, to cardiovascular disease, and, latterly, we are working with integrated health and social care teams with people with multi-morbidity to show that that also is very effective and feasible for them.

What is needed now is for communities of practices to be doing this whole scale so it can be properly evaluated using appropriate methodology so that we can see a bit more about the economics and the impact. But it is feasible, highly popular with the people who do it and a better way of working. That is why we are commending it not just for diabetes but for the majority of long-term conditions.

Q18 Chair: Can I probe you a bit further? You say “the majority”. You started with diabetes because that is an obvious case. There have to be long-term conditions—possibly some of the new forms of long-term conditions—where the Year of Care is more difficult, more of a challenge. Are there areas you focus on where it is particularly appropriate?

Dr Roberts: The principles of what I am advocating are a very simple approach, which is that you start with the population that you are concentrating on from your register, or from a risk stratification tool in some way. You then invite them, essentially to sit down and have a discussion that is forward looking about both how they would like their care to be managed and how they would like to contribute to this. The critical issue is that you have, in some way, to prepare them to be more involved in the consultation than they normally would. They need to know their results, their finances on this and they have a model for the whole community care, how to do neighbourhood care teams. It always happens. But I stand there and say, “I demand evidence. Get used to thinking critically, please. Evaluate.”

Q19 Chair: The key point about a Year of Care is that it is different for each—in theory, at least—individual patient.

Dr Roberts: That is the point. It is a common approach so that everyone can understand it. Public Health England, NHS England and Health Education England could all begin to put their priorities on to this model. It is a common approach and ends up with a personalised solution for each of the 15 million people.

Q20 Chair: Then, asking the economist question, how do you price 15 million individual personalised years of care?

Dr Roberts: Well, I am going to ask him.

Professor Maynard: Thank you for that. This is the issue. Here we have an obviously well-intentioned and nicely designed intervention. There are lots of them about. This one is very effective, but it has to be accepted that it is a pilot and you really need to do a proper evaluation. The timing of how far you go with pilots before you do evaluation is important. Our problem is that we have lots of ingenious doctors—there are a couple here—always thinking of new things to do, how to change A and E, how to change community care, how to do neighbourhood care teams. It always happens. But I stand there and say, “I demand evidence. Get used to thinking critically, please. Evaluate.”

Q21 Chair: But there is a prior question before you even look at evidence about how Dr Roberts’s idea works in practice. You have to have some theory about how resources can be attached to a personalised Year of Care model—

Professor Maynard: Indeed.

Q22 Chair:—moving away from tariffs for standardised procedures towards resource allocation per patient. You have to have a theory about how you are going to do it in order to have a theory to test in research.

Professor Maynard: Yes.

Q23 Chair: How far down that road have we got?

Dr Roberts: Just as a contribution to this, we have not got nearly as far as we should. You will be aware of social income bonds, the concept that a number of people put in money and carry some of the risk around putting in this new intervention—for the reasons that Alan says, you have to have it in there—and then they will, after a period of time, reap the benefits, if such there are. There are a number of initiatives round the country, and one that I am aware of—because it is in my local patch—called “ways to wellness” is about putting in social income bonds for the sort of things that Judith was talking about across the community. They have begun to do some of the economics and finances on this and they have a model for the whole population saving—and that is the thing—and then they divide it by the number of people and get an artificial figure for what it will be per person. They come up with around £150 to £200 saving per person. Some of this and these models are beginning to be
thought of practically and it might be useful for you to see their thinking.

Q24 Chair: It would be interesting. The whole concept of a Year of Care is another one of these concepts that is much talked about. How you attach resources to a Year of Care seems to me to be a critical question. You acknowledge that we are not as far down the road as we need to be, but we ought to be having a look at anybody who is out in front, if it seems to me, and it would be interesting.

Dr Smith: What Dr Roberts has been talking about there with the Year of Care represents a different philosophical and cultural approach to care. It is about working with people rather than the health service doing things to them. So much of our health service is organised on that basis. Even a lot of the way that we pay general practice at the moment is about paying them to have people in to do certain checks and screening, or whatever it is. That is what is critical. As Professor Maynard was saying, if we are working to design really good experiments on this kind of different philosophical approach—which I think all of us would instinctively support: it feels like the way we would like to work, with professionals to help us manage our conditions—we need the researchers working closely with the practitioners and managers from the outset to design the intervention, and measures and the hoped-for outcomes. I would add into that, “With patients and users involved in that process.” So then, right from the outset, we had something that is a really good large-scale and quite longitudinal study. It needs those researchers involved from the outset. It is about that bringing together of the rigour with the cultural change. This is complicated stuff, but it does not mean we should not be trying to do it.

You are absolutely right that the payment, and economics, in some ways, drive so much behaviour, and, at the outset of that sort of experiment, I would be suggesting you need to be experimenting with some different incentives and payments as part of that, whether it is for the network of primary care practitioners or of primary care practitioners with specialists, whatever that may be.

Chair: Given that the process started in 1974, I am looking forward to the next step.

Mr Sharma: You are familiar with that.

Q25 Grahame M. Morris: May I move on now to effective commissioning? To continue the points that Dr Roberts was making regarding the treatment of diabetes as an example, I have seen in your written submission your concerns about the fragmentation of commissioning and some of the other barriers to effective commissioning, given the new architecture that we have, with clinical commissioning groups. Do you want to elaborate on that for the sake of the record?

Dr Roberts: Yes. It is one of the two big barriers. One is healthcare professional attitudes and the other one we found, as we did our feasibility work, was about the issue of fragmented commissioning. In a sense, the new structure has not been designed around this integrated approach to long-term condition management. There has not been—and there still is not really—a long-term condition strategy for England. The components of care that the practices and the CCGs discovered as we were looking at the Year of Care programme were three. One was that there had to be change within primary care and, as you know, that is commissioned from NHS England and the local area teams. Second is the aspect that Judith was talking about, which is much better community support, healthy living centres, exercise on prescription and social prescribing. In a sense, that falls more within the health and wellbeing boards and working with the local authorities, and that is very positive. The third thing is of course—the bit that I have said we need to play down but it is critical—that people do need acute intervention, the best medicines and the best traditional clinical care, and that is the bit that is commissioned by the clinical commissioning groups.

So the three big groups of intervention that people with long-term conditions need and need to have joined up, is, the new world, led by three different commissioning mechanisms. NHS England for primary care, health and wellbeing boards for the community services and CCGs for specialist services. Obviously, I know everyone is trying to work to merge, meld and do the best that they can, but our evidence found that this was not helpful and it would be better if there was an overall view for how long-term conditions should be commissioned.

Q26 Grahame M. Morris: In relation to the quality and outcomes framework, thinking about the current architecture of commissioning, is that problematic in terms of inhibiting better integration in commissioning services for long-term conditions?

Dr Roberts: I would be very scared about talking about this if your GP member was here, but, to comment as a non-GP, the impression as we go and work with primary care is that QOF has had quite a negative effect for long-term conditions within practices. It emphasised the single disease and the tick box. For instance, highly common musculoskeletal conditions are not really QOF conditions and get lost. QOF has undermined the capacity for primary care to work in a really rounded generalist way. It has moved most of the care to nurses, some of whom do this very well, but we have discovered none of them has consultation skills in any form in their training. They are trained in different ways to do different things. It has been unhelpful in a number of respects.

Q27 Grahame M. Morris: Thank you. I do not know if any of the other witnesses have any strong thoughts on barriers to effective commissioning. I did particularly want to ask Dr Smith about the evidence from the study that Nuffield had done, but if anyone would like to contribute...

Dr Smith: Before that, in response to what Dr Roberts was saying, I think clinical commissioning groups are well placed to commission for long-term conditions. Why do I think that? When we look back over 20 years’ evidence of different forms of primary care-led commissioning, what we find time and again is that...
what they are really interested in is long-term condition care in primary and community services, not the secondary specialist care, and there is certainly no evidence that they can have an impact on the hospital side of care. That is where I say they will naturally want to focus their attention and where they can have a real impact.

The other thing is that we will be publishing shortly some research that we have done in partnership with the King’s Fund, where we have been looking at a set of clinical commissioning groups and the extent to which they see themselves as responsible for primary care services and quality. Quite a number of them do see that as part of their responsibility and feel that they have to be able to influence primary care and the sort of services it delivers if they are going to have an impact on long-term conditions and, indeed, urgent care. So, while there are some structural issues in the current reforms that could make that difficult, I think that thoughtful innovative clinical commissioning groups could push ahead and really start to have an impact on long-term conditions and primary care. It is about looking for the opportunities rather than getting too preoccupied with structural barriers.

Q28 Grahame M. Morris: Without getting tied up with structures and so on, would it be advantageous if the health and wellbeing boards were the commissioners in terms of particularly the management of long-term conditions and commissioning preventative-type approaches to health? I am thinking of evolving policy on such issues.

Chair: That was first proposed to this Committee.

Dr Smith: Evolution would be significant there because many of us would quake at the thought of another reorganisation of commissioning. One of the profound problems that commissioning has faced over the past two decades or more has been the regular reorganisation or, as Professor Maynard always rightly puts it, “re-disorganisation” of commissioning.

The other caution I would sound here goes back to research evidence. The research evidence base on what has always been called joint commissioning, or partnership working, is not terribly strong in terms of outcomes for users and carers. In fact, there is a new, very thoughtful good study from the university of Birmingham that came out in February—I think it was a National Institute for Health Research study—of what are considered leading-edge examples of joint commissioning but suggesting that it is often in the area of achieving outcomes that these sorts of arrangements struggle. It goes back to this—that they might be quite positive for those people working in them and how they feel about working within those arrangements, but, in terms of the actual outcome, the evidence is equivocal. So we have to be cautious about assuming that that is an automatic solution.

Q29 Grahame M. Morris: Professor Maynard, you wanted to say something there. I want to come back to you about the evidence, but—

Professor Maynard: You want to go back.

Q30 Grahame M. Morris: You mentioned the university of Birmingham study, but could you say something about the Nuffield’s own study into Calderdale, Somerest and the Wirral? What evidence did you discover there about moves towards integrated commissioning, that is that a good model that could be applied elsewhere?

Dr Smith: The study to which you refer was focusing on the commissioning of care for people with long-term conditions in those three geographical areas. You talk about integrated commissioning, but what is interesting about that study is that the integration we saw, more significantly, was between the commissioners and the providers. We saw very collaborative work going on between what at the time were primary care trusts and practice-based commissioners. Whether it was the hospitals or mental health organisations and so on, the collaboration was happening there.

Q31 Grahame M. Morris: Rather than between health and social care.

Dr Smith: Yes, there were some with health and social care, particularly in the area of dementia. The example I remember there is the work being done in West midland in commissioning new forms of service for people with dementia, particularly round early diagnosis and treatment. But, as I say, more significant in our study was the integration we saw with providers, and we can perhaps come back to some of the issues it raises.

The final thing I would say that we saw in that study—and it was carried out between 2010 and 2012, which was clearly covering a period of very major restructuring and transition—was that, when we talked to and interviewed colleagues from local government in particular, they were finding it difficult because of all the changes to the NHS structures and relationships, so joint commissioning arrangements were being, in a sense, undermined and challenged. The other thing to point out is, of course, that local government was going through significant reductions in funding and people were changing on that side as well, so it was a difficult situation to be doing commissioning, albeit people were doing so.

Grahame M. Morris: Thank you.

Professor Maynard: If I can come in on the whole issue of commissioning, the difficulty as you try and develop community initiatives, and hopefully evaluate them, how do you take resources out of the providers? So if you put diabetes care into the community, the risk is that the resources are still going to stay in the hospital. They have this hopper of bodies that they can treat, and they pull down the hopper and get payment by results. The incentive system maintains the income of the hospital, which is a bit frustrating when you are trying to economise and improve quality. The risk is that you do your community stuff and improve the quality, but you are not really doing much in terms of saving resources because, basically, we are price takers. So if you are a CCG, we cannot fix the price, which is a bit strange. If you are Marks & Spencer buying knickers, you would want to adjust the price.
We are also quality takers in the sense that we are not really quite sure what we are buying. We do our best to find out and assure ourselves about what we are buying, but the quality measures are quite poor. That inequality in bargaining power between providers and the commissioners is a continuing problem. As Judith says, it is jolly good if you can get good collaboration and openness in your providers, but they are being crunched up by Monitor to make sure they hit their targets of returns and make a profit, and we, as a CCG, are also trying to make sure we balance. Commissioning is quite difficult.

The final point I would make is to agree with Judith. CCGs do have scope to begin to look at the quality of primary care and work with them through the GP forums. That is beginning to develop, but, of course, the GPs are extremely sensitive at the moment because, if you are trying to, shall we say, cut down outpatient follow-ups, that is affecting the GPs’ workload. GPs are very fragile about anything that increases their work load at the moment, because, as the Nuffield evidence shows, GPs are working a damn sight harder: the consultation rates have gone up quite sharply and some of them are quite near the end of their tether.

Q32 Chair: It does rather beg the question whether rethinking the way services are delivered within primary care and between primary care, social care and the rest of healthcare, you might not end up with a scenario that was more rewarding for both the GP and the patient because it used the GP’s skills more effectively than many of the consultations GPs currently undertake.

Professor Maynard: That is so, and, being the usual provocative economist, as you begin to move from corner-shop GPs to Tesco Express, you might begin to get much greater use of specialist nurses, with the reservations that Sue has mentioned but you can use specialist nurses as substitutes for GPs as opposed to complements to GPs? That, again, has a research base that we can argue about.

Q33 Chair: It was one of the questions that were prompted in my mind by Dr Smith’s earlier suggestions around NHS general practice, that its two strengths were the co-ordinating function, provided we can do that on a 24/7 responsibility basis, but, more importantly, the single list. I wonder—and you were talking about networks and developing scale in primary care—whether the concept of a single list still means anything if you are talking about a much larger scale of practice in primary care or whether the natural consequence of scale in primary care is more specialism in primary care so that the individual GPs do not have a list that covers maternity and elderly care, for example.

Dr Smith: For me, having the population basis to primary care is really important even as it moves, as I think it will, to a greater scale. What that population base—we can call it the list—ends up meaning might be different. If it is a population of 50,000 that a particular large merged partnership or a federation is responsible for, that gives them the basis for what we were talking about, for doing preventative work, proactive work, for thinking about the sorts of services and all of that.

As to the point about the connection each of us has with an individual practitioner, whether that is the GP or the nurse, a lot of people would argue that that has been to quite a large extent broken down anyway. That needs building back into the new thinking that people are starting to do about primary care because there are some people for whom that connection with the particular practitioner is particularly important, and, given the topic of the conversation this morning, people with long-term conditions, particularly complex long-term conditions, will very much need that person who they relate to, who co-ordinates their care. It may be less important if you are someone who is much more rarely using primary care, but the point is that you can have that continuity and, in a sense, the list works for you in that way when you need it.

Q34 Chair: Are you not saying that for some people continuity is important and for other people it is not?

Dr Smith: Yes—

Q35 Chair: But are you sure what the concept of a list associated with the practice means if the list is 50,000 people? We are all registered with the NHS because we all pay for it, but beyond that I am not sure the concept of a population-based list means anything to the individual. It certainly does to the use of resources for demographic health purposes.

Dr Smith: It goes back to what they do with that population. If they have that list and they—I do not know—know that someone smokes or weighs too much or they want to work with them in a certain way to do something about that, it is going to mean something to someone when the practice proactively gets in touch with them and offers them some interventions and support. But for other people it might just—

Q36 Chair: The practice, if it has a population of 50,000, is indistinguishable from just the NHS. It is not a personal general practice any more, is it?

Dr Smith: That is the challenge for the scaled-up—

Q37 Chair: It is not necessarily wrong for that, let me say.

Dr Smith: No. The challenge for these scaled-up models—some of them now exist as merged partnerships, some are called super-partnerships, others are federations and networks—is how they work at scale but yet retain the personal connection with people and provide that support. This goes back to general practice and primary care becoming more complex because of what we are talking about this morning: people with long-term conditions living for much longer but with a different range of needs. In a sense, how primary care responds to that is absolutely about dealing with both the personal on the one hand but also the population approach on the other. People are working that out. It is not the majority, but there are groups of primary care practitioners who are working to do this. There are many others who would like to, if they had the time and the space. I absolutely support what Alan says, that many of them are at the
end of their tether and do not have the head space or the time to think through these new approaches.

**Dr Roberts:** It might be worth remembering that 65% of work in general practice is already long-term conditions and I accept that there may be more that comes there, but it is not managed at all in terms of being efficient or effective. People are just coming in and having a small amount of their issues dealt with in a most inefficient way. The advantage of a list, whether it is with the practice or a group of practices, is that you can then start to organise this in a way that we can see, from the impact of our work, that it then begins to make a difference. We have not got the data because one of the tragedies is that there is very little data on how practices organise within themselves. So you cannot show at the moment, sadly, that if you spend slightly longer with a person and plan for their next period of care—and then they do not come back—that you have made good use even of time resources let alone work force resources. But the list should help that to be organised.

**Q38 Andrew George:** First of all, my apologies. As with a lot of the members, it seems that this morning there is a serious problem of diary clashes. If the area of questions that I raise repeats areas that may have been covered before, I apologise. In the evidence you presented, Professor Maynard, you question the received wisdom about—which I will broadly paraphrase—the approach that discourages the use of acute admissions when scale episodes occur with long-term conditions. The accepted mantra is that of course we should avoid the acute episode happening in the first place and then, if an acute episode were to happen, we would avoid unnecessary admissions and achieve the most rapid discharge possible from acute hospitals. You seem to be questioning that. To what extent do you think that all of the discussion around this is using honest language? Often, commissioners talk in terms of the worst place for a patient to be is in an acute hospital—if that is the case, it seems that senior Royals are put at great risk by going into acute hospitals and staying there for quite long periods of time—which concerns me. Is it that it is medically risky for them to go there, or is it that we are being dishonest and really talking about the efficient use of resources and that we want to save money and achieve greater efficiencies by avoiding unnecessary admissions and achieving earlier discharges?

**Professor Maynard:** The first point is that it is statistically proven that the NHS is more risky than bungee jumping. The error rates are quite high. They may kill you, maim you and give you a nice infection, and that is in the public and the private sector, so it is not an ideological point. You can see that healthcare is risky, so you obviously want to get them into the right position. The position we were arguing for earlier on was essentially that we have not got a robust evidence base that says, “Does it work? Does it maintain the quality and length of my life at a reasonable cost?”—its cost-effectiveness. We do not have that evidence base. Therefore, there are many fashions like, “Community care is good.”

What is community care? We have to break it down and look at different groups and different interventions. But, even when you do that, you still have the problem of evidence, and it is poor. We like to denigrate A and E and say it is all collapsing and that hospitals are even more dangerous. They are clearly appropriate places at times during the pattern of care. If you are having an acute episode, what you want is a good diagnosis in the hospital and exploitation of the economies of scale in terms of the diagnostics. They can throw you into an MRI scanner and work out what is going on.

We tend to overemphasise and generalise. The role some of us have been talking about this morning is to say, “Stop, we really must move from pilots,—which are all fine and dandy—and evaluate in a very systematic way.” Judith was saying yes, in about five years and I would agree with that. You need to have a mechanism of reining in impatient politicians, like your good selves, who want instant answers. Sadly, the world does not work like that. If we are going to get a good evaluation, we all have to be patient and to give them the time for diagnostics and to review their condition before a managed discharge. Is that not true?

**Professor Maynard:** That is the risk. One has to be very cautious both about reducing the number of beds and about mergers because, again, you are back to, “Where is the evidence?” We have known for about 20 years that mergers do not work, as we mentioned earlier on, so we have to be very cautious and ask all the time, “Where is the evidence?”, and really say, “If you are going to do something like change the composition of your A and E and put more GPs into A and E, where is the evidence that that works?” GPs are damned expensive. They may be effective at controlling the trivial demand going into A and E—perhaps 20% and 30% of it is trivial and the GP could manage it and keep it out from the specialist people—but one all the time is saying, “Where is the evidence, please?” and you can put up a sign. We do not know. “Everyone is doing it.” we might say, but we are not sure whether they are doing is cost-effective.

**Q40 Andrew George:** Most of the assessments of those approaches appear to be on the immediate judgment of how many patients of those GPs in the receiving units manage to avoid being admitted to hospital. There never seems to be a follow-through as to how many then are readmitted to hospital because of a misdiagnosis. Is there any work of that nature going on?

**Professor Maynard:** I am not aware of it; maybe Judith is. It is a classic example of you put a policy
Dr Smith: As to the desire for care to be in the community—whether that is home-based or in some other community facility—that is probably what the majority of us would want, and I think there is evidence around patient experience and outcomes from a quality perspective that that can be a positive thing. Also, as Alan has suggested, hospitals can be quite dangerous places as well, but also the majority of us, given the choice, would rather be at home. We have also explored the fact that it is on the cost-effectiveness side of things that we really do lack evidence about the alternatives, so it partly begs the question of: why is it we want to make the shift? If it is around quality and outcomes, we are probably on a reasonable track, but given the financial context in which the health service is working—one thing looks like it is going to remain austere for at least another decade—the cost-effectiveness aspect becomes even more important. What feels to me to be really important is the need for research to be working closely with practitioners and clinicians from the outset to carefully design these different interventions that are used to try and shift care elsewhere in place of proper measures and then have them through a long-term study, not requiring results after a year—when, at best, probably people have just got some of the governance and other arrangements in place—but over three to five years to see what works or does not.

Q41 Andrew George: Is this a fair analysis? In other words, is the mantra wrong? It seems to be accepted financially driven. Those decisions are usually quite arbitrary and "stick the GPs in and then the GPs out." The bases of those decisions are usually quite arbitrary and financially driven.

Q42 Andrew George: This is the last one from me. You would accept my assertion at the beginning, as to such decisions being clinically driven, that it would be better and more honest to say that this approach is one that needs to be explained in resource terms and to use language such as that it is about the efficient use of resources to avoid unnecessary admissions and to achieve earlier discharge. That would be a more honest narrative.

Dr Smith: In resource and quality terms. I would always put the two together. For me, effectiveness is about those two.

Q43 Chair: Dr Roberts, do you want to comment on that?

Dr Roberts: Listening to this, I think the reason that we are in the situation that we are now is because we are just looking at one part of the system—the obvious one, in fact, where we are up against it at the moment—which is emergency admissions to acute hospitals. By only concentrating on those, in a sense, and only accepting that we are going to do two things to people—"Shall we do them there or there?"—we miss the point of how we should be managing the whole population, picking up things that Judith said earlier about the potential for CCGs to manage the whole system of long-term conditions, and move from, "We are going to treat and do things to you," to, "We are going to involve you much more throughout your whole life in how this is going to happen."

Q44 Mr Sharma: Before I put the question, I hope that the present Secretary of State for Health, Professor, takes your point of view on the mergers.

Professor Maynard: I will rely on you to tell him.

Chair: He will be here in a couple of weeks. You can ask him then.

Q45 Mr Sharma: Dr Roberts, in a typical CCG, what sort of changes would be required to successfully implement a delivery system for care of long-term conditions based on the Year of Care approach? What are the essential prerequisites for establishing this delivery system in a local care area? Where would you look?

Dr Roberts: You can say where you would start and go from there.

Q46 Dr Roberts: You can say where you would start and go from there.

Chair: Professor, takes your point of view on the mergers.

Dr Roberts: Okay. If a new place wants to start doing this, a clinical commissioning group—they have to have a clear understanding of the principles that I outlined before, of what we are talking about and what in fact the delivery system is so that they can see it. Therefore, it would be enormously useful if the centre would say, without prescribing—I am very keen that there should be not prescribing that one must do things—"This is an extremely good way to work and you should start designing your services around that." I think a clearly articulated narrative is needed. Then there needs to be some local support for this. There are two elements that are going to have to be done. Primary care needs support and training: it is not just what you do differently in primary care, but how you do it. That is why it needs to be quality assured, and, by that, I mean training that would be the same everywhere that gives the impact that we expect. That has to be available for primary care. That training needs to address attitudes. We know at the moment that 60% of GPs do not endorse people being independent decision makers. Training that challenges these points of view is the starting place. You are not going to change your ways if you still think people are here just for you to do things to them. So it has to incorporate challenging attitudes, helping people to get new skills, to support people and coach them to be better able to solve problems themselves.

Then, it helps them to reorganise. We have this house model and say, "How would you build your house in your practice to enable this to come about?" Commissioners need to commission that sort of training. I would like to see that happen locally, but then I would like to see groups of CCGs, or groups in primary care that are doing this, come together for mutual learning as to how it worked and what the barriers were. There are a couple of barriers. There
are some barriers to do with IT, and it would be great if there was national support for overcoming them. These are also barriers to do with lack of consistent metrics and it would be very helpful if there were some national approach to that. Then there are the incentive barriers that I dealt with before in that this approach is not part of the core primary care contract and it would be helpful if it was. Have I answered anything you expected?

Q47 Mr Sharma: I am sorry for the long question, but I am sure that you answered.

Dr Roberts: Is there still an element I missed?

Mr Sharma: Thank you very much.

Dr Roberts: Thank you for asking.

Q48 Mr Sharma: How successfully can the delivery system model address multimorbidities by treating the patients, not the disease?

Dr Roberts: We as clinicians see them, in a sense, as a series of organs and conditions, but people see their symptoms and how this affects their life. If they have more than one condition—for instance, a heart condition—that may make it less easy to exercise. If you have diabetes, it would be very good if you exercised. So it is a question of pulling this together or people cannot make sense of that in their daily life. I believe there is about to be some work published from Glasgow, from very disadvantaged populations, that shows that when you interview people with multiple long-term conditions—who, if you observed them, you would think would really be quite burdened by their condition—they do not talk about their conditions at all; they talk about living their life and the difficulties that they have on a daily basis. They do not talk about conditions. The approach that I am advocating, the delivery system, in some respects takes that point of view and asks them first, “Tell us about life.” That is how all of us professionals manage to work on is how all of us professionals manage to cope with our views and that wanting our condition to be got in there and dealt with properly. The approach that people have in practice worked out is how you pull together all these little bits of medical information and enable them to be put in the pot, but it is a pot that is led by the life of the person who is the centre of all of this.

Q49 Chair: That approach presumably has particular application to people with what you describe as the new long-term conditions.

Dr Lowton: Definitely, absolutely. I was just thinking, as Sue was speaking, that the adults who had liver transplants in childhood certainly told us how well they were, how healthy they were. When we asked them about the co-morbidities they were experiencing, they included cystic fibrosis, kidney disease, heart disease, rickets and a wide range of really quite complex conditions, such as cystic fibrosis-related diabetes. But we also need to be mindful that many people with long-term conditions cannot be self-managing and independent as though they were an island. There is a lot of family and unpaid carer support that underpins and enables these people with long-term conditions to live productive lives. My slight concern is that by focusing on the patient’s independence and self-management we are at risk of ignoring the huge family support that goes into allowing people to grow older with their long-term conditions.

The other thing is how we would manage the uncertainty that a lot of these people with long-term conditions face. Certainly, through our research with people with cystic fibrosis, one of the common questions in their minds is, “When will I die? How much longer have I got?” One of our respondents with a childhood liver transplant who had cystic fibrosis too said to our researchers, “It’s all right. I am working on the cystic fibrosis life expectancy of 40 and I am not quite sure how the liver transplant plays in with that.” Paediatric services are very good at providing family-centred care with psychological support, but once young adults leave paediatric services, they are cast adrift. We need to pay attention to that psychosocial support because what are we treating people for? People want to grow up, to work and to have relationships. They often need support from health services to achieve that.

Q50 Chair: Can you mean from health and social care services?

Dr Lowton: Yes, social care services, indeed.

Q51 Chair: That brings us back to one of Grahame’s questions about the role of the health and wellbeing boards. Without wanting to go round another element of “re-disorganisation”, the development of integrated commissioning across institutional divides is surely central to the delivery of any meaningful Year of Care but also reinforces the difficulty of attaching resources to it, to which Professor Maynard says, “Show me the evidence.” Unfortunately, you will never make any progress in life at all if you never do anything unless there is a precedent. I think it was Ralph Waldo Emerson who said that it is “the hobgoblin of little minds.”

Dr Lowton: The only thing I want to raise in relation to things like social support or social work is that, in specialist centres, social workers are highly experienced in knowing the conditions of their patient population, but often, when people with new long-term conditions are trying to live in the community and being assessed for disability, the disability assessors have absolutely no idea about what their condition involves, that, yes, some days they may be very well but the next day they may be unable to get out of bed. This becomes a problem when people try to get the benefits they are entitled to and assessors do not really understand the conditions that they are living with.

Chair: Okay.

Q52 Mr Sharma: What changes to existing delivery systems are necessary for personalised budgets for long-term conditions to work effectively? That was to anyone.

Dr Smith: I was looking at Dr Roberts.

Mr Sharma: The question is for anybody who takes the initiative to answer.
Dr Roberts: At the risk of repeating myself, the Year of Care team are in fact providing all the training and support for teams to do personal health budgets. I say that because this delivery system model is perfect for personal health budgets. At the moment, as you probably know, it is only being advocated for people who are in receipt of continuing care, but even when it gets extended beyond that, so you have your group of people, they are supported to define what is important to them in life. Patients have a discussion with somebody who is trained in this care planning process, and then, instead of being referred to things, they have a pot of money which they are supported to spend on different things. It is a process that, particularly with this culture and attitude change for professionals, has helped the current personal health budget proposal enormously.

Dr Smith: I will add there as to personal budgets that, when we think about commissioning, there is a spectrum right through from national commissioning of specialised services at one end to personal budgets at the other end of the continuum. There is not a one-size-fits-all for commissioning. For some services, the personal budget will be right, for some it is the national level and for others the CCG and so on. That is important to remember. We have had some useful studies of personal budgets, some encouraging results in terms of impact on quality of life and certainly some cautious positive messages about the cost-effectiveness side of things. That is certainly my reading of the evaluations.

The other thing to bear in mind is the costs. Arguing those approaches. Also, they are not going to be right for everyone—the point that Karen was making about people having different needs. Some people are going to be much more dependent or need to be too; much more closely with statutory or other services. For someone with dementia—and they often not have family and carers locally who can advocate for them—it may not be appropriate. But for others—particularly, it has been found, in the area of physical disability and perhaps younger people as well with physical disability—it could be highly appropriate. It feels to me as though they are a manifestation of the shift from doing things to people to giving people more of a role in defining and managing their own care. They are not the overall solution. They are part of it and will work as part of the spectrum.

Finally, for the CCGs—who have quite a restricted pot of management resource—understanding how to use personal budgets, alongside all the other kinds of challenges they face with A and E and general long-term conditions, commissioning and what they are going to do about primary care, there will just be practical questions about how much time they can focus on developing that approach.

Q54 Grahame M. Morris: While we are on the issue of personalised budgets, there is a bit of an urban legend here, that the individual, particularly in relation to long-term care, would prefer to be treated in the community in primary care? Thinking about if you consult a dermatologist, why would I choose the dermatology—or seeing a GP with a special interest in dermatology—or seeing a GP with a special interest in a specialist nurse, why would I choose the community-based option? Is there any evidence to suggest that people would, given the choice, be more inclined to place their personal care budget in the community rather than with the hospital?

Dr Roberts: I do not know if I am picking you up right, but there are only certain things that come within the remit of personal health budgets. In fact standard clinical care—drugs and so on, and hospital care—is not within it. It is the care that you need to live effectively, the sort of social care and care in the community. Sometimes, people choose to replace a physiotherapist coming in with going out to an aromatherapy session. For them, the social gathering of that is better for them and they get benefit. It is that sort of option, as I understand it, that we are talking about.

Dr Roberts: This is second hand, but the team I work with have been working with people and there is evaluation, as Judith has said. It is a huge burden for local CCGs, but, in terms of the greater order of things, the profound thing it has done is help professionals understand that people make their own decisions that are right for them and that there is a whole range of things that may be beneficial that are outwith what we used to just do to people, “You will have this and you will have that.” So it is a cultural change that I think has been quite important. I am personally not sure, even without the money, that
Q56 Mr Sharma: Patient-centred care by definition puts the needs of the patient first. What evidence is there that patients with long-term conditions would welcome a shift to primary and community-based treatment for their own conditions? How can patients be convinced that a move away from acute sector treatment will bring benefits for them? First, are they convinced and what benefits do they have?

Dr Lowton: For people newly ageing with long-term conditions there are certain groups who would not want to shift to primary or community care—for example, adults with cystic fibrosis and adults with congenital heart disease—primarily because the specialist expertise is still within tertiary centres. In the research that we have done, participants have told us that they will deliberately bypass a GP because they do not perceive a GP to have any understanding of why they are going to consult. Often, GPs would put everything, for example, down to cystic fibrosis, when in one case it was actually appendicitis and by the time this young woman had got admitted to hospital it was a burst appendix.

On the other hand, there are reports from our participants of very good GP care where a GP has taken a long time to learn that patient’s condition over their whole lifetime. I was thinking earlier, when we were talking about Tesco Express GPs with large lists, that there are GPs with very good expertise in rare conditions, who perhaps could be identified for other patients in the community so that they could become their GP. Also, we have people growing older with Down’s syndrome, with congenital heart disease, who very much welcome a shift to primary and community care that actually cares for them once they become adult. Again, there are people with expertise in, for example, dementia in Down’s syndrome, who can properly respond to their needs and also the needs of their carers.

Q57 Andrew George: In relation to that answer, taking the example of the cystic fibrosis patient—and I can understand that the rarer the condition the more likely it is that the patient would feel more reassured to see a consultant in the acute sector rather than chance it, as it were, with their local GP who may dabble, as they see it—what are the cost implications? What does it mean in terms of the GP’s own budget, in terms of what they pay for the care of their patient? What impediments are there, or what disincentives or incentives are there, for the GP to refer or not to refer that patient in those circumstances? Do you know?

Dr Lowton: I am not an expert in cost implications, but I would say, from a commonsense perspective, if the patient can get themselves to the right person at the right time then, ultimately, their care will become their GP. Also, we have people growing older with Down’s syndrome, with congenital heart disease, who very much welcome a shift to primary and community care that actually cares for them once they become adult. Again, there are people with expertise in, for example, dementia in Down’s syndrome, who can properly respond to their needs and also the needs of their carers.

Q58 Andrew George: This is not a criticism, but, if you cannot answer the question about what you understand to be the incentives and the cost drivers within the system in relation to referrals from GP to secondary care, can any of the other panellists explain what they understand to be the nature of the accounting system that applies cost to a patient referral that may or may not be managed at the surgery level in primary care but may be referred to secondary care in the case of the cystic fibrosis patient who is referred on a regular basis perhaps? I do not know.

Dr Smith: We are effectively talking about commissioning and it is going to be about how—taking that as an example—care for people with cystic fibrosis is commissioned. That is going to come back, I would guess, with that condition, to very much a discussion between NHS England and clinical commissioners.

The other thing I would say in relation to that as well is that, going back to what we were talking about earlier, building up of primary care, whether that is through networks, federations or larger partnerships, that is where there is potential to have GPs or nurses with special interests and skills who can serve that larger population of 50,000, 70,000 or whatever. One could imagine within that a small team for—I do not know—say, a population of 100,000, a network of practices, who take a particular interest in people with Down’s syndrome and their primary and community services. But, ultimately, all of that does need to be, as I say, put in place. It is going to need to be commissioned and goes back to what we were talking about earlier, the role of the CCG and commissioning for long-term conditions, both what it needs to be, as I say, put in place. It is going to need to be commissioned and goes back to what we were talking about earlier, the role of the CCG and commissioning for long-term conditions, both what it needs to be in place within primary care as well as how it spends its money on specialist services and indeed works with NHS England to spend money on more specialised care, which is another complexity that the clinical commissioning groups are having to handle.

Q59 Andrew George: Just so I am absolutely clear—this is a final attempt and it may simply be me exposing my ignorance of how this process works—a patient with cystic fibrosis presents with an acute episode, goes to see a GP and the GP then refers to the acute sector at no cost to the GP. There is no financial incentive or disincentive implication in terms of that particular referral to the GP, the GP’s budget or, indeed, who is paying for that particular referral. I want to be clear where the cost consideration lies: who makes that budgetary decision, or is it entirely clinically?

Professor Maynard: If the GP refers, the resource consequences for the GP are minimal. There is an element in the QOF which says “We will look at your referral rates,” but that is quite blunt and novel and has relatively limited effect. For most GPs, we do not have distributions of things like referral rates. We do not have distributions of blood tests or x-rays. Managing GPs, even if it was our role as a CCG, is extraordinarily difficult because it is rather a data-free
environment. But it is going to improve. We are going to get better resources there.

Chair: Good.

Q60 Andrew George: So it may become more budget driven and less clinically driven.

Professor Maynard: It may do. Some of the leaders of the profession are now talking about wanting everyone to be salaried. So they are beginning to think about what should happen. Aneurin Bevan blundered: he should have nationalised them in 1948.

Chair: Grahame.

Q61 Grahame M. Morris: I completely agree with that sentiment, I might say.

We touched on this a little earlier. If we think of the health economics arguments, as well as the output, support, managing long-term conditions in the community rather than in a hospital-based setting, where appropriate, what do we need to do in terms of training for GPs and other staff? What do we need to address? Do we need to have more GPs with special interests? Do we need to have more specialist nurses? What are the training implications that we as a Committee need to highlight in our report for the Department if we go down this route?

Professor Maynard: Can I jump in and say—because I am an economist, aren’t I?—that these people have to manage budgets? These people have to manage resources, and their management of resources affects me as a patient and everyone in the community. Yet we teach them little in the way of statistics, economics and the issues of evidence. Therefore, I would agree that we should beef up the undergraduate and postgraduate training of GPs and consultant general practitioners because they become clinical directors with a clinical budget. The poor souls are thrown into this with very little expertise. They are bright and they pick it up, but it should be part of the revalidation process that they are made aware of these sorts of things.

Q62 Chair: So they should attend an economics course as part of revalidation.

Professor Maynard: That is absolutely essential, Stephen. The doctors will have other views.

Q63 Grahame M. Morris: You have made a valid point there, that in seven years of medical school training there is nothing in terms of commissioning in that, as far as I am aware. I was thinking about specialised training in order to treat the long-term conditions in dermatology, diabetes and so on. It is valid that they should have some understanding of the health economics of it and commissioning as well, but, in terms of being able to deliver the service from a clinician’s point of view, how do we need to change that?

Dr Smith: My take on this would be that, when you look at it in the international context, general practice training in this country has moved a long way. Medical students spend time in primary care from very early on now as undergraduates, and a significant body of their training does happen in a community in a general practice setting—something that is certainly not the case in many other countries. So we have achieved a lot there.

I know that colleagues in medical and nursing education are thinking carefully about this, but almost the next frontier in this area for us, though, is the specialists and where they are trained. My sense would be that that is still often too focused in the hospital setting. The implication of a lot of what we have been saying this morning has been about specialists working differently with networks of general practice, or at least in some of the ways Karen has described in terms of linking quite differently with patients and their families over a much longer period. So it is perhaps about some of the specialist training and where that happens. It would be nice to think that, if we are going to scale up general practice, have more general practice networks, larger partnerships and so on, that that could become a training ground for nurses, doctors and indeed other health professionals who are looking for a more specialist career as well as those who are going to pursue a generalist route.

Q64 Grahame M. Morris: Might I ask Dr Roberts, though I know time is short, how does a GP become specialised with a special interest in whatever it is? How does each training is involved before they are a GP with a special interest in whatever, dermatology or—

Dr Roberts: Some of those criteria were laid out about 10 years ago, with the Colleges for different specialties, laying out what would be needed and periods of mentorship with specialists and things like that. Before we assume that it is making GPs into specialists, though, which is sometimes of use, particularly around technical things like taking off lumps and bumps and ENT—there are some technical things that seem to have worked very well—they have not worked that well for all long-term conditions, and I would pick up some of the things that Judith mentioned about not saying, “How many specialists do we need?” but, “How are we going to get the specialist knowledge into primary care?” It may be that it is more important to concentrate on specialists working differently because they have been trained—they really know all the specialty—than getting the GPs to learn a bit of the specialty. So it is horses for courses, I think.

Q65 Grahame M. Morris: How long would it take for a GP to be trained as a GP with a special interest rather than a specialist? Is there a set period where a GP would—

Dr Roberts: I would have to go back to the things that were in those documents from about 10 years ago, but essentially it is a mentorship and an apprenticeship process locally. It might involve going on a masters course in the biology of that particular condition, but it is basically sitting in and being mentored locally by a specialist. I would have to go back.

Q66 Grahame M. Morris: How long would that take?

Dr Roberts: I think it would be an ongoing process over two or three years, but I am now making it up as I go along, so I need to look back at the documents.
Q67 Grahame M. Morris: Maybe you could send us a note, if you don’t mind.
Dr Roberts: I will have a look back.
Grahame M. Morris: Thank you.

Q68 Chair: I think we have covered the ground that we wanted to cover. I would like to close by bringing us back to the question of evidence and the focus of how we move this argument forward, because even Professor Maynard, who has played the role of self-appointed sceptic in the panel this morning, has not seriously argued with the proposition that what is required is a more patient-focused—putting words into your mouth—service, a service that is better able to listen to the priorities of patients, respond to those and to deliver a joined-up service. It is very hard to argue against that.

If it is to be anything other than common sense, supported by evidence of how to turn those words into reality, the question, it seems to me—and, given that Professor Maynard started off by saying this has been going on since 1974, it is a fairly urgent question—is how to equip ourselves with robust evidence about which models, and there is no perfect solution here, deliver better outcomes at better value than the alternatives. Are there any suggestions you would offer, picking up Grahame’s question—“What should we put in our report?”?, in simple terms—about how we move this argument forward so that we do not sit here in five years’ time and agree that there is no evidence?

Professor Maynard: We have already talked about trying to make clinicians more economically literate. There is also a big challenge of making managers, whether they are clinical or non-clinical, more literate in these skills. I am finding, in NICE, that the challenge in saying, “Where is the evidence?”, trying to get people to evaluate, works because they are GPs and they can tolerate my intolerance. I found it much more difficult listening, maybe because they are GPs and they can tolerate my intolerance. I found it much more difficult to listen to the priorities of patients, respond to those and to deliver a joined-up service. It is very hard to argue against that.

Q69 Chair: Without wishing to be excessively bloodthirsty, as to the people who launch pilots that were clearly never going to work, presumably there should be some career penalty for that.

Dr Roberts: The ones I am thinking of were designed by the academics, though, because they could see that that was something that would be useful to research.

Q70 Chair: Yes. Even academics can be subject to a career penalty.

Dr Smith: I support all that has been said, but I would add to it. There is a responsibility on the system, for which I guess I am meaning the Department of Health and NHS England in particular, in terms of how at that level leadership is given to what we are talking about, so that there is proper support and leadership given to the idea of, say, a five-year programme of experimentation around particular interventions. We are talking about long-term conditions, and this is indeed long-term change, long-term work. It is hard, it takes time and it is not a quick fix. Quite a significant cultural change needs to happen at those senior levels in terms of saying, “It is okay for this to be a five-year programme,” and yes, absolutely, that the researchers, the managers and the clinicians should be required to work together to design the intervention, design the measures and see it through. Indeed, if it is found not to work, it might be better to stop the intervention earlier as well, so it is not just a question of waiting for five years. It is about the readiness to say—and I guess it almost becomes like NICE guidance—“That is not appropriate to carry out,” or, “Yes, that is highly effective. We will get on
and roll it out.” There is a central leadership question that needs wrapping round this to enable particularly managers in boards to continue on with what would be, in a sense, a countercultural approach.

Q71 Chair: That is presumably particularly relevant to the group of people that you raise.
Dr Lowton: Yes. Being an academic, I am feeling thoroughly bushed.
Professor Maynard: We survive.

Dr Lowton: There are developments. For example, I work at King’s College London and we have King’s Health Partners, which is an academic health sciences centre. The university works very closely with partner foundation trusts, particularly, for example, in the area of stroke care where we have academics working with clinicians and managers to try to make sure that this research is going to end up benefiting patients.
Chair: Thank you very much. On that note, thank you for your attention. Thank you very much indeed.
Wednesday 16 October 2013

Members present:
Mr Stephen Dorrell (Chair)
Rosie Cooper
Andrew George
Barbara Keeley
Grahame M. Morris
David Tredinnick
Valerie Vaz
Dr Sarah Wollaston

Examination of Witnesses

Witnesses: Professor Alan Silman, Medical Director and Director of Policy and Health Promotion, Arthritis Research UK, Baroness Young of Old Scone, Chief Executive, Diabetes UK, and Dr Peter Aitken, Chair of the Faculty of Liaison Psychiatry, Royal College of Psychiatrists, gave evidence.

Q72 Chair: Can I begin by apologising on behalf of the Committee for keeping you waiting beyond the published start time? We had one or two internal issues to deal with. Apologies for that, and secondary apologies in that we believe there is going to be a vote on the Floor of the House in 10 minutes. We will be here for 10 minutes and then we will be away again.

Professor Silman: I am Alan Silman, Medical Director of Arthritis Research UK, which is the largest research charity funding arthritis and musculoskeletal research in the country. It also has a portfolio of activities aiming to support patients and health care professionals and to advise on health care policy.

Baroness Young: I am Barbara Young, chief executive of Diabetes UK. We do the same for people with diabetes and people at risk of developing diabetes.

Dr Aitken: I am Peter Aitken, a doctor and psychiatrist, and chair of the faculty of liaison psychiatry at the Royal College of Psychiatrists. Our particular interest or specialty is the interface between medical and psychological symptoms.

Q73 Chair: Can I start the questioning? I want to jump into the middle of this, because the Committee has expressed the view many times—and we have heard evidence from many witnesses—on the importance of a greater community focus on services for people with long-term conditions, greater emphasis on early intervention and prevention. All those arguments will be very familiar. We have also heard it said many times that that delivers better services, but there is no evidence to support the proposition that it relieves pressure on acute services. I would be interested to hear your answer to those arguments will be very familiar. We have also heard it said many times that that delivers better services, but there is no evidence to support the proposition that it relieves pressure on acute services.

Professor Silman: There is a patient journey as they go through these diseases, and the journey varies. Sometimes people have flares and sometimes they are relatively well, but they need care throughout that period. Whether in a community or a hospital setting, we are certainly people with diabetes need access to specialist services when they require them as well as services in the community and in primary care. For people with type 1 diabetes the balance is more towards the specialists that need to lead their care, and for people with type 2 it may be more towards primary care being in the lead; but they certainly need that integration and the ability to access the range of services when they are required.

Baroness Young: The mental health story is straightforward. Whether in a community or a hospital setting, we are not integrated with the provision of medical care for long-term conditions. If you take something like diabetes or arthritis, where perhaps 25% or 30% of people will have a depressive disorder as part of that mix, as soon as you are admitted to a general hospital there is almost no mental health provision for your mix, as soon as you are admitted to a general hospital there is almost no mental health provision for your...
Baroness Young: Could I comment on what we also discovered in our study, which was that barriers to some of these more cost-effective patterns of integrated care were happening? Quite often, the things that had to happen in order to save the money had to happen in community or primary care, and the saving would realise itself elsewhere in the jungle, usually in secondary care. Likewise, there would be time differentials. Some of the mechanisms, like the introduction of multidisciplinary foot care teams, have a pretty immediate pay-off in terms of cost reduction. Others, like patient education or introducing a Year of Care approach, have a much longer-term sort of payoffs. The barriers of both when and where the benefit out come were to us quite substantial. There are very few that could be realised quite quickly in the same part of the system—that is in those sectors gaining the benefit out quickly in the same budget. What we do, drives very clearly the need for a pooled budget of some sort in order to be able to realise these benefits.

Chair: It is a huge subject. Valerie want to come in, briefly, and then Graham.

Q74 Valerie Vaz: Who is picking up those patients who need mental health care? Are they being picked up at all?

Dr Aitken: In the general hospital, it is extremely patchy. There have been a number of mapping exercises trying to identify what the provision of health psychology and liaison psychiatry might be nationally. That work will need to be done with rigour and with support from an institution like the London School of Economics. We would need to know the answer to that question because, where there is a service like the Rapid Assessment, Interface and Discharge service at Birmingham City hospital, the economics are clear: for every £1 put into a service like that, £4 comes back to the health economy.

Chair: We will come back in 10 minutes hopefully and Graham will lead off. I apologise for the further disruption.

Sitting suspended for a Division in the House. On resuming.

Q75 Grahame M. Morris: I am sorry for that interruption. I want you to elaborate on your replies to the first answer. I am very pleased that you heard the evidence from Professor Maynard. He was a bit disparaging, if that is the right word, about the lack of evidence that has been presented on which decisions are being based. What are the main costs in redesigning the services so that they are more integrated, so that they are community-based?

Professor Silman: First, it is important to say that if we need to understand costs we also need to understand benefits. One of the benefits of being able to show that there is an improvement in health and satisfaction. An improvement in health requires that we have the data to show that the change in service configuration has produced a benefit. One of the challenges for most long-term conditions—and particularly those that Arthritis Research UK are responsible for—is the lack of data to show benefit. Within the NHS we are very good on having data on acute hospital episodes, but we are very weak at having the data to show that there is a change in health status in long-term conditions.

One of the costs—and it is an important consideration—is that we need to invest in both developing and being prepared to collect data on both the process and the outcomes of care. These are aspects that Arthritis Research UK can provide more information on if you would like.

Q76 Grahame M. Morris: Okay. Baroness Young takes that there is demand from patients—if we are talking about whether this is evidence-based or anecdotal—to have diabetes services delivered in the community. I can understand that. What is your view of the effectiveness of the care of long-term conditions for both arthritis and diabetes in the community? Is it more effective, even though patients may desire it, than going to a major general hospital to have their monthly blood tests or whatever it is? I can understand that it is desirable to be treated locally, but is the localised service more effective?

Professor Silman: I can answer the question in relation to arthritis and here the issue is less about where the care takes place. For example, in musculoskeletal diseases there is not the requirement for access to high tech, so the issue is access to expertise rather than the geographical location where the care takes place. For people who have a chronic condition, most of the time they do not require access to specialist expertise. They may require it at various stages, and that access can be delivered within primary care, in the community or at a local hospital. The important thing is that patients have the right access at the right time, and where it is and in what kind of building is less important. There is evidence to suggest that is the case.

Baroness Young: Perhaps I should correct a misapprehension that I have given. What patients are telling us is that they want their care to be joined up and, as was said by Alan, they want to be able to access the right care at the right time. They do not need specialist care when they have a complicated problem, and it can be delivered in the community by a specialist if their specialist is coming out of the hospital or it can be delivered in the hospital.

The important thing, first of all, is that general practitioners are skilled up in order to be able to play a full role in the care of people with diabetes, so there
is an education issue. There is also a shared information issue. Diabetes is pretty well placed in terms of its being one of the best specialities for having a good dataset, but that needs to be shared between primary, community and secondary care—and with the patient, hopefully, so that they are also in possession of all the facts. There needs to be a joined-up process. The commissioners, the providers and the patients need to get together to plan and design that integrated care pathway, so that the join-up happens and that the individual parts of the pathway work with each other, share information and that people are properly skilled for the role that they are going to take in that pathway.

Q77 Grahame M. Morris: To sum up, you have told us that the NHS spends £10 billion on diabetes generally and about £5 billion on arthritis and musculoskeletal and related conditions. Is that money currently being well spent? In terms of the changes that you are proposing—the integrated care pathways—would they deliver improved efficiency and better reach as well?

Baroness Young: The current care pathway is hugely inefficient. If you look at one example, patients with diabetes—and one in five hospital patients has diabetes—stay in hospital on average for three days longer, irrespective of what they are in for. That is not necessary. If we had proper specialist diabetes care teams in hospitals that were providing the right sort of care from the day of admission, we could know that excess length of stay down considerably, which would be a huge saving, and likewise if we improved the care in primary care and community care, because about 80% of the cost of diabetes is dealing with the complications rather than the primary condition. We believe that there is sufficient evidence that if you enable patients to be diagnosed early, and to be educated for self-management so that they can properly look after themselves, and that they have the 15 essential annual checks that they need, you could reduce the complications by about 80%. There is plenty of money in diabetes, but it has been spent in the wrong places.

Q78 Chair: Is that broadly the same for mental health?

Dr Aitken: Yes, I think that is right. The point I was going to make on your question about cost is the importance of rigorous evaluation. Where we are seeing new transformative mental health services emerge, such as the RAID model, it is precisely because we have good data and robust evaluation that we are able to answer the question and say, “Put £1 into that kind of service, you will take £4 of cost out and you will get your quality benefit.”

Q79 Grahame M. Morris: It is quite interesting that you should say that, in view of the fact that Norman Lamb has said today, there having been a huge issue about mental health services and whether there is adequate capacity and so on. Is there enough money in the system to enable us to engineer these changes, these multidisciplinary teams, in delivering an integrated service?
diabetes, because certainly not getting any education at all is a bit of a no-brainer; if you do not educate people, the likelihood of them being able to self-manage is pretty low.

Q81 Dr Wollaston: Many of the patients I used to see really valued the specialist diabetes nurse they could phone up with their results and get specialist feedback. Do you feel there is a role for that across more long-term conditions, and whether there is any evidence base about how much that saves the system as well as adding to patient satisfaction?

Baroness Young: Certainly, in a number of the studies that we have in our report, the role of the diabetic specialist nurse was paramount in patient care. The diabetic in-patient nurse is really important in making sure that people get good care and can get discharged promptly.

In care in the community and in primary care, the diabetic specialist nurse is a resource for patients but also for health care professionals, in that much of the training of general practitioners and practice nurses, particularly in support for patients with diabetes, comes from the diabetic specialist nurse. Much of the education for patients comes from them and the day-to-day being at the end of a phone. Being able to give support and advice that would prevent something from going seriously wrong and therefore resulting in the need for expensive intervention by a doctor or even in-patient care, is where the diabetic specialist nurse is really valued by the patients. It is important to an integrated service.

Q82 Dr Wollaston: It is certainly interesting to look at any research that shows the cost-saving work.

Baroness Young: We have commissioned a part of a bigger study, showing where diabetic specialist nurses have played a role, but I would not have come back to the Committee to see whether we have any research that demonstrates the cost-effectiveness of the diabetic specialist nurse standing alone.

Q83 Valerie Vaz: Can I follow up on that? Is it dwindling or going up?

Baroness Young: At the moment, we are really worried about diabetic specialist nurses—this is in common with many long-term conditions—because the current squeeze is having several effects. One is that quite a number of them have been downgraded—they are deskilling the role a bit—and there are places where we know that posts are being held vacant because of the financial squeeze. Those two factors would really concern us.

The thing that we would be looking to see, apart from protecting the level of these posts, is getting a standard agreed accreditation process for their training. At the moment, people coming in through a whole variety of routes call themselves diabetic specialist nurses, some of whom will be highly skilled and some of whom will be less so. It is important that there is a common agreed standard, and we have developed that with the diabetic specialist nurse community. We now need that to be recognised by the education and nursing authorities.

Q84 Valerie Vaz: Do they definitely help in not having hospital admissions?

Baroness Young: The combination of good general practice and practice nurses, help from specialist doctors and specialist nurses on the phone or in person [to the primary care or community staff] from the primary care-in-the-community staff, and the availability of those skills to help with training patients so that they have some structured education, are the three things that really help reduce hospital admissions.

Q85 David Tredinnick: Do you think that the integration of services across health care and social care provides the best opportunity for maintaining and improving quality of care in these times of financial stringency?

Dr Aitken: If I may start, it is essential for mental health simply because when we are meeting people, we are looking at their biology, their mental life and their social anthropology, because people live in groups and families, have roles and jobs, and it is that interplay that allows somebody to experience quality of life. If, by division of our service models, we are required to look only at the neurobiology and cannot consider the psychology or have easy access to social remedy, we are constrained in our effectiveness.

I would suggest that colleagues in social care find the same darkness: if they are trying to manage somebody and there is a medication need, and they have to make a referral and go through several processes to bring the right agency to bear, it has clearly got to be inefficient, and it is not good for the patient’s experience and not good for the delivery of biopsychosocial care.

For us it is the most natural thing in the world to create an integrated system. It requires mature commissioning and further work on currency, because the types of incentive we have in the current system do not lend themselves to promoting the right sort of behaviours by acute providers and mental health providers and so on and so forth, so there needs to be some revision. However, where you see mature commissioning working well—the Torbay system is a good example of that—you have staff that are co-located, the skills are in the same building and they can gather around the person in real time; seven steps of interagency referral can become perhaps two telephone calls and a conversation over coffee. It works.

Q86 David Tredinnick: For clarity, as far as long-term conditions are concerned, that very much applies—that integration is essential?

Dr Aitken: Yes.

Professor Silman: There are a couple of dimensions here worth considering. First, patients with chronic conditions, particularly those that lead to disability, rely very heavily on their carers, so there is a requirement to support both the patient and their carers, and this is where social care is so important.

Secondly, there is the issue in terms of things like prevention; people with chronic musculoskeletal decisions fall, and you can maybe do things about falling by providing aids, appliances, handrails and so
on in the home. There is evidence to suggest that some fairly simple remedies can both reduce disability and prevent morbidity and serious episodes. The challenge is having the data systems that will allow the integration of those, so that you can fully assess their cost-effectiveness and value.

**Baroness Young:** Could I put a slightly different slant on it for diabetes, because I think it is different? Although, when they get older and have multiple morbidities, people will require social care as well as health care, in the early stages of diabetes—many people live through it for many years before they ever have any symptoms—the important thing is that the health system is joined up rather than the health and social care systems being joined up. In the early stages of diabetes, many people live for 10 years with it before they have any symptoms at all. Not only do we need to get the health system joined up so that there is risk assessment and early diagnosis, with people getting the right sort of advice and education for self-management, and the 15 essential checks every year to try to prevent them from getting to a point where they will need social care at all. That joining-up of the health care system is really important.

**Q87 David Tredinnick:** Professor Silman, you mentioned carers, and my colleague Dr Wollaston mentioned self-management earlier. Wearing another hat as Chair of the Parliamentary Group for Integrated Healthcare, which is more to do with bringing complementary and alternative medicine into the health care system, we had a meeting last year where Trudy Reynolds, the project manager of the personal health budgets pilot study at Oxford Health NHS Foundation Trust, gave a presentation to the House. She said that the pilots showed that personal budgets were working very well and that patients were getting greater satisfaction, and that the pilots were getting greater choice and greater flexibility. She also added that not only are they getting better satisfaction from being able to choose therapies but it is freeing up carers, so freeing up valuable time. Is that a model that you support going forward?

**Professor Silman:** That is a really interesting topic because we know that approaching 50% of patients with long-term conditions, patients with rheumatoid arthritis and fibromyalgia, are exposed to; studies seem to suggest broadly the same level of benefit. Does that mean that they are all equal, or is it saying something about the context in which those therapies are delivered? Clearly—I guess that Arthritis Research UK would say this—there is a research agenda to try to understand whether it is the therapies or whether it is the context and the circumstances, the patient’s self-belief and other aspects, that might impact on how care is given.

We are also concerned about chronic long-term conditions, as patients can end up spending quite a considerable amount of their own resources. If the evidence for real benefit is lacking, that is something we need to think about.

**Q91 David Tredinnick:** I am going to move on to ask another question, unless anybody wants to come in on that. What service integration do you think exists at present, and how soon could genuinely integrated services be put in place—in the context of the Health and Social Care Act, I suppose?
Dr Aitken: I touched on a number of pilot examples of where integrated care is helping, particularly with the over-75s population, and the population with diabetes in north-west London, and so on and so forth. My instinct is that, as the commissioning environment matures, the pace for commissioning integrated services will increase. We are also looking forward to learning from the pioneer bids that are in the process of being announced, which I think will help further the evaluative evidence for their effectiveness. Certainly, from a mental health perspective, we welcome that.

Q92 Chair: Is there any evidence of the pace of change increasing?
Dr Aitken: I do not know the answer to that question.
Baroness Young: I certainly have a view about it.

Q93 Chair: The Committee is always interested in a view but even more interested in evidence.
Baroness Young: It seems to me that holding our breath waiting for commissioning to improve is quite a long shot, and we have waited for a very long time for commissioning to improve. Certainly, the model that we are promoting is twofold. One is that there needs to be an increased focus on care planning, with the patient involved and at the centre, so that the patient is the integrator, as it were, around their needs. Secondly, rather than simply relying on the commissioners suddenly getting a light-bulb moment, we ought to bring commissioners, providers and patients alighting into the same planning framework into the delivery process. Quite frankly, I would do away with the purchaser-provider split if I was advising you, but certainly, while it is still here, we need to encourage that way of jointly planning and delivering services between commissioners, providers and patients, otherwise we will wait a very long time while commissioners find their feet under the new system only to be faced with yet another change to the system. That, basically, has been the story of commissioning for the last 20 years.

Professor Silman: An experiment is about to happen in Bedfordshire where they have decided to look for a totally integrated system of managing musculoskeletal care. They put out a tender which was successfully bid for by a combination including some patient charities and other providers who are going to provide integrated musculoskeletal care, from a person going to see their general practitioner for back pain to, as I understand it, the delivery of hip and knee joint replacements. As an entity, as a concept, it is one that we should support. We need to be aware of whether we can measure whether that leads to improvement in quality of care for patients. That leads on to the fact that we have to accept that, whereas, for example, in diabetes there are some really strong biomedical markers of improvement in quality of care, for many long-term chronic conditions we do not have those. For example, Arthritis Research UK has commissioned some work developing a musculoskeletal patient-reported outcome measure across different levels of care—primary care and secondary care—with the agreement of the different specialist groups, because we need such data to be able to show whether these experiments, which are conceptually attractive but expensive, actually deliver health care benefits.

Baroness Young: Could I offer the Committee a paper we have done that pulls together the models of integrated care that already operate in diabetes? It is too early to be able to tell whether they have done the job yet of producing improved quality and reduced cost.

Q94 Chair: We have asked from several points of view for opinions about the state of the evidence base, and I think I am right in saying that every answer has assumed we have been interested only in evidence from within the UK. There was an implied question of whether anyone is actually looking for evidence outside the UK, because other people face exactly the same problem.
Baroness Young: Our paper on costs and quality improvement draws from other elsewhere in the world.
Dr Aitken: We have mentioned the Kaiser Permanente system, which is a useful place to look to see some evidence. The benefits of integration, certainly with mental health, is delivering a dividend.

Q95 Chair: It would be interesting to have the references for that, because we are told repeatedly that the evidence base is thin. If that is the case, we should look more broadly.
Dr Aitken: It is Kaiser and veterans. They also share—

Q96 Chair: Indeed—the usual band of suspects.
Dr Aitken: It is good data properly evaluated. Mental health in this country needs the same level of rigour applied to our outcomes and processes as these systems internationally do. If we had that, we would very quickly move to a place where we knew exactly what to do.
Chair: Thank you.

Q97 Valerie Vaz: Can we move on to the Year of Care and “house of care”, Baroness, that you mentioned earlier? I am not sure whether it is something that crosses all the disciplines, but could you tell us what it is and whether it would apply to the other long-term conditions, and then the other two could come in?
Baroness Young: We, with others, instituted a series of pilots looking at how you could improve care planning for patients with diabetes, primarily based in primary care. That was successful in terms of patient appreciation for being involved in care planning. It was successful in demonstrating what needed to change in primary care in order to be able to do successful care planning, and it was deemed to be cost-neutral in terms of ability to deliver it. That has now been taken and widened to look at its applicability to other conditions like stroke, heart disease and others. Our slight anxiety is that it is now being called the “house of care”, which is a set of principles that need to be in place to allow that sort
of effective care planning to happen, but it was very much a set of pilots that looked at how primary care should operate rather than how this integrated pathway across primary, community and secondary care should work.

Although we are very supportive of the Year of Care—we are delighted that that model is being adopted as showing potential for other conditions, particularly because it does bring the patient right to the centre of planning for their care, and that is where true integration happens—if a patient has multiple morbidities, planning for their particular care means that account has to be taken of their multiple morbidities.

The one anxiety we have about the whole co-morbidities debate at the moment is what I call grey goo. If you are not careful, you work at such a level of abstraction of principles, because that is the only thing that is in common between different conditions, that you end up losing the very specific focus on the distinct things that individual conditions need. In the case of people with diabetes, it is very much education for self-management, the 15 essential care measures that they need to have delivered every year and access to specialist care at the point that it is required. We would be anxious if there was a sort of general care planning process that delivered a load of general interventions and lost sight of those specifics.

Q98 Valerie Vaz: Can you describe what exactly it is when you say that patients are at the centre of care?

Baroness Young: It is very much about changing the way in which GPs and patients interact, not just the annual processes.

Two very key things are that the patient is provided with information in advance about blood sugars, cholesterol, blood pressure and various other tests that they have had, so that they can have a think about those before they come to their care planning meeting; then there is at least an annual care planning meeting with the general practitioner, which is a longer consultation than the eight minutes. That allows there to be a discussion between the patient and the doctor about what issues are coming out of the information base, the issues that the patient is anxious about and the things that the GP thinks need to be considered, and they can jointly make a plan that will take them through the next year of what needs to happen. The pilots demonstrated that by doing that, at the same cost, even though the up-front process was more expensive because it took longer, you could reduce the number of visits to the GP that the patient had as they felt more confident about their care because there was a care plan in place and the practice nurse was able to take that forward, and also hopefully—though I do not think we have yet demonstrated that it would—it could reduce the number of patients being propelled into crisis where they then have to go for secondary care.

Q99 Valerie Vaz: So there is a care plan for, say, someone with diabetes, but what about other long-term conditions that may or may not go together with that? How is that intertwined?
Q100 Valerie Vaz: It is a data problem?  
Dr Aitken: The datasets are beginning to emerge. For example, if one looks at the minimum dataset for mental health cross cutting with hospital episode statistics, for example, we are beginning to get some really interesting data pictures about use of accident and emergency by people who are known to have schizophrenia or bipolar disorder, for example. So we have some very large datasets out there. They also need to be mined in a multidisciplinary way. We need groups of experts having a look at those datasets and being helped to see the pictures that they can reveal to us.

Rigour and evaluation is going to be the key that unlocks what we do next, so I would go back to my plea that, when we set up these models, these social experiments, we make sure that we put in the evaluative research programmes around them that deliver quick learning. We are not looking for three years from now. We want to learn as we go, but we want the journey measured, please, so that we can decide after six months, “That is not the way to go. We need to turn that way,” or, “This looks like a purposeful line of inquiry. Let us have some more of that, please.”

Professor Silman: Can I address the issue that Baroness Young was talking about in relation to the multi-morbid environment? We know that 80% of patients with osteoarthritis have another co-morbidity. As the population of people with chronic conditions ages, we are going to see increasingly large numbers of people with multi-morbid conditions. There is a challenge there.

Baroness Young talks about the grey goo. What is going to be very difficult if we are to be integrated care is having a care plan about your arthritis, a care plan about your hypertension and a care plan about your depression and so on. We need to be very clear what care planning can and cannot deliver. Care planning can and cannot deliver. Care planning is the trading discussion where the one individual there will be some trades. The care planning meeting is the trading discussion where the risks of one course of action versus another are traded out. That is why the expertise is essential. This is not protocolised care. This is the grey area with protocolised care, where you have to make a judgment. If I give you this medication, it is going to prolong the heart rhythm in a way that puts you at risk of a heart attack or dropping dead; or, if I do this, it is more likely to increase your risk of stroke. It is finding that balance and then agreeing that this is the way forward to help you get to where you need to be.

Q101 Chair: Surely that is the whole point, is it not, that there will be things that are specific for each condition for which care planning is not the answer.

Baroness Young: That is where I part company with how it has been described so far. It seems to me that, for most patients, there will be some conditions that are their primary anxiety and then there will be other things that go alongside that. What remains to be seen is how effectively we can skill up primary care to be able to deal with the comparatively fine grain of several primary conditions, because care planning will be no good to man or beast if it does not deal with the specifics of your diabetes, if you have diabetes, no matter how well or poorly looked after it is.

Q102 Chair: I would like to hear Dr Aitken’s colour on this.

Dr Aitken: I will give you an example of a multidisciplinary meeting happening in a general hospital setting, which is what I do day in, day out. Our patient will have multiple things wrong with them and we will be having a discussion: “What is it you want to do? Let us bring in our experts from cardiology or diabetes or from heart disease, and let us have a conversation, because this is pretty tricky.”

We have an evidence base for these disease states but we do not have a particularly secure evidence base for what happens when these things occur together. Each of these disease states might be treated with medicine going to NICE guidance, and there might be particular therapeutic approaches that each would choose to take, but when they all occur together in the one individual there will be some trades. The care planning meeting is the trading discussion where the risks of one course of action versus another are traded out. That is why the expertise is essential. This is not protocolised care. This is the grey area with protocolised care, where you have to make a judgment. If I give you this medication, it is going to prolong the heart rhythm in a way that puts you at risk of a heart attack or dropping dead; or, if I do this, it is more likely to increase your risk of stroke. It is finding that balance and then agreeing that this is the way forward to help you get to where you need to be.

The communication with the general practitioner then becomes absolutely pivotal. We have done that piece of work and used up that time. How do you then communicate the essence of that to the absolutely busy primary care physician and their team, so that they can support that work going forward?

Q103 Valerie Vaz: Can I follow on? How difficult do you see this when it is being rolled out throughout
the country? Are there barriers to this implementation? Do you have any positive examples from, say, Scotland or Wales? I do not know what they do there.

Professor Silman: It is interesting. On the back of what Diabetes UK has developed, including getting people from the diabetes community, we thought about the opportunities for care planning in relation to chronic musculoskeletal conditions, and there are some difficulties.

There is an advantage in conditions like diabetes or high blood pressure, where you have some very strong biomedical markers. The problem in implementing care planning for many other long-term conditions is actually understanding what it is that we want to change, what it is that constitutes quality of care for patients. Then you throw into the mix, for example, the complexity that with many of these conditions people have chronic pain, fatigue and depression. What is it that we want to achieve? What are the goals that we are working towards with patients, so that they understand the aim of their care plan? These discussions are happening. It is starting, and there are some difficulties.

What is it that we want to achieve? What are the goals that we are working towards with patients, so that they understand the aim of their care plan? These discussions are happening. It is starting, and there are no easy answers to that, but I think they are fundamentally important for patients.

Baroness Young: There is evidence of the care planning process being effective in a single condition. For example, Tower Hamlets, which used to have incredibly bad indicators—it was one of the worst 10% of PCTs—for diabetes care, introduced a care planning process and has gone on to become one of the best performing areas.

My concern at the moment is that, in the effort to get something that is genuinely integrated across a whole range of conditions, any movement in implementing an effective care planning process for something like diabetes, which is a very medicalised condition, and quite rightly so, will come to a halt while everybody struggles with this much bigger integrated process, and that we will not get the gains that we get now from integrating around the diabetes care pathway but that they will be submerged.

Chair: We appealed for brevity at the beginning.

Q106 David Tredinnick: I am curious about the problem of different treatments for different conditions—the multi-morbidity problem. As someone who has used traditional Chinese herbal medicine for many years for general well-being, I am struck that perhaps we have something to learn from people who, over 2,000 years have found how different herbs interact with each other, and perhaps come up with the sort of combination that they call the chief, the deputy and the messenger—an old joke here, as it mirrors the Whip’s Office. They have at least two or three herbs that all interact together to deal with a number of issues in the body, and they may use up to 20 herbs mixed together. It seems to me that we may have something to learn from Chinese medicine at a time when we are facing the problem of combinations of medicines but really do not know what they do when they are all put together.

Chair: We will have one response to that.

Dr Aitken: I am very grateful to have a chief pharmacist who does her best to help when there are more than two medicines in the system, but it is complex. It is an area that is difficult.

Q107 Dr Wollaston: I briefly want to come back to the point about when you have a multidisciplinary meeting but there is the challenge of communicating that back to the GP. There is much interest at the moment in patients holding their own records. What progress do you feel is being made on that issue, and is that the way forward, not only in encouraging self-management and understanding but in actually making sure that everybody knows what the results of that multidisciplinary meeting were? Very often the patient does not understand it, and the decision does not get communicated to the GP, sometimes for weeks.

Baroness Young: I could outline what is happening in Scotland. They have an integrated diabetes information service that is accessible by patients, general practitioners and practitioners in secondary care, but it is very much about diabetes rather than trying to design a fully-integrated patient-accessible record.

Q108 Dr Wollaston: Is that about the patient holding their own notes?

Baroness Young: It is not about the patient holding their own notes.

Q109 Dr Wollaston: Do you feel it would be better if we went down that route?

Baroness Young: It is an online access system to the front end of their medical record, as it were, for their diabetes. The Scots decided that, if they were going to wait for a fully-integrated information system covering a whole range of conditions, they would have to wait for ever, and that they should go and make progress now on diabetes.

Q110 Dr Wollaston: Is the problem with that, though, if you have several long-term conditions, that the patient might be able to access the diabetes part of their record but would not then be linking in if they had multiple conditions? Do you therefore think we need to move to the principle that patients are able to access their entire online record, and give permission to who else can access it?

Baroness Young: The other thing that we need to be conscious of—particularly in diabetes, where there is strong correlation between type 2 diabetes and social deprivation and ethnicity—is that part of the problem is how you get patients to engage with their condition at all. The idea that somehow they are going to fall over themselves to access their records or to be the main repository of their records is quite a challenge in that environment.

Q111 Dr Wollaston: Before I move on to the next part of my question, because it is to Dr Aitken, can I state for the record that I am married to a full-time consultant NHS psychiatrist who is also chair of the parliamentary liaison committee for the Royal College of Psychiatrists?

Having got that one out of the way, can I go on to the point that you have already made, Dr Aitken, about
the benefits of liaison psychiatry for those with long-term conditions? I presume that the £1 invested for £4 saved comes from the RAID study in Birmingham. Today Norman Lamb made the comment—I refer to his remarks—that there is an "institutional bias" in the NHS against mental health. I am interested to know whether you agree with that comment, because that has importance if we are going to shift funding within the NHS to long-term conditions, including psychiatry. How much of a challenge do you see that as being?

Dr Aitken: The college position was that it recognised the institutional historic bias. Parity of esteem has been accepted. NHS England has accepted that all its work streams will tackle the parity of esteem issue. What that means is that, when services are being planned, the same attention to a mental health service would be afforded as might be given for a cardiology service or a cardiac surgical service. The notion is that mental health would be planned and resourced on a level with other areas of medicine. Psychiatry and the Royal College of Psychiatrists have gone a long way to helping the world see psychiatry as a piece of medicine. Perhaps for a decade it looked as if psychiatry was not part of the medical family in quite the way that radiology, pathology or other medical disciplines might be. The general feeling is that that has been to the detriment of making the case that psychiatry in medicine should be invested in and that it should support the leadership in transforming mental health services. That is the college position.

In terms of "progress towards," we see an intellectual acceptance of the argument. It is not about the practicalities of how you put that right at a time when everybody's budgets are under pressure. The proof of the pudding will be in the eating, as we see together, after subsequent rounds of commissioning. It looks as if the balance of investment that would be needed, particularly to help the depression burden, will be of a level commensurate with the investments made in cancer services or other parts of the NHS. Again, we are going to require tight economic evaluation of exactly what the case needs to be, and how that ought to be met.

Q112 Chair: Can I interrupt rudely? Having disrupted the Committee because we had a Division in the Commons, there is a Division in the Lords if you need to vote on it.

Baroness Young: I think I shall ignore that one.

Chair: I am sorry, Sarah.

Don Redding: I am Don Redding. I am the director of policy for National Voices, which is a coalition of health and social care charities—around 130, including those who were here previously—and a better quality of care and support for people with long-term conditions is one of our current priorities. Part of our work is a strategic partnership with NHS England.

Q115 Chair: It is hardly the most important question, but I would like to ask a question of semantics first. You both report that you represent users of health and social care services, and there is a piece of semantics—a phrase that volunteers itself—about whether the people that you represent are patients or service users. How do you refer to them when talking about an integrated service?

Don Redding: First, we carefully do not say that we represent patients or service users, because we represent the 130-odd charities who are our members, particularly to help the depression burden, will be of a level commensurate with the investments made in cancer services or other parts of the NHS. Again, we are going to require tight economic evaluation of exactly what the case needs to be, and how that ought to be met.

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which is not quite the same thing. We switch between “patient service users, their carers and families,” which I think has been in use since the CQC was set up, and “service users,” which I increasingly prefer as a shorthand, but after a lot of chiding as well from people who use these services, “people,” “people with needs,” or “people who need co-ordinated care.”

**Liz McAnulty:** There is a lot in the name, and the word “patient” is not in keeping with the new trend towards self-management. It implies passiveness, patience and so on. From another world—I used to work as a midwife many years ago—the notion of “a patient” for a pregnant woman was seen as highly offensive. Those women were very active in managing their care, so woe betide any midwife or doctor who referred to a pregnant woman as a patient. I think we may move a little bit. It may well be semantics, but if we are truly to respect patient autonomy—people autonomy—in the management of their conditions, and if the notion of partnership actually means anything, whatever word we use, we need to ensure that the person really does have an equal say—and indeed a greater than equal say—in the management of their conditions.

**Q116 Valerie Vaz:** I think they call us “one”, don’t they?

**Liz McAnulty:** Yes, or “poppet”.

**Valerie Vaz:** We don’t have names.

**Q117 Chair:** In other words, there is no easy solution to this conundrum. However, we are all familiar with the philosophy and the objective, and I think it is broadly shared, which is that there is a dilemma around the language. There is a lot of talk about building services around people and treating people, not conditions, and engaging people. Dr Aitken refers earlier to walking with the person through the system. How far are we converting that rhetoric into reality, and what more do we need to do?

**Don Redding:** I will speak first from the point of view of somebody who is very involved with the drive for more integrated care. National Voices helped to produce a narrative, which has been adopted by all the national system-leading organisations and by all the pioneer applicants, that redefines integration as being about person-centred, co-ordinated care. It is made up of a whole set of statements about what somebody would be able to say if they were getting care of that type, such as, “I can plan my care with people who understand me and my carers, and who allow me control and who bring services together to deliver the outcomes that are important to me.” There is quite a lot in that about goals and where the goals come from, which we may return to.

I have just returned from speaking to the National Children and Adults Services Conference for the social services directors and local government and so on, and I have been doing the rounds of other such conferences. The realisation and understanding that co-ordination must be built around the person and is not a matter of structural change, merger of organisations or building of budgets—although any or all of those things may be required to support the person—is penetrating quite rapidly around the system. What I fear is getting half way with it, getting to a point where people are clear about the need to co-ordinate services around the person but are mainly co-ordinating the services, if you understand what I mean. They own the pieces on the board—the services, the professionals, the budgets and so on—and they feel that, if they can configure them a different way around the person, it will be better. From the point of view of service users, people who are trying to self-manage or trying to live with disabilities or chronic conditions, they are saying that it falls short because it does not understand that this is about “me being able to take some control, set the goals and determine the direction of the care and support that I receive.”

We are keen to ensure that we get the person-centred bit, not just the co-ordinated bit. There are signs of progress, signs of momentum picking up and we can, I am sure, talk further about that.

**Liz McAnulty:** Yes. From the database of the Patients Association, on the helpline, which runs from 9 to 5, Monday to Friday, we get thousands of contacts each year, and it is very clear—the evidence is there—that there is a lack of integration of services, and that is what patients need. Through our other work at the Patients Association, where we link with and assist trusts to implement a good complaints system, and we provide project work for them, integration is happening in pockets. I can give you more detail, but I can say that we understand that there are good examples in Calderdale, Bradford and in east Lancashire, where there is evidence of greater integration.

**Q118 Chair:** Taking Mr Redding’s point, is that integration or personalisation?

**Liz McAnulty:** I would not be able to speak to that just at the moment.

**Q119 Chair:** That is the real challenge, is it not, of building a personalised service—as Mr Redding quite rightly said, going beyond taking the existing organisations and making them work better together, and actually building the service round the needs of the patient rather than co-ordinating the existing structures?

**Liz McAnulty:** Yes.

**Q120 Chair:** Mr Redding, do you have somewhere you would suggest we go to look where it is actually working well?

**Don Redding:** The Minister will be announcing, I think next week, that the pioneers that have been chosen are to move at greater pace and to provide learning for others. Those, I suggest, are places where you could look, and they have had to put together applications that say what it is they are going to do, and why and how. I hope that, as those surface and become public, everybody will get a better look at what is going on around the place.
Some of these areas that are being talked about have a population of up to 2 million, with multiple numbers of CCGs, local authorities and provider trusts working together. Others are less sizeable than that, but perhaps have a little more local coherence and clarity as to where they are going, and they will provide other valuable sources of learning. Some have the voluntary and community sector in formal partnership with them to pursue this, and are consciously going to make use of that sector to extend their reach and to build community support for people to live more successfully with their conditions. There will be a lot of rich things to look at there in due course.

**Chair:** Thank you.

**Q121 Valerie Vaz:** I do not know if you were sitting in the audience when the previous panel was here, but you will know we touched on this Year of Care, or “house of care”. Could you let us know what your understanding of it is?

**Liz McAnulty:** From the work of the King’s Fund and other organisations, it is a very useful conceptual framework to have a “house of care”, but those of us who have been around health and social services for many years have seen models before, and we now need to see these producing some goods from the patient perspective. In many cases where we see moves towards integration, we are hearing from the patients that care feels more joined up, with positive responses from patients about improvements in care, but it is piecemeal at the moment and it is very difficult for a lot of people, particularly those with multiple conditions. That is the left wall, the informed patient. It is about developing people so that they are engaged patient. It is about the fact that you need to develop your work force so that they can work in that way.

**Q122 Valerie Vaz:** What is meant by “house”?

**Liz McAnulty:** I think the analogy is quite useful in some respects because, in parts of the country, rather than a house it feels like two rather dilapidated tower blocks with no links between them, and it is impossible for patients to navigate their way through. It clearly is helpful to policy makers, because the idea seems to have caught on very widely across the country. If it works, that is good, but underpinning it must be the notion that the patient or the service user must be at the centre of health care. Evidence of that will be, for example, that at the moment GP services are not patient-centred: they are doctor-centred. A lot of outpatients departments—9 to 5, Monday to Friday—are certainly not patient-centred. When we see services opening up until 8 o’clock at night or at weekends when patients are able to use them, that will be helpful. That will be evidence that it is patient-centred. When patients do not have to queue on the phone for half an hour every morning to try to get a 10-minute appointment with their GP, and if they have multiple conditions they are only allowed to discuss one, then we will be moving on to something that is more patient-centred. However, at the moment we have a long way to go in achieving that. Those things—making it more patient-centred—do not cost a lot of money.

**Q124 Valerie Vaz:** This is happening in the community. It is much easier in a hospital, is it not? It is multidisciplinary.

**Don Redding:** With each other.

**Q124 Valerie Vaz:** With the DIY manual for building the house. It has been adopted, some while back by the Royal College of General Practitioners as the model for generic long-term conditions, so that relates to the discussion that you were having with Baroness Young that the primary care practitioners see it not just as being for diabetes but for other conditions. It has been taken up and is being actively promoted by the Domain 2 team at NHS England, who held a two-day conference in London recently, which was basically taking its lead from the “house of care” model. The initial reason for displaying it as a house was to build from the understanding that, to initiate good care planning, which I think was well described previously, there are different dimensions that you need to tackle. It is not just about having a longer consultation, for instance. It is about developing people so that they are able to participate as more engaged individuals, more able to use health information and to think about setting some goals that come from them, which is very difficult for a lot of people, particularly those with multiple conditions. That is the left wall, the informed engaged patient. It is about the fact that you need to develop your work force so that they can work in that way because they have not necessarily been used to doing so. That is the right wall—the health care professional who is ready to work in partnership with people in that way.

As you accurately described it, the roof is organisational processes. If you cannot then change the way that a clinic is set up so that you can ensure you are giving people at least a longer annual consultation to cover all that ground, which involves your administration systems, how you set the practice up and how you train receptionists—that is an example of the organisational process, and communicating from the hospital to the GP might be another part of that.
The realisation was that you must have commissioning as the foundation—as long as we have this system of commissioning—because people are going to need to put in place, as a result of that care planning conversation, a menu of things that range from the specialists, who know their specialist bits of care that the previous witnesses were talking about, through to what happens with their home care, for instance, and what happens with the allied professionals who are working with them, and moving into what is called the “more than medicine” part of the offer.

It was an important realisation from the Year of Care pilots that if, for instance, somebody’s own goal is to do with, “I want to be more active and I want to be out in the community more, because I have lost that,” then you need places to offer them, to refer them to, which are nothing to do with medical knowledge necessarily but which are community support. One example in Year of Care is men’s cookery classes in the Bengali community centre, which would help the Bengali guy in Tower Hamlets who is struggling with his diabetes and who is going to get both community interaction, which helps mental health, and dietary advice, which is going to get him exercising by going to and from it. The commissioners—and this is very dear to our hearts, coming from the voluntary and community sector—need to be able to commission not just the integrated diabetes pathway but a pupil of support that enables people to achieve the goals that they would set for themselves which are around not just health but well-being.

**Q125 Valerie Vaz:** You are saying that this model could pick up multiple conditions?

**Don Redding:** You asked whether patients could understand that model. Certainly, the experience has been that, when you use this model, a pictorial model, with professionals and people who work in services, they get it quite quickly, so that helps. We support it because we feel that it is one of the few places where, as Liz was saying, we have gone beyond a model and have done some demonstration. We think it is flexible enough that it could be moved to different communities of practice; the house you build in Somerset might be different from the house you build in Wakefield according to local circumstances, who is involved and how you want to change the organisational processes, but it still needs to be a house because it still has to change those four dimensions. I hope that helps conceptually.

**Q126 Grahame M. Morris:** I have some quick questions about carers and so on, but one just on this particular issue about the “house of care” model, which is quite intriguing. Is there a wall or window for carers? Are they part of the design brief?

**Liz McAnulty:** My understanding of it is that the patient who is at the centre could be linked up with the carer, because the carers very often are the advocates for the patients. They would act as the advocate in that, so it is a very important part of the “house of care”.

**Don Redding:** For us it would need to be. If you go back to the earlier statement that was drawn from the narrative for person-centred co-ordinated care about working with one’s professionals and others, and that they “understand my needs and the needs of my carers,” that is very definitely in there. Key to any resulting support offer should be that it supports the carer who is probably providing the bulk of the care. That certainly will come through the Care Bill and its provisions around assessment of the needs of both individuals and their carers.

**Q127 David Tredinnick:** I want to ask you about the integration of services across health care, social care and housing, suggest to you that it is the best opportunity for maintaining and improving the quality and extent of care and see whether you agree with that.

**Liz McAnulty:** I am sorry, would you just repeat that please?

**Q128 David Tredinnick:** I am really asking a question that I asked the previous group. Do you agree that there is a consensus now that integration of services across health, social care and housing provides the best opportunity for maintaining and improving the quality and extent of care? Is integration the key, boiling it down to a phrase?

**Don Redding:** Yes, it is. For us it would need to be. If you go back to the personal health budget pilot that the Department of Health has been running in Oxford, the Oxford Health NHS Foundation Trust, where they were finding that patients who had control over their budget and their treatments were getting greater satisfaction. They liked the flexibility. I remember one particular example where a patient had chosen piano therapy, which may not be prescribed on the NHS, but under...
this regime they could choose what they liked and they were getting a lot of satisfaction from it. It was improving their quality of life. Secondly—and I mentioned this before—carrers were getting flexibility; they could do part-time work that they had not been able to do. Do you think that personal budgets, where the direction of the funding that an individual receives is under their control, is the way forward? Do you see that as a future paradigm?

Don Redding: There is no doubt that there is an appetite for the roll-out of personal health budgets and for that to keep pace and momentum. Again, if you look at the pioneer application bids, most are setting ambitions around that because they understand it to be part of the personalisation that needs to be supported. I know of people who were very sceptical of personal health budgets who finished up being very impressed by the pilots and their evaluation, and by examples of the kind that you have talked about. At the sort of leading edge of some of that practice locally, there will also be some push for people to be able to join their budgets up, and to be able to act together as commissioners of their care where they think they may want similar things. I definitely think it is going to be a fast-increasing part of the landscape. I get a little wary sometimes when I hear people say quite baldly that they feel that that in itself solves the integration question, because then the person will not be able to integrate their care. They will not. The care and support that they need will extend far beyond what the personal health budget will cover. However, it can make a crucial difference. I think the people’s sense of self-efficacy—a slightly icky phrase—the sense that you can take some control of your circumstances. Just getting that right, even in the first steps, is very important for people with multiple long-term conditions. It is a key moment.

Q132 David Tredinnick: That is very helpful. Going back to what Liz McAnulty said earlier about the time that doctors see patients for 10 minutes, and maybe that is limited to talking about one condition—according to research, one of the reasons that people turn to complementary and alternative medicine is that they can get longer consultations, perhaps an hour for a first consultation. Would you agree that that might be one of the reasons why patients look in that direction? Have you any experience of that?

Liz McAnulty: Do you mean in order to have longer?

Q133 David Tredinnick: I mean to feel that they have longer to discuss their issues—the time issue which you have alluded on.

Liz McAnulty: Yes. From the Patients Association’s database we know patients will use alternative therapies, and we will encourage them towards this, but to have longer care is not usually the reason they would do it. What they need is longer care time from the GP, practice nurse or consultant. Very often it is not that they need a longer time per se but that, because of change of personnel, they are having to repeat themselves, going back to stage 1 of their health condition, and maybe of four or five conditions. If it is a locum doctor or another person at the hospital, one of the complaints patients make to us is that it is obvious sometimes that the doctor or nurse to whom they have been referred has not even read their notes. So the issue is actually not so much more time but making efficient use of the time available.

Don Redding: Can I add quickly to that? The one thing that we hear again and again when we look into this is that people react with tremendous relief when, having worked their way around the system and finding out things that nobody was telling them, they finally locate that person for whom they have been looking. That person is somebody who will spend time and build up a picture, who will become for them the person who knows their stuff, whether that is diabetes or whatever, but who knows them too and who can help them with that negotiation between their circumstances and their preferences and what they might need from the system.

There is absolutely no reason why we should expect that always and ever to be a GP, because people can find that elsewhere. Specialist clinical nurses are often the nearest thing that people get to that. They are too often based in hospitals. I have to say, and should be more in primary care, but it might be a Macmillan nurse or a dementia adviser. They do not need to know the full medical picture. If we can work out a system that is about a proper care planning process that you will get at some point in the cycle, but which can then be taken forward by that one trusted person, whether it is a GP, practice nurse, specialist nurse or a befriender and adviser—

Q134 Chair: A pharmacist.

Don Redding: It could be a pharmacist. There is no reason why that should not work, and that can give people someone who they feel can spend that time with them, who does understand them.

Q135 Dr Wollaston: My next question touches on those issues. There seems to be a consensus that we are hearing as a Committee that more health services, particularly for those with long-term conditions, should be delivered closer to the service user’s home and within primary care. In your experience, is that what patients welcome, or do you think that patients prefer to have more of their care taking place within secondary care?

Don Redding: There is no generalisation that would provide an answer to that. If you look at, say, surveys of people who have survived cancer and ask where they want their follow-up care, about a third might say that they are happy to use the GP. Another third may say they want to be going back to the specialist in the hospital, and another third may not have strong views. I just give that as one example, although it was from a survey some time ago.

Q136 Dr Wollaston: So you would say that we cannot generalise, in other words, the opinion for diabetes—

Don Redding: I do not think you can generalise. There is the fear of change, though. We support wraparound care closer to home, if it can be achieved, and we need to get the resources out of secondary care and closer to people. Obviously, however, people have a fear of change because, in particular, they do not
want to feel they are going to lose access to a particular consultant or specialist nurse who happens to be based in a hospital trust.

**Q137 Dr Wollaston:** The other issue, of course, is capacity. I know, Liz McAnulty, that you touched on that when you were talking about how people want to have better access, in terms of the time of day they access primary care, but then they also want to have longer appointments. Of course there is a tension, because there is a work-force crisis within general practice, but there might be a trade-off; but if you end up having appointments at different times of day you might find that there is less time available for those longer consultations. Do you have a view about that tension and those problems?

**Liz McAnulty:** Yes. It keeps coming back to the issue of self-management. The vast majority of patients, particularly those with long-term conditions, already manage their own conditions for 99% of the time, and they would be capable of doing even more than they do. However, in order to manage—as any of us need to manage—you need to have information. One of the things that we hear people being very anxious about in the general population through our helpline at the Patients Association is the further cuts to the service. There are all sorts of anxieties around and about, such as “We have only had”—we heard this mentioned this week—”25% of the cuts. What is the service going to be like when the other 75% happen?” To be realistic, we know that there is not enough resource to meet the growing need. Something has to give. Patients are very capable of understanding more information about exactly how much money there is going to be available for health and social care in two, three or five years’ time, so that they are not left a bit like children wanting the holders in vain when actually the parents cannot find the money for the week.

It is about enabling patients to manage their condition and to act as meaningful partners in their health care and social care relationships by making sure that they have the knowledge about the money and other resources available to be realistic about what their demands are. I do not think that patients necessarily need longer visits. They need more effective visits from people who have read their notes. That is not a criticism of GPs or doctors necessarily, the vast majority of whom are doing an excellent job, but we frequently get complaints from patients that when they go to the doctor they are allotted only 10 minutes; they can only discuss one of their problems because they will not get more than 10 minutes.

**Q138 Dr Wollaston:** Sure. For you, therefore, it is an issue of the premium of time that we heard about from Dr Aitken earlier, about that and the continuity being valued. Coming back to a point, you just used the term “cuts”, but of course the Nicholson challenge was about redistribution and saying where that money went. Do you think that there is an issue about explaining to people that a service redesign shifts resource from secondary care to primary care? If we talk about that being a cut, it is a different terminology from saying that we are shifting that resource into a more integrated service that is primary care-based. That is a shift rather than a cut, but it feels like a cut, and the story that you hear is about the cut in a hospital service rather than there being a better service somewhere else in the system.

**Liz McAnulty:** Yes.

**Q139 Dr Wollaston:** How do you feel we can explain that?

**Liz McAnulty:** I cannot go into exactly how, although I think a key role for Health and Wellbeing Boards and the other new structures is to explain to patients more about why and how the changes are taking place. There is certainly anxiety among patients that there are cuts going on, and that it is affected by their age. Now a great deal is being done by doctors and other health care workers to assuage people of that—that you will not be discriminated on the basis of your age. We are also aware that there have been surveys recently showing that there has been an increase in patient satisfaction with the NHS, but it is giving the information to patients in a meaningful way that needs to happen.

**Q140 Dr Wollaston:** You mean explaining where the resource is, but it may have disappeared from one place but is available and more appropriate within another place?

**Liz McAnulty:** Yes.

**Dr Wollaston:** Right, thank you.

**Q141 Barbara Keeley:** I have a question on social care, which I unfortunately think we have to describe as having been cut. Could you tell us how important you think social care services are for those with long-term conditions, and how well served they are by social care departments currently? I understand that National Voices has said that people with moderate needs should receive funded social care. I think you will understand that that is difficult at the present time. My local authority is moving from “moderate”, which it has preserved for a very long time, to “substantial” this year. If you want, you can say more about why you think people with moderate needs should be served.

**Don Redding:** It is part of the campaign ambition that not just ourselves but the Care and Support Alliance of which we are members—I am sure you know it well—have carried for some time. We appreciate how difficult it is to realise these things, but, while we have strongly supported the provisions in the Care Bill and worked to strengthen them and help them to align with health in a positive way, they will be less meaningful if it is such a restricted group of people that can access that set of entitlements. It is a campaign goal. It is not a budget that we have been able to fix, if you understand me.

**Liz McAnulty:** In answer to your first question, the social services are incredibly important, and patients value those services, particularly people with long-term conditions, most of whom want to remain at home as long as they can. We have come across some really good examples of where health and social...
services have worked together to make that work effectively, but there is also some concern.

I happened to be at the helpline when one of our staff took a call from a very distressed person on Thursday of last week. An elderly gentleman’s wife was being discharged from hospital, but he had just been told that she would need a carer to come in on three occasions each day to help her and that he would have to pay for that. He was really upset on the phone, and said that he had no idea that this was going to happen.

There was clearly a lot of anxiety, and I understand from colleagues at the Patients Association that this is not unusual, and that there is considerable anxiety. Whether the anxiety is due to lack of knowledge of the service or in how these matters are being presented to patients, there is clearly a need for clarity for patients about what it is that they have to pay for and when. There is a built-in conflict if people have to pay for their social care but not their health care and there is going to be a drive for patients to stay in hospital longer than they need to. It is perverse.

Q142 Barbara Keeley: I do not know what others might think. From my casebook, I would say that the shock of discovery of having to pay for things does hit quite a lot of people.

**Don Redding:** If I could just add to that, it is not only in social care but also in community health services that, essentially, we have seen that rationing has been hardest in the place where we want to start moving more resources to. The direction of travel has been wrong. We have a much reduced force of registered district nurses, for instance, and more use of health care assistants in that environment. We have to place some hope and work more in that idea that, when making their plans for integrated care, people can look at the whole budget for a place. As I say, some of these places are big places and the budgets that they put together are big budgets and the future in those places has to be bringing people together so that the boundaries between services become much less visible, particularly to the people who want to use the services but also to the people working within them.

Q143 Barbara Keeley: The second question is about carers and how you think they fare under current provisions, and specifically to what extent carers should have a voice in the design of services given their role.

**Don Redding:** We have to start looking at this in a different way. You have to start looking at. “Who is the carer?” It is the person who is living with the conditions. “What is the care service?” By and large it is the carer; they are providing 90% of additional care. “Where is the support system?” That is family and community, so we need to think about who is mobilising that. Then we need to look at how the health and care services plug into that picture and support it. So, absolutely, I think that the principle of co-designing and co-producing health and well-being with groups in the community, with carers and with people with conditions themselves, is the way that we need to be going.

Co-designing is about a lot more than informing, consulting or occasionally engaging with people. It means that you take them into the shared vision and purpose of what you are doing, and they become equal partners in helping you to deliver it. Along the way, one of the benefits of that, touching back to Dr Wollaston’s question, is that people then gain an understanding of where it is that you are going, and they own that as much as you do. It solves your stakeholder engagement issues if people who are caring for or who have the conditions that you are redesigning the service for are saying, “This is what we want.”

Q148 Barbara Keeley: You mentioned carers earlier in answer to Grahame Morris, in terms of the care that they provide, and as advocates. They are certainly providing the bulk of the care and then act as advocates. That is important, but do you think that there is a danger of losing track of the fact that they may be patients themselves, that they may have conditions, stresses and depression— their own conditions? Often in a family situation, it is the person who is slightly more well who does the caring, but it is very easy to overlook them, for everything to be centred round the patient and not seeing that the carer is a patient as well.

Q144 Barbara Keeley: I mean unpaid family carers.

**Liz McAnulty:** Again, we have had a number of approaches from relatives, where they have gone in and have been told that they must come in and feed their aunt or mother or whatever. That is a real worry, you would not have a problem and you would not need to be trained how to do it, but administering drugs is a bit of a different thing, is it not?

Q145 Barbara Keeley: If it was feeding a relative, you would not have a problem and you would not need to be trained how to do it, but administering drugs is a bit of a different thing, is it not?

**Liz McAnulty:** Yes. We know that administering drugs is done very often by carers at home, and there is some anxiety about whether they have the right doses. Of course the pharmacists are wonderful in the way that they present the medication, but there is still some anxiety. That is something that patients are very used to doing themselves, but it is difficult for some carers to have to clean up their mother or father.

Q146 Barbara Keeley: Personal care?

**Liz McAnulty:** Those kinds of situations, yes, but I think many carers do that all the time without mentioning it.
Don Redding: I am sure that is true.
Liz McAnulty: Yes, it is, but that is all the more reason why the carers should be involved along with the patients in designing the service. They know best what works in these long-term conditions, both for themselves and for the person they are caring for. They know what good service looks like, and they know where waste is occurring in the service, so they are ideally placed to be part of the design team.
Chair: You have been extremely helpful to us, and extremely patient with us as well. Thank you very much for both. We will reflect on the evidence that you have given in preparing our report. Thank you very much.
Tuesday 29 October 2013

Members present:
Mr Stephen Dorrell (Chair)
Andrew George
Barbara Keeley
Charlotte Leslie
Grahame M. Morris
Andrew Percy
Mr Virendra Sharma
David Tredinnick
Valerie Vaz
Dr Sarah Wollaston

Examination of Witnesses

Witnesses: Dr Peter Fisher, Clinical Director and Director of Research, Royal London Hospital for Integrated Medicine, and Professor George Lewith, Professor of Health Research, University of Southampton, gave evidence.

Q149 Chair: Gentlemen, thank you very much for joining us this afternoon. As you know, this is an inquiry we are doing into services for people with long-term conditions. We are looking forward to the evidence you are going to present to us about the role that complementary medicine can play in this process. Could I ask first that you briefly introduce yourselves, please?

Professor Lewith: I am George Lewith. I am a professor of health research at the university of Southampton in the primary care department. I have done quite a lot of research in this area. We have a unit dedicated to looking at integrated medicine in primary care.

Dr Fisher: I am Dr Peter Fisher. I am a clinical director of the Royal London Hospital for Integrated Medicine, which is part of the University College London Hospitals NHS Foundation Trust. I am a doctor, a consultant physician, I practise homeopathy and I am also a physician to Her Majesty the Queen.

Q150 Chair: Thank you. To get the session started, could I ask first of all purely a question of semantics? There is confusion caused these days, I think, by the phrase “integrated medicine”. Does it apply to what we used to call complementary and alternative therapies or does it apply to service reorganisations? I wonder if, from your perspective, you have any thoughts on the semantics of it. More importantly, I would like to go straight into the question of the evidence base for integrated medicine, how substantive that is and how that is pursued through peer assessment, peer review and made available to your professional clinical colleagues.

Dr Fisher: Yes, I accept there is some scope for confusion about the term “integrated—or, as the Americans say, “integrative”—“medicine” in that very frequently it is used to mean integration between primary and secondary care and integration between primary care and social care, whereas we tend to use it more in the sense of integrating various forms of complementary medicine. What is useful is the concept, which I believe you can find in the Department of Health’s submission—it mentions Kaiser Permanente in the States—of horizontal and vertical integration, vertical integration meaning between secondary and primary care and horizontal meaning across secondary care. We certainly do both of those in our hospital. For instance, we have a good collaboration with our cancer care colleagues. But, for instance, in the area of insomnia—and this is an extremely prevalent problem for which good treatments do not exist actually—we integrate, so we have a social care unit within our hospital and, increasingly, we are implementing vertical integration with primary care. There are some problems with the contractual situation which inhibit that, where we would like to get on with it but are facing bureaucratic obstacles.

Professor Lewith: The issue of evidence is complex. If we look at the whole NHS from the perspective of a GP, which I am—although I retired, it kind of gets into your bones, as anybody who is a GP will tell you, and it is difficult to lose it—there is not a lot of evidence for many of the things we do in day-to-day practice. Having said that, in my 30 years of doing research in this area, it has been very difficult to get funds, so there is a scarcity of money available in spite of the fact that I worked with a House of Lords Committee in 2000 to create PhD and postdoctoral fellowships through the Department of Health and we were able to secure quite a few of those in Southampton. We have more evidence than we did 20
years ago but we do not have enough evidence in some areas and in others we have none. The evidence in terms of specific therapies is very powerful for acupuncture, pretty powerful for some of the mindfulness meditation approaches and reasonably powerful for some of the herbal medicines. The evidence is probably non-existent in areas such as reflexology and aromatherapy and patchy in others, such as healing. So there are various levels of information that we have from rigorous randomised placebo-controlled trials. The current NIH policy of increasingly looking at pragmatic studies that inform clinical decision making at the bedside or in the consultation is a very powerful way to look at complex interventions such as complementary medicine because they are all complex; they involve a lot—certainly an enhanced element—of placebo and non-specific components along with, probably, some specific effects. That is the evidence that is emerging. They are quite difficult to investigate and evaluate. The most powerful treatment that most GPs have at their disposal in many chronic long-term conditions is the contextual effects of seeing the doctor. One of the ways we develop evidence is to learn from the complementary therapies about what they do so effectively and reproduce it in conventional medicine. If we take a more anthropological statement about what this means contextually in terms of our society—why is it that 15% of the population each year look at CAM, and that figure rises dramatically, sometimes up to 90% in chronic and long-term conditions—is there a different kind of evidence? We have powerful evidence that says that many people use complementary medicine to empower and enable themselves to self-manage, from cancers through to complex, difficult-to-diagnose-and-treat conditions like fibromyalgia and many of the long-term conditions like arthritis and diabetes. In all these chronic conditions, without fail, we get very high use of CAM. If you ask the patients why they are using CAM, they talk about different kinds of consultations, consultation environments and empowerment processes and that is something that we really need to take notice of if our new NHS is genuinely going to be patient-centred and that good consultation is a very powerful way to look at clinical decision making at the bedside or in the consultation. One of the ways we might develop evidence is to learn from the contextual effects of seeing the doctor.

Chair: I am a professor in a conventional department of general practice that last year came third for quality in its RA in the UK. I would not survive a minute if I did not think that the multiplicity of research methodology that we have available to us is not adequate. The issue is how you pose the question. It is about how you design the question, the kind of questions that you ask—not about the research methodology—and whether the questions are valid from the patient’s perspective about complementary medicine. Very often, the double-blind randomised controlled trial with a placebo is impossible to construct from a patient’s perspective in terms of a CAM intervention because a CAM intervention is too complex and multifaceted to do that—we need different kinds of studies—but they are certainly BMJ-publishable studies.

Dr Fisher: If I may add one thing to that, there are issues—essentially, I agree with George—around the interpretation of studies. For instance, it is a sore point with the acupuncturists that NICE refuses to recognise acupuncture for osteoarthritis of the knees. There are two different ways of controlling it. You can either compare it with normal treatment or you can compare it with sham acupuncture, which essentially means bad acupuncture where you put the needles in the wrong points and superficially. The problem is that that is an active placebo and the trials show that it does have some effect than nothing at all but less effect than real acupuncture. But, of course, from the patient’s perspective the choice is not between having real acupuncture and bad acupuncture. Hopefully, they are going to get either good acupuncture or nothing. That is the real choice. NICE refuses to see that way because it does not recognise that sham acupuncture is actually an active intervention. So there are issues around the interpretation of the results if you apply a very simple drug kind of model.

Professor Lewith: We can get into a very complex argument about—

Chair: I am fully aware of that and am also conscious that—and I should have made it clear at the beginning—we have a vote at 4.30 and another panel of witnesses so we are needing to move reasonably briskly. Can I go to Andrew and then to Sarah?

Q153 Andrew Percy: Thank you. We are all interested in the evidence on the effectiveness of alternative medicine, particularly those of us like me who have no medical background. I have family members who have used alternative treatments and they seem to think that they have worked and others who have not had that success. So I am wondering, in terms of this evidence of the effectiveness, what is the actual approach with alternative therapies? Is it about managing the pain and discomfort or is it about dealing with the underlying pathology?

Professor Lewith: It is both. If we take the example of acupuncture, which is the best researched because it has had the most money spent on it—which I started writing about, in methodological terms, 30 years ago—it takes away the pain. There is good evidence that good acupuncture will take away pain in a variety of different conditions. If you start moving an osteoarthritic knee because it is less painful, you will get repair and reconstruction. So conditions which you may think are chronic are probably remediable to movement. If you have a positive consultation environment, an encouraging process, a treatment that is pretty safe compared to non-steroids—the anti-inflammatories you buy over the counter which kill...
2,000 people a year in this country—and you have a process of encouragement happening with diminished pain, you will get some degree of actual repair and you will get an improvement in quality of life. The choices for a GP are, “Do we refer to an acupuncturist? Do we refer to physiotherapy? Do we give the patient some non-steroidal? Do we encourage them to take exercise?” And how effective is that from a GP without enough support?

Q154 Andrew Percy: If there is no addressing of the pathology, what is the benefit of the alternative therapy?

Professor Lewith: You and I, if we are lucky—or unlucky—will probably live to about 90. I am pretty good on going to 80 but I am not sure about 85 to 90. You and I will develop a series of chronic long-term conditions which will be incurable, with probably a 50% chance that one will be a cancer which we will not die of; we will have to live with it and we will die with it. That is the human condition. We have hospitals that are designed to cure specific conditions and they are full of old people with multimorbidity on polypharmacy.

Dr Fisher: This does raise a very big philosophical issue, which in homeopathy specifically we call constitutional treatment, which can be summarised as treating the person not the disease, and our hospitals has a very positive feedback. If you look around the feedback, broadly speaking it divides into two things. One is, “They were so nice to me. They treated me as a whole person and they thought not just of my knee—or my cancer or whatever—but me as a whole person.” The other thing is, “What it worked—relieved the symptoms when other things did not.” If you look at the history of medicine, there is probably no time in the entire history of medicine when this idea of treating people rather than diseases has been as eclipsed as it is now. I know about any other time or indeed any other place in medicine the idea was of treating people as a whole, not saying, “Okay, this is a disease. I am a specialist in that, but you have to go and see somebody else for that disease.”

Q155 Andrew Percy: It sounds to me, particularly on homeopathy, which is the one I would be most sceptical about, as if you are saying that simply sitting down and talking to somebody who has rheumatoid arthritis and making them feel better about themselves has an effect. Physiologically, delivering a homeopathic remedy does nothing to them. does it?

Professor Lewith: That is a long debate, but I am talking about the context and there is evidence for and against homeopathy that we can come to later. If I take a whole pile of people in a general practice and consult negatively with them around sore throats and say, “Why are you bothering me with a sore throat? Haven’t you read what it says in our instructions? Just go away and look after your sore throat.” or if I say, “Look, I am really sorry, you have a very bad sore throat. Do come back to me in five days if it is not better,” what difference do you think that different process makes in the symptoms that they present with over the next two weeks?

Dr Fisher: If I can comment on that as a homeopath and rheumatologist: somebody who has at times starred at doing conventional rheumatology, I do homeopathy on patients with rheumatoid arthritis all the time and I would not do it for two minutes if I thought it was purely placebo. I have absolutely no problem about maximising the non-specific effects of the consultation, but I do not think it is true that homeopathic medicines have no genuine real physiological effect.

Professor Lewith: To finish my point, you will halve the time they will get symptoms if you are nice to them. It is really simple. This is actually quite important because if you halved the time that people had flu, you would halve the time off work. So being nice to people and approaching them as whole people has a big effect on their symptoms. It is not woo-woo; it is not nuts. There are huge volumes of clinical trial evidence that tell you that.

Q156 Andrew Percy: But that could be delivered within regular medicine.

Professor Lewith: It could be delivered within regular medicine. That is exactly what we are trying to say. I specifically said that we need to learn the lessons from complementary medicine and deliver them better conventionally, but you are not going to get GPs who are working 14 hours a day within the current health system, and who are all pretty disillusioned, to have increased compassion. We need to find a solution to the management problems that have been created in primary care and the staff shortages. But we could do it. It is quite possible to do it.

Q157 Dr Wollaston: Coming back to that, yes, absolutely this is about the consultation environment, the doctor as drug and the lesson that conventional medicine has to learn from those approaches.

Professor Lewith: Yes.

Q158 Dr Wollaston: But is there not a problem when you are delivering something for which there is no
Dr Peter Fisher and Professor George Lewith

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Can I take your discussion in placebos? There is no proof that it is effective beyond the placebo effect. There are a number of double-blind placebo-controlled trials where you can show that homeopathy has any advantage over a placebo. I completely agree that the placebo effect is powerful, but I also understand that it is relatively short-lived. I am slightly concerned that you imply it could be a cure for everything. Where we have these are not long-term sustained benefits and there is a risk, in there not, with undermining the confidence that somebody has in their clinician, if they are telling them that something is proven to be effective when there is no proof that it is effective beyond the placebo effect.

Professor Lewith: Can I take your discussion in several sections?

Dr Wollaston: Yes.

Professor Lewith: You are wrong that the placebo effect is not long term. You are simply wrong. Look at the data. Secondly—

Q159 Dr Wollaston: But there are people who disagree with you on that, who would say that that is contentious.

Professor Lewith: You are welcome to disagree.

Dr Wollaston: I am not saying that at all. I am saying others disagree with you on that.

Professor Lewith: I know there are others who disagree with me on that, but that is not what the data tell us. The published meta-analyses of these are not long-term sustained benefits and there is a risk, in there not, with undermining the confidence that somebody has in their clinician, if they are telling them that something is proven to be effective when there is no proof that it is effective beyond the placebo effect.

Professor Lewith: Can be.

Dr Wollaston: Any treatment does not hit 100% of people. The second issue is that complementary medicine is not just homeopathy. The third issue is that we use non-evidence based treatments in primary care more than half the time in all sorts of conditions. From irritable bowel through to insomnia and childhood colic, we are continually reassuring patients that we are going to give them something, for which we have no evidence, to alleviate what often is a short-term, benign or acute condition that will self-resolve.

Q160 Dr Wollaston: Yes. So you are suggesting that we give something that has nothing in it that could cause harm.

Professor Lewith: I am not suggesting that we use homeopathy in primary care. I am not specifically talking about homeopathy and I am not going to go down the homeopathic track because I think that is a blind alley. We have had debates about homeopathy and I do not want to engage in those debates. There is a lot more to complementary medicine than homeopathy. Homeopathy is not complementary medicine. Complementary medicine, or integrated medicine, is a much broader field that encompasses some evidence-based treatments, some treatments for which we have little evidence and some treatments for which there is equivocal evidence. If you want to return specifically to homeopathy, I can give you some information and I can tell you what I feel about that as a balanced view. If you look at the 200 or so RCTs in homeopathy—and Peter will talk more knowledgeable about this than I—you will see the evidence cuts both ways, that there are some positive trials and some negative trials. Most of them are very small and many of them are very poorly done.

Dr Wollaston: Therefore, you cannot really—

Professor Lewith: Therefore, what we have is, “We do not know.” We have a situation where we do not have a clear answer because we have equal positive and negative systematic reviews which interpret the questions differently. If your statistics are really good, you will realise that the way you ask a question in a systematic review prejudices the answer. There have been homeopathic reviews, published by The Lancet that have said homeopathy has a real effect and then the same data have been taken with slightly different questions and reached in a negative review. That is because it is clearly statistically insignificant. If you do not have the data to ask the question, you will reach different conclusions.

Dr Wollaston: I am sorry, but it is not true that the trials are of very poor design with very low numbers? If you have a poorly designed trial with very low numbers that cannot be statistically significant, it cannot be included as a positive study because it is clearly statistically insignificant.

Dr Fisher: I am sorry, but it is not true that the trials are of very poor design with very low numbers? If you have a poorly designed trial with very low numbers that cannot be statistically significant, it cannot be included as a positive study because it is clearly statistically insignificant.

Dr Wollaston: Can you perhaps share some of those? Later on could you give the Committee a list of those ones? That would be helpful.

Dr Fisher: By all means, yes. There was a study commissioned for the Swiss Federal Government that found 29 studies in upper respiratory tract infections and allergy, of which 26 were positive. The other thing about pragmatic trials is that they have shown—they have mostly been done in France and Germany—that integrating homeopathy gives better results and very often for the same or less cost with fewer drugs, even when corrected for the fact that, for instance, patients who use homeopathy tend to have healthier lifestyles, are less likely to smoke and tend to be better educated, and that is important and relevant. You can correct for those. Of course, they are not randomised in that you cannot force people to have one—they are making a choice—but when you
correct for those differences you find that homeopathy gives you better results for the same cost and very often with fewer drugs. That is important.

Q163 Dr Wollaston: Do you feel that a lot of this is the phenomenon of the context of the consultation—

Dr Fisher: No, not in those—

Dr Wollaston:—and the effect of the clinician and how they are consulting?

Professor Lewith: You cannot have your cake and eat it.

Correct for those differences you find that homeopathy prescribed about half the number of non-steroidal drugs and they are, as George has already pointed out, a dangerous class of drugs. Similarly with anxiety disorders, they had better results and one thing they did look at specifically with that was lost opportunity—in other words the allegation that you are sometimes made against homeopathy that you are wasting time and delaying effective treatment. They specifically looked at that and found it not to be true—that there was no lost opportunity.

Q167 Dr Wollaston: But do you think there is a problem with marketing something for children that you label as a vaccine when it has no detectable components within it and no—

Dr Fisher: I do not think they would be allowed to market it as a vaccine.

Dr Wollaston: I have seen it. It is a real issue.

Dr Fisher: I do not approve of that.

Dr Wollaston: You do not approve of that. Thank you.

Professor Lewith: We are pretty rational people. We are just trying to present you with the evidence.

Q164 David Tredinnick: I want to get on to the general subject, but while we are on homeopathy, let's put this in another context, in the last Parliament the Science and Technology Committee ran an evidence check on homeopathy and decided that there was not much evidence out there, and since then, it is my understanding—and I would like you to comment on this—that a lot of research has been done. In fact, I am looking here at the International Homeopathy Research Conference held in Barcelona this year in which there are a whole mass of different trials that have been brought together. I think it was attended, but please correct me if I am wrong, by speakers from 20 countries and attendees from 31 countries. I looked out just one trial here about sleep, anxiety and depressive disorders, the so-called EPI3 programme, which appears to show that by combining homeopathic medicine and conventional medicine you get greater patient satisfaction, a better result and also you reduce the amount of conventional drugs that are being consumed. Would somebody like to comment on that and then we will move on?

Dr Fisher: The EPI3, yes, is a study done by the University of Bordeaux and they had three groups: one was musculoskeletal, one was upper respiratory tract and the third was, as you mentioned, sleep and anxiety disorders. Essentially, what they did was to compare French GPs with "orientation homéopathique" doctors. This means that they are not dyed-in-the-wool homeopaths but, in the French way, they have a diploma and they are allowed to put their names in the Yellow Pages as "orientation homéopathique". They compared the patients and the outcomes. What they found, for instance, in musculoskeletal disorders was that the severity of the conditions was very similar and the outcomes were similar. The difference was the number of non-steroidal drugs prescribed. The homeopaths prescribed about half the number of non-steroidal drugs and they are, as George has already pointed out, a dangerous class of drugs. Similarly with anxiety disorders, they had better results and one thing they did look at specifically with that was lost opportunity—in other words the allegation that you are sometimes made against homeopathy that you are wasting time and delaying effective treatment. They specifically looked at that and found it not to be true—that there was no lost opportunity.

No, not in those—

Professor Lewith: You cannot have your cake and eat it.
acupuncturists and, soon to be, herbalists. There is a dramatic advance in the education and quality of the people providing complementary medicine in this country, who are now increasingly regulated through the PSA. That was not the case 30 years ago. In any branch of medicine, we get idiots: we get them in conventional medicine and they make stupid claims—hopefully they get struck off by the GMC—and we get them in homeopathy, in acupuncture and in chiropractic. If we look at the relative risk and benefit, it costs you and me quite a lot to be insured as GPs. It costs an acupuncturist about £150 a year. Actuaries do not muck about. As far as I can see, if you were an actuary you would be looking at the real risk of adverse reaction, being sued and likely harm. Those are at least an order of magnitude—if not more—that the risk of conventional medical practitioners than most complementary medical practitioners simply because we do more harm as conventional medical practitioners and we are more likely to do more harm. Therefore, our actuarial risk is very much higher. There has been a hugely positive trend in improving training in complementary medicine, but you cannot possibly expect us to defend the idiots.

Chair: I do not want this to degenerate into a dialogue.

Q168 David Tredinnick: We need to move on but just on that safety issue, Arthritis UK published a report on complementary medicine and found that 20, I think—most of them—were all safe.

Professor Lewith: There were two reports, one on complementary medicine and one on complementary practice.

Q169 David Tredinnick: Of the 20 therapies, I think they found that acupuncture was effective in osteoarthrosis, rheumatoid arthritis and fibromyalgia, to name but a few. Can we focus now on long-term conditions, which is the subject of the inquiry? You are saying that complementary and alternative medicine is effective in long-term conditions when integrated into conventional treatments. Can you explain that?

Professor Lewith: I can explain that in that, where we have evidence, the use of things like, as I mentioned earlier, acupuncture and complex psychological interventions such as mindfulness are powerful. They give people, particularly with things like mindfulness meditation, things that they can do for themselves over the long term which are quite constructive. Things like the practice of tai chi and various different, what might be loosely described as, complementary medicine exercises—and you might include yoga in that as well—are also very powerful and enabling and the evidence is quite strong that if you persist with these approaches you get long-term health benefits. We know with cancer that people who use complementary medicine on their cancer journey, which is between 20% and 40% of people with cancer, get a huge amount of ability to self-care and a lot of positive survivorship skills from using complementary medicine, not as a cure but as a long-term survivorship process. There are other areas which we need to look at, but the general impression that we get when we look at CAM versus non-CAM use in almost all chronic illness is very positive patient feedback and improved self-care and self-help. That is what we really need to head for in many older people with long-term incurable conditions because that is what we will probably all get.

Q170 David Tredinnick: Dr Fisher, your hospital apparently has the highest rating in the United Kingdom in terms of satisfaction, or very nearly. Is that right?

Dr Fisher: Yes, from two independent sources—Dr Foster and NHS Choices.

Q171 David Tredinnick: Is it right that you have pioneered integrating different treatments, leaving homeopathy aside for a moment, and that there are other therapies that you have brought together? Is that right?

Dr Fisher: Yes, over a very long period. We are part of one of the leading medical academic centres in the UK, University College Hospitals London. For instance, we integrated acupuncture into the NHS and applied research to remember when people thought that we were mad Maoists when we did it—in 1973, I believe.

Q172 David Tredinnick: As to this patient satisfaction, you also provide herbal medicine.

Dr Fisher: We provide herbal medicine, homeopathy and a variety of psychological interventions. Increasingly, as I say, we are integrating vertically with primary care, although that is sometimes inhibited by the contracting situation, but also horizontally with other colleagues in the trust.

Q173 David Tredinnick: To what extent does the approach of bringing complementary medicine into the mainstream require the co-operation of practitioners? Perhaps you could tell us whether you have that in your hospital.

Dr Fisher: Of course you must have a very high degree collaboration of colleagues. Gradually, we are winning.

Q174 David Tredinnick: We are talking about doctors, are we?

Dr Fisher: Healthcare professionals. Actually, very often, the interest is greater in other healthcare professionals. Midwives, for instance, are very interested, as are nurses and physiotherapists. A large number of physiotherapists now use acupuncture. So, very often, it is other health professionals, but of course the co-operation of the big cheeses, who are generally doctors, is essential.

Q175 David Tredinnick: My last question to you—and then I will turn to Professor Lewith, if I may—relates to your experience in your hospital where you are using these different treatments and you have co-operation with your practitioners to do so. What impact has that had on referrals, secondary care investigations or interventions? Do you believe there is any detectable difference in referrals to hospitals?
Dr Fisher: It is something we have not studied formally—it is quite a complicated issue to study—but we do believe that we simplify matters. Some of these people are seeing multiple specialists, having multiple treatments for nominally—and I do emphasise “nominally”—what are said to be different diseases. But very often it is just the way we think of things, putting things into boxes. A very wise consultant once said to me, “The reason doctors make a diagnosis is not for the benefit of the patient. It is for the benefit of the doctor.” That is because you put it into a nice little box and you feel you are in control of it, whereas disease is inherently a chaotic process. Very often, people are being shoved into multiple boxes. I think we can simplify things and reduce the number of treatments, although I cannot point to hard evidence. I wish I could.

Q176 David Tredinnick: Thank you. To both of you, focusing on long-term care, is the risk of requiring a secondary care intervention higher if a long-term condition is treated using integrated medicine?

Professor Lewith: We are not sure. There is some evidence to believe that that suits it may be lower. We suffer from a lack of good research funding in good units. Now there is a changing culture among primary care researchers that complementary medicine is something that is legitimate to look rather than something that is illegitimate, but we do not have enough information to answer that properly. So probably yes, but the balance of evidence is not clear.

Q177 David Tredinnick: This is my last question. There is a vast amount of money spent on research every year. Do you think there is enough spent on establishing the effectiveness of these integrated therapies?

Professor Lewith: A few years ago, I published a paper in the BMJ—I published with Ernst—showing that 0.00085% of the NHS budget was spent on what might loosely be called complementary medicine when 15% of the population was using it every year. I have spent three decades trying to raise the level of that research because these are questions that need answering. We have got somewhere and there are some really good things happening, but it is still a very small cottage industry and it needs to be bigger in response to patient needs.

Q178 Grahame M. Morris: Clearly, you are excellent advocates and you are practitioners of alternative medicine and homeopathy and so on, but my questions are about demand in the system. Under the terms of our inquiry today, we are looking at the management of long-term conditions and whether they could be better managed with an integrated approach. What is your assessment of the demand in the system currently in terms of numbers of patients and perhaps a proportion who would seek to have alternative therapies?

Professor Lewith: I will answer this very briefly from the data that we have from both the UK and Europe. Probably between 15% and 20% of European populations want to have access to integrative medicine. When they have chronic conditions that figure probably goes up, from the data we have, to about 50% to 60% of the population with chronic long-term conditions. The caveat is that sometimes these are not great surveys, but we can see from the demand in Germany—and there is no reason to believe that the population in Germany is radically different from the population in the UK—that it is very substantial and it is a demand that is not being currently met by the NHS. I can leave Peter to talk from first-hand experience about that.

Q179 Grahame M. Morris: Is there any difference between the assessed demand—or the studies that you referred to from Germany and elsewhere—in a hospital setting compared to in a community setting? If I might ask a supplementary as well because I know time is short and other people want to get in, in terms of who pays—the $64,000 question at this time of tremendous pressures—is it your considered opinion that the system, that the NHS, should meet the costs where there is demand and perhaps a proportion who would seek to have a universal insurance-based system so there is a fee for service, which is very different from the NHS and that puts different pressures on the provider. I do not think I should talk about whether I think complementary medicine should be provided as part of the NHS. There needs to be a real national debate about what the NHS should provide. The people should make the decisions about how their taxes are spent. I have a very firm belief in British open debate and justice, but we are in a very difficult position in our current financial climate with the decisions that we make about what we should and should not provide within the NHS and whether we should provide better beds or better newspapers at a cost. I firmly believe that universal healthcare is a fundamental human right, but I do not know what level the taxpayer will wear and what level the politicians will provide.

Dr Fisher: The evidence from France and Germany suggests that it does not add to cost but does improve outcomes. This has been studied by the German “Krankenkasse”, the large insurance companies, with essentially that conclusion. As for the pent-up demand, there is a lot, we are very aware. Indeed, we employ a lady in our hospital, who is sitting right behind me, who spends a lot of time dealing with queries from patients: “I want to be referred and I cannot. My GP will not refer me. What can I do?”

Q180 Grahame M. Morris: In your hospital, Dr Fisher, do you know what proportion of patients pay for alternative or complementary treatments?

Dr Fisher: We do not know. We are an NHS hospital so all our patients come in on the normal NHS terms and conditions. We know that a high proportion of patients, particularly with chronic diseases—50% or
higher—do use complementary medicine and also that they very often do not tell their doctors, actually for the wrong reasons, because they think their doctors will poo-poo it or not understand it.

**Professor Lewith:** The majority of people who use CAM do not communicate that to their conventional carers.

Q181 Grahame M. Morris: I suppose it is my opinion, and I know we are here to hear yours, but I have visited the German health service and the Autowawert health insurance facility—admittedly some years ago—and personally I did not think it was a patch on the provision and the arrangements that we have, but maybe you have a different perspective.

**Professor Lewith:** There is good and bad in every system and I think the Germans have very easy access to healthcare. We tend to use GPs to ration healthcare. There are arguments for and against both. There has to be some kind of rationing because the demand is huge and there will have to be some kind of co-payment system. I do not think that is a decision for doctors to make. That is a decision that we all make together.

**Chair:** Happily, it is not a decision for this Committee either.

Q182 Charlotte Leslie: Can I ask, how responsive are clinical commissioning groups to the demand for commissioning of integrated medical treatments?

**Dr Fisher:** That is a complicated question and a very fluid one. At the moment, we have a system whereby we have agreed a number of care pathways, for instance for fibromyalgia and irritable bowel syndrome, insomnia and cancer where the CCGs—it was the PCTs but the clinical commissioning groups have just inherited them—will agree to see patients without asking questions, without prior approval. We then have a large number of other areas where we do require prior approval but we have an agreed system whereby we have a tick box and it is adapted for the condition, “This patient has tried these two of the following drugs or has had chronic complex problems,” and a number of pre-agreed criteria for things that fall outside the pre-agreed pathways. So we do have a system that more or less works, although there are still quite a lot of patients who are unhappy about it.

Q183 Charlotte Leslie: Have you seen a change in attitude on the move from PCTs to CCGs? Has there been a culture change or a change of attitude in that move?

**Professor Lewith:** Complete chaos.

**Dr Fisher:** The quick answer is that we have heard very little from the CCGs because they seem to be preoccupied with other things. We are a bit nervous about what they might do when they finally get their act together.

Q184 Charlotte Leslie: You have said in the past that you think commissioners often do not hear the evidence of cost-effectiveness of integrated medicine approaches. Do you stand by that and why do you think that is?

**Professor Lewith:** There is an inherent bias. For instance, if you look at any trial on antidepressants which has been followed up for a year, you will see that the real treatment and the placebo treatment groups are both better a year later, with often very little difference. If you look at any pain trial in acupuncture which is followed up for a year, you will see the acupuncture group and the real treatment group are better at the end of the year. That demonstrates that placebo lasts a long time, even if you think acupuncture is a placebo. If you look at the cost-effective data, you get really powerful data from acupuncture for OA in a knee, probably about £3,000 per QALY. I think it is £3,000 or £4,000 per QALY, yet NICE sets up guidelines which say, “We are only going to look at real versus sham trials, not at the pragmatic trials,” whereas when they look at exercise, how would you do a placebo for exercise? They look at pragmatic trials for exercise. We know that exercise does a lot of good, but we cannot design a placebo because it is a complex intervention. So there is an institutional bias against complementary medicine in the interpretation of perfectly legitimate scientific data.
Q187 Charlotte Leslie: So in a sense, are you saying there is a subconscious commercial driver that is affecting—

Professor Lewith: There could be.

Dr Fisher: No. I am not saying that. I am not attacking the pharmaceutical industry. I am saying that there is so much work doing it that way that it is almost difficult to see that, “Actually, you could do it this way.”

Q188 Charlotte Leslie: Let us say that changed. What capacity is there for trained staff and resources to supply integrative medicine treatments at the moment if they were to be commissioned?

Professor Lewith: There are a large number of well-trained complementary therapists out there who have PSA-recognised—

Dr Fisher: I think you mean HPA.

Professor Lewith: They are Professional Standards Authority-recognised, which is the bigger regulator, and they would work for much less than the average GP.

Q189 Charlotte Leslie: You are saying it is a system’s reluctance to change something new—

Dr Fisher: For us, as an NHS provider, they have to be statutorily regulated. It is a complete no-no: if they are not statutorily regulated, we will not employ them and I think for good reason. The step to statutorily regulating some of the professions is a very small one.

With the herbalists, the Government are committed to doing it, I believe. The acupuncturists are very well trained. It is a small step, but we cannot take the responsibility to employ somebody who does not come with the proper statutory regulation.

Professor Lewith: The hospice movement drives on complementary medicine, it is very much about whole-person care and we give lots of people a good death with that in mind—and it will increasingly be so for both malignant and non-malignant disease.

There are a large number of complementary therapists who work in a perfectly legitimate way within the hospice movement, sometimes voluntarily but sometimes for a relatively small salary. There is an untapped capacity out there of well-qualified, registrable, employable people.

Chair: We need to move on.

Q190 Valerie Vaz: We have had a lot of evidence from various organisations and people regarding long-term conditions. They range from things like diabetes and epilepsy to motor neurone disease and Duchenne and Becker muscular dystrophy. Could you outline how your patient-centred integrated medicine would work in relation to some of these long-term conditions?

Dr Fisher: Our biggest single area is musculoskeletal disease, which is indeed one of the biggest causes of disability in the country. Osteoarthritis is just about the commonest disease there is, we will all get it if we live long enough. The NICE document on osteoarthritis is a pretty miserable guideline: “Take your painkillers until your knees are ready to be replaced.” That is a slight parody, but essentially that is what it amounts to. There is not a huge amount to offer. We offer acupuncture, herbal treatment, homeopathy and a range of treatments and get very good patient feedback. Then we discharge the patients, after a course of treatment, back to the GP. Very often, they get sustained treatment and then they can come back. Many of these things could and should be offered in the primary care setting.

There is an issue around the contracting arrangements. One I have encountered very recently is our insomnia clinic. When we set this up, we got into trouble because we had a tidal wave of referrals and our trust was saying, “Why aren’t you meeting the 18-week wait target?” We said we were not expecting the tidal wave. Then there are the insomnia online programmes. We wanted to institute an online programme such that a patient could be referred and we would say, “Okay, we will assess you and you can use this online programme.” Our trust initially said, “You cannot do that because you are taking the business away from us and I had to bang my fists on the table and say, ‘Don’t be ridiculous. One, we are healthcare professionals, not bankers, we should be doing what is right, not what is profitable. Second, it is not true that it will take business away, we will get the name out there and we will be giving people the right thing and it will encourage more referrals.’”

But, at the same time, we also recognise that there are quite a lot of complicated cases. Many people with insomnia are dependent on sleeping tablets. Interestingly, nobody appears to know how many. Everybody agrees that a lot of patients with insomnia are dependent but there appear to be no data on how many—an interesting little lacuna. Those patients do require specialist advice on how they are going to get off the tablets, so that we would do in our secondary care centre. But it was really rather irritating, when we were trying to do the right thing, to run into this problem about rivalry between primary and secondary care. Only some fairly strong arguing changed their mind.

Professor Lewith: I think you are trying to ask how we would deliver it and I will give you an example. We have an increasing problem with men with prostate cancer because we are getting better at diagnosing it. There is more diagnosis, more follow-up, a 30% increase every five years in the number of people being seen in hospital with prostate cancer. We know that anxiety is the primary trigger for radical intervention in men who do not need radical intervention. They get anxious and want it out, after which they have a 50% chance of incontinence and impotence—so a very diminished quality of life. Almost certainly, the data that we have are strong evidence that there is no increased 12-year survival between those who have an operation and those who do not. So we need to reduce anxiety to reduce costs, improve quality of life and reduce radical interventions. Mindfulness is a very good way to do that.

I have designed and am now delivering with one or two groups of Macmillan nurses in UCLH Macmillan Cancer Centre an online mindfulness-based programme for these men which they will accept. It is difficult to get old men to accept talking and mindfulness, but we have designed a way to do that
that seems to work. We could then deliver that in conjunction with specialist clinics, get them off the books and minimise operations. Those are the kinds of things that we can do practically. It is not about replacing conventional care. It is about learning the lessons and working within.

Q191 Valerie Vaz: Can I move on quickly to some of the long-term conditions? There are two or three that a patient gets. You spoke very eloquently about patient-centred care. How would you deal with those multiple conditions, the multimorbidity?

Professor Lewith: You would deal with them by asking the patient what they want rather than delivering what your specialty demands. You are moving back to a generalist approach, to a patient-centred approach, so you may give them goals and suggest some approaches with herbs, with exercise and approaches with acupuncture for their pain. So you will get one or two approaches that you may be using and one or two approaches that they may use themselves to keep them off their long list of polypharmacy and as active as possible.

Q192 Valerie Vaz: How does that work? Obviously diabetes and obesity go together, don’t they, so how do you—

Professor Lewith: You can work that in the same way that you can run a good musculoskeletal clinic if what a rheumatologist works well with the physiotherapist. Your physiotherapist can provide both acupuncture and conventional physiotherapy. So it is provable. A third of our physiotherapists in the NHS are acupuncture trained. It is just a question of getting it happen.

Valerie Vaz: Thank you.

Chair: Can we have a brief question?

Q193 David Tredinnick: Just for your information, there is a mindfulness course in the House that is being run for the second time. It is completely oversubscribed from Members of Parliament.

Dr Fisher: There you are.

Q194 David Tredinnick: I think one or two of us know a bit about it. I have two questions to finish. What are the benefits to patients of encouraging greater independence and self-care in the management of their long-term conditions?

Professor Lewith: They are huge. That is a really difficult question.
Examination of Witnesses

Witnesses: Professor Nigel Mathers, Vice Chair of Council, Royal College of General Practitioners, Alastair Buxton, Head of NHS Services, Pharmaceutical Services Negotiating Committee, Emily Holzhausen, Director of Policy and Public Affairs, Carers UK, and Victoria Matthews, Assistant Long Term Conditions Adviser, Royal College of Nursing, gave evidence.

Q196 Chair: Ladies and gentlemen, thank you for waiting patiently for this evidence session. I should say that we have a vote coming in the House of Commons at 4.30 so we are on a very short time frame. Could I ask you briefly to introduce yourselves and tell us where you come from?

Professor Mathers: My name is Nigel Mathers. I am a GP in Sheffield. I am also vice-chair of the Royal College of General Practitioners and I am a professor of general practice at the university of Sheffield.

Alastair Buxton: I am Alastair Buxton. I am a pharmacist. I work for the Pharmaceutical Services Negotiating Committee. We represent NHS community pharmacies in England.

Emily Holzhausen: I am Emily Holzhausen. I am director of policy and public affairs at Carers UK, representing family members who care unpaid—6.5 million of them.

Victoria Matthews: I am Vicki Matthews. I am a specialist nurse, recently retired from 30 years’ full time in the NHS, and I am here representing the Royal College of Nursing today. I believe I am what is called “vintage”.

Q197 Chair: Thank you very much. I would like, if I may, to begin by asking each of you to answer a general question to get the proposition on the table which the Committee will then wish to follow up. You will know this session takes place in the context of our inquiry into services delivered for people with long-term conditions and each of you from your different professional standpoints will have, I am sure, some key points you want to make about how services need to change compared with what we have now in a way that will deliver both better value and better quality to the target group we are talking about—people with long-term conditions. Can I ask you each for two or three key points, rather than a laundry list of 27 points, that need to be addressed? Could I start with Professor Mathers?

Professor Mathers: Thank you, Chair. I have four points. One is, if we are to improve the quality of care for people with long-term conditions, we need to move to a whole-system approach. By that I mean the “Year of Care” model with the four different components, where we have engaged patients and practitioners, a practice infrastructure that supports the process and a commissioning base.

Secondly, care planning should be the norm in terms of delivering care to people with long-term conditions in general practice.

Thirdly, we need to focus on multimorbidity. All the NICE guidelines, all the pathways, are designed for people allegedly with only one condition, but most people have multiple conditions.

Finally, if we are to deliver this, we need to shift more resources into primary care.

Alastair Buxton: Unsurprisingly, I would say that I want my profession—community pharmacy—to be playing a much greater role working with our colleagues from primary care and also in secondary care. When we look at the services that we provide in community pharmacy, the most important relating to long-term condition management is ensuring that we help people to optimise the use of their medicines because we know that at least half of people do not use their medicines effectively.

We also want to ensure that people are able to self-care and to avoid long-term conditions if possible. There is a big focus within the community pharmacy sector on supporting people to live healthier lives. We also want to help people who do have long-term conditions to live independently within the community. We believe that getting all of that together as a community pharmacist offering can sit alongside what would be described as the first pillar of the NHS, being hospital, and the second pillar, general practice, community pharmacy, primary care, and our other primary and community care colleagues. We should be sitting there ensuring that we are able to work, in a more holistic team-based approach, with our general practice colleagues and to start to take on more of the burden of long-term condition management, working collaboratively with general practice.

Emily Holzhausen: The first would be recognition of where care happens for people with long-term conditions. That is primarily with people with the long-term conditions supported by their families, so of course we are talking about 6.5 million people there, understanding that the system impacts on those families enormously. So it would be an impact test: what decisions do you make that help people care? Are the decisions you make going to tip somebody into unemployment if they are caring full time, or are you going to support the family to care in this situation long term?

Families tell us that they would like more integrated care. They would certainly like more information and advice up front, which means that they need to be identified early, both by healthcare professionals—and there are some great examples of where people do that—but also across with social care.

Quality is definitely going up the agenda for families. We are starting to measure some of those issues for families as well, so across health and social care the “families and friends” tests and other measures that are in place are absolutely critical.

Victoria Matthews: For us—and I speak both for the College and as a nurse—we support moving care as close to the patient and family’s home as possible. For us, the key issues are, for example, the allocation of community resources. With a larger proportion of care taking place nearer to the home and in the community, there is a more urgent approach needed in terms of allocation of resources and skills of the community work force.

Also increasing staff numbers, particularly community nursing, is an area of grave concern. The work force expanded and peaked in 2010, but in the last three years we have seen a fall of 1,744 full-time roles,
which is equivalent to 3.6% of the work force. District nursing also has been declining year on year, with a 17% decrease. So we do need to increase numbers to bring care closer to home.

Self-care is essential, particularly in the management of long-term conditions. It brings many benefits, not just for the individual but for clinicians, commissioners, for Government and for society as a whole. It empowers people to take ownership of their condition, aspects of their treatment and managing their lives yet to be lived. You must not forget that a lot of people with long-term conditions are young people who still have a life ahead of them. But I would say, look at this document here, “Clinical Guidelines for Chronic Conditions in the European Union”; and I quote: "The role of chronic disease management, including the role of the patient in managing their care, merits much more attention. However, we should not allow our continuing focus on prevention to diminish. Despite decades of work in the areas of health promotion and disease prevention, we still have a long way to go in identifying cost-effective actions to address the main risk factors responsible for chronic diseases." So self-care is much more complex than those two words might suggest.

The next issue for the RCN is specialist nurses and a single point of care. We know they are fit for purpose. We know that at the moment they are probably suboptimal and could be utilised much more effectively.

Finally, there is public health and prevention. Even with the budget being ring-fenced, the RCN has real concerns over future funding for preventative services as local authorities position themselves to provide these services during considerable financial constraint.

Q198 Chair: I am obviously going to allow it open to the Committee, but it is very striking that all four of those high spots focused on things, apart from anything else, on the need to rebalance services towards the community and I guess, if we had heard that at any time in the last 25 years, we would have heard similar points being made. I wonder if, just as a matter of fact, whether you think resources into the community. Shall we do it in the same order?

Professor Mathers: The evidence I have seen is that resources for primary care, community care and general practice have reduced in the last three years by a substantial amount, in real terms by £400 million. The resources are moving in the wrong direction at that moment. The way to address that is through integrated care, particularly integrated primary and secondary care as well as integrated health and social care in terms of working as multidisciplinary teams, for example. I can give plenty of examples, but from my own practice—

Chair: I do not want it to be a dialogue. That is an answer to the first and second questions.

Alastair Buxton: I would certainly agree with that. From my perspective, the way that we in pharmacy can start to help to shift the care into primary care is, on the assumption that our GP colleagues and practice nursing colleagues are increasingly going to be taking on a greater role managing people who currently are being managed in secondary care, we would look to try and create some space for them within their practices by shifting, but using a collaborative approach, certain patient cohorts into community pharmacy. For example, there have been discussions recently with some GPs about moving people with hypertension who have recently been diagnosed and do not have any co-morbidities, who are relatively simple, if you like, patients to manage at the start of their life of long-term conditions. Shifting them to community pharmacy would give space for more complex patients to be managed in a more thorough manner in general practice but with an expectation that, as they become more complicated, potentially, they then transition back to the general practice taking on the wider part of care.

Q199 Valerie Vaz: What would you do?

Alastair Buxton: For example, we currently have two services, which are doctor-led medicines optimisation services, the MURs, which use review service and new medicine service that we offer to lots of patients: 2.8 million people received an MUR—a medicines use review—last year. Quite a large number of them are people with asthma, for example. So, I would like to see six pharmacies providing MURs and the new medicine service. The vast majority of, about 90%, of pharmacists do provide MURs. I would like next year for them all to have to provide that service and to have to offer it to patients with asthma.

Q200 Valerie Vaz: I am trying to get to what you said about patients with hypertension. What exactly would you be doing with them? Is it just about managing their drugs?

Alastair Buxton: It would be patients to be managed in a more thorough manner in general practice now but transferring that responsibility to community pharmacy, so they get shifted across following the same NICE and prescribing guidance and so on.

Q201 Dr Wollaston: Do you mean the pharmacist would be prescribing the drugs and reviewing and taking their blood pressure?

Alastair Buxton: That could be one approach, or where there is no need for modification of doses we could use a repeat dispensing service where the GP has authorised products for prescribing for some time, or the use of patient group directions and other legal techniques to modify doses rather than modify drugs, for example.

Emily Holzhausen: I can only talk on the evidence from families, which is that it is not moving in that direction. The census has shown us an increased number of people taking on care and an increase in the ill health among carers as well. This has been the
subject of quite some debate as to where resources lie. Certainly, if we look at the report published by the Royal College of Physicians, it is talking in the Future Hospital Commission about those sorts of services being based far more in the community. So, for me, it is unlocking the types of payment arrangements that are there, these different services, with people who work in secondary care looking at far different roles to be able to bring the care closer to home.

We are very mindful of the fact that some families have to travel further and further for specialist treatment and that takes a huge toll on them. If you look at parents of disabled children, they can be travelling up to hundreds of miles away—or cancer treatment, for example. While people make the best of the transport that is there and a lot of volunteers help them to get there, it is still a huge commitment and that puts a lot of pressure on families. We need to be mindful of the way we organise things and the wider impact that we have on families, but, on the whole, while people want the best specialist care, it is better to provide care closer to home in terms of wider impacts.

Victoria Matthews: I agree with what everyone else has said and I liked what you said about “unlocking” things as well. I said earlier that many specialist nurses are working at suboptimal level because of artificial constraints and I think that the direction of travel to bring care close to home is still not right and we do have a way to go.

If you look at the community nursing workforce, 38% of nurses are 50 or over and a huge number are going to be retiring in the next decade. We need to have a major rethink about how we attract nurses to work with long-term conditions in the community and avoid these silos, particularly with the specialist nursing, that we have seen in tertiary and secondary care in the past.

Chair: Thank you very much. David Tredinnick wants to ask about commissioning, I think.

Q202 David Tredinnick: What examples have you seen of good commissioning of primary and community services for long-term conditions under the new arrangements and what barriers are there to successful commissioning?

Professor Mathers: The clinical commissioning groups, of course, do not commission primary care and there is not a facility to do that except through things like quality improvement projects and service development. What would be really helpful is for all CCGs to develop strategies for long-term conditions and develop programmes of work around care planning, long-term conditions, delivering multidisciplinary teams through a quality improvement programme, and then that would need to be supported by the local area teams of the NHSE but also by the local health and wellbeing boards. It would be a big step forward if all CCGs were required to produce strategies for long-term conditions using this mechanism because, at the moment, there is not another way to do it. For example, all CCGs need a strategy for diabetes, dementia and end-of-life care, to name but three. But, as I say, the mechanisms are not easy to do it. It is really hard to deliver this.

In Sheffield, we have a CCG that is committed to introducing care planning into everyday care and there are 88 practices in Sheffield. We have created this quality improvement programme and, of the 88 practices, every single one signed up to engage in developing care planning. So GPs are willing to do it, but it is just about freeing up capacity and providing a mechanism whereby they can, for example, introduce care planning for long-term conditions.

Alastair Buxton: In terms of a good example of commissioning, I would cite one example from 2010 where the PCT on the Isle of Wight used the medicines use review service within the community pharmacy contractual framework to focus on asthma patients, and this was before we had a national asthma target. They also trained other healthcare professionals, practice nurses and GPs, to ensure that all patients were receiving the same message. That was a good example of getting everybody in primary care working together. As a focus of the service was ensuring that people use their inhalers and use them properly. That saw emergency admissions for asthma fall by 50% over a three-month period and the number of asthma-related deaths fall by 75%. That was created on that, South Central SHA—as it was then—rolled that across the whole of the area and saw similar results, which were investigated by the Cambridge Consortium, and saw a positive impact on reducing hospital admissions. But I have to say that is one good example. Sadly, in community pharmacy, we seem to have seen more bad examples of commissioning in the past and rather piecemeal approaches taken.

From our perspective, we see a national approach as allowing us to drive greater patient impact in community pharmacy. The 2.8 million MURs that we are providing every year would not have been provided if they had previously been commissioned by PCTs. We recognise that is working against the localisation agenda, but, if we accept that that is a strong driver and will continue to be so, we would at least suggest that one of the solutions is to look for more standardisation because, as NICE codifies a way that healthcare professionals treat conditions, we should not see significant differences in the way that a healthcare professional manages asthma or hypertension on the Isle of Wight compared with Sheffield, for example. There may be different approaches in different people undertaking that management, but we need to ensure that we do not duplicate effort at a local level, creating service specifications and designing services, because the PCTs were terribly good at doing that and wasting an awful lot of commissioner time.

Emily Holzhausen: It is probably right to recognise that the changes in the structure have halted or de-commissioned some quite progressive work that was happening. Carers Trust has undertaken a piece of work—because it runs a lot of local carers’ centres—looking at the level of CCG commissioning of carers’ services and support and has found there has been not a hiatus exactly but that things have been put on hold in quite a lot of areas. In good areas of commissioning, we get good joint commissioning between health and social care to support families and there are numerous different examples that have...
happened. In Kensington and Chelsea, for example, there is commissioning of link workers that go into GP practices to offer to link up with the rest of the services that exist—so to look at managing the whole family, if you like, with all the different issues that they might have. In other places, like in Hertfordshire, they have used breaks funding very creatively around commissioning. Another area I know of in the past that has used commissioning well around breaks funding has given funds directly to GPs to prescribe breaks. So there is a whole range of different commissioning out there, but I also think that it is still early in the days of health and wellbeing boards to look at the level of support for carers. Places like Southwark have very detailed examples of the type of population living with they have, looking at their joint strategic needs assessment, but others are not yet well developed.

Q203 Andrew George: Can I be clear on that particular point? Is it that the new structure has created an impediment to innovation in new ways of integrating, or is it simply that the process of change has slowed the progress that was previously being made?

Emily Holzhausen: At the moment, it would be fair so say that the structural change has been the largest change to services. I am sure there are new impediments that people had not thought of before, but that in itself has taken a little while to get going again.

Chair: Do you want to come in on this?

Victoria Matthews: Briefly to say that for us good commissioning is commissioning that integrates, listens to and acts upon the voices of a whole range of health and social care professionals, but most importantly, listens to and acts upon the voice of the person living with the long-term condition and their families and carers and does so in an truly democratic way, not just a piecemeal, by-service thing. There are many examples of fantastic, innovative commissioning, and I guess good commissioning is commissioning that is brave, innovative and thinks outside the box, for want of a better term.

Chair: Very quickly, David, and then I will go to Barbara.

Q204 David Tredinnick: Some of you may have heard the previous session and I wonder what you feel about patients who might want to go down the outside the box, for want of a better term.

Professor Mathers: Personal health budgets can be very useful there in terms of, if someone has a continuing long-term condition need and is eligible for a budget, then the individual will have freedom to decide, with their broker, how they spend that money and that may well be integrated care, complementary medicine, acupuncture or whatever. That seems to me entirely appropriate under the system that we have.

Victoria Matthews: May I briefly come in there and pick up on a point you made about brokerage? The RCN fully supports personal health budgets, but we have to be mindful that there are some people who on the surface appear to be perfectly capable of managing their personal healthcare budgets but may have subtle and complex, maybe cognitive problems where they do not make such appropriate decisions. This is where it is important that key health professionals broker and help navigate—that good decisions are made in terms of what care package they need, whether it is complementary or orthodox medicine.

Q205 Barbara Keeley: This question is to Emily Holzhausen because it is about carers. What are the implications for carers of greater treatment of long-term conditions in primary and community care? You have already touched on travel as an aspect and presumably that would improve in primary and community care rather than travelling to specialist hospitals. I have a few sub-points. What should the priorities be for NHS and local authority care services if they are seeking to assist? Is it supporting community carers in multidisciplinary care teams and care planning? The first point is, is it even realistic to talk of this? Is it asking the right extra layer for people who are already busy—care workers and family carers—to say they should be involved? Do they even have time to do it?

Emily Holzhausen: There are lots of really important questions here. The first point is that there are definitely inherent benefits in treating people closer to home. Very often, people feel more comfortable and the travel is better. The risk, of course, is that there is an unwritten expectation that family, or the person with the long-term condition, will take on more themselves. Certainly, I know in the past there used to be situations where carers would feel that it felt like a bit of a break if somebody they cared for went into hospital. We need to be very mindful of the fact that if parents of disabled children are doing very complicated medical procedures at home and being trained to do so, in the best cases, by nurses and other community professionals, we need to involve people in all of this. I am always surprised that we train professionals and require even healthcare assistants and care workers to be highly trained and yet there is an expectation that the family will just go away and do it. Many a time I have had a man or a woman on the phone saying, "I don’t understand, the workers have come in and they will not move this person. I am only 5 foot 2 and I have to move my husband who is 6 foot 1 on my own, but they cannot because of health and safety reasons." We need to be careful that we are not building up problems for the future.

As I said, about 2 million people have given up work to care; about one in five or six people will do so in their life. There is a great amount of stress that people feel when they are trying to care for people and it is not just about people in their own homes but also increasingly about people caring at a distance, mothers and fathers living further away from sons and daughters, not being on hand to know that things are well and functioning. Where there are opportunities for this as well is around the use of technology; the ability to see different patient records, the ability for consultants to do remote consulting, telecare and telehealth and also just how people use technology.
We have produced a report recently which shows that only about 30% of people use technology for health and care, yet the vast majority of people use it in everyday life, and I am talking about internet technology as opposed to the ordinary telephone. So there are some definite positives and negatives. We do need to improve identification of carers and the link straight into support. Although it might take more time up front, long term it makes economic as well as moral sense.

Q206 Barbara Keeley: As to the last point about care planning, the involvement you touched on, does that mean an extra burden? Is it realistic or would people welcome it?
Emily Holzhausen: The health and social care sector is probably stretched at the moment. To incorporate that, we need to look at where it has worked well. Certainly for people with complex conditions, there is evidence to show that you bring the family on board earlier, you teach one person and you teach a generation. I worry a little that there is not enough flex in the system to be able to do it for everybody. Again, this is where we are finding the use of the internet and online tools for people with lower level needs—if people can self-serve through those kinds of tools and be empowered in that way—to be quite an investment. But we have to get this right. If we look at the demographics—you are all familiar with that—we simply cannot afford to ignore this issue and that is why the Committee is considering in particular with the pressure on our health service, how we manage that, but also for families, we cannot continue to have long working lives until we are at least 67 and state pension age and care for our relatives. Equities will collide at that point with different responsibilities, as they are doing now.

Q207 Dr Wollaston: I wanted to return to the issue of funding. We have heard some strong arguments in the evidence that we have received that the resources need to shift from secondary to primary care. I know, Professor Mathers, you have called for an urgent review of the payment-by-results framework. Why do you think it does not support effective management of long-term conditions and what would you suggest we replace it with and why?
Professor Mathers: The problem with payment by results, of course, is that you receive money for every episode of care, so actually it is an incentive to see more people in secondary care because, obviously, the more often you go into hospital the more the income increases. We think it is really important that payment by results, of course, is that you receive money for every episode of care, so actually it is an incentive to see more people in secondary care because, obviously, the more often you go into hospital the more the income increases. We think it is really important that payment by results is reviewed and that different ways of funding long-term conditions in primary care are looked at.

Q208 Dr Wollaston: Could you talk us through what you would want to see in its place and why that would be more effective?
Professor Mathers: It would be more effective to have the joined-up health and social care budget, for example. I am not talking about integrating primary or secondary care budgets there. I am talking about, if we had in the community an integrated health and social care budget, it would enable care planning to be delivered far more effectively by multidisciplinary teams and reduce the number of hospital admissions, particularly unnecessary hospital admissions of frail elderly. As long as there was not cost shifting between health and social care—and I have been assured that that is not the case with the new integration budget—that is the way to tackle the issue of providing the right resource in the community for the right person at the right time. Through multidisciplinary teams, Practices do have multidisciplinary teams but they do not generally include contributions from secondary care, nor indeed from social care. That image, that vision, for multidisciplinary teams has to include, for example, a community geriatrician and a social worker as well and practices working together in federations because there is an integrated nature of that integrated budget, I think we could deliver much better care for people with long-term conditions by keeping them out of hospital.

Q209 Dr Wollaston: It is very complicated, is it not, because even now NHS England commissioning GPs, how do you personal budgets and other budgets? Do you think it should involve one simple system, or do you find all the different sources of funding difficult and complex?
Professor Mathers: I do not think it is possible to devise a system that you could apply all over the country in every single circumstance. It is very complicated at the moment, but I believe we need a stepped approach, we need a stepped economy. We really do need very of getting the funding right to support the delivery of care to people with long-term conditions. The pilot sites are very important and there are lots of good examples, such as Torbay, which has integrated health and social care budgets to some extent. There is lots of good learning out there that we should somehow bring together into a range of models, a range of options, a menu of choices for different areas to say, “We could do it this or that way,” because those relationships on the ground in the different areas are so important in terms of delivering what we want to deliver. Does that answer the question?
Dr Wollaston: Yes. As you say, there is not a “one size fits all” but at the moment there is such a different range of sources of income. Are you finding it very complex?
Professor Mathers: We are finding it extremely complex. The RCGP, in conjunction with a number of other organisations, has set up the “Action for Long-term Conditions”. The “Action for Long-term Conditions” includes organisations such as the Health Foundation, NHS England, NHS Iq, the Richmond Group of Charities, the Royal College of GPs and various other contributors. We are trying to collect all this learning and part of the work programme is to have one stream that looks at the different models for trying to do this because we have the complication of Monitor influencing all this as well. It is incredibly difficult and complicated, but we cannot do it without contributions from all the different stakeholders, which is why we have set up the “Action for Long-term Conditions”.
Chair: We are not going to solve that problem in the 25 minutes left to us, so, Andrew, do you want to ask another question?

Q210 Andrew George: Yes. You said a moment ago that you are not impressed by, or rather oppose, the use of the payment-by-results system and yet at the same time say that there should be other methods of resolving the management of long-term care through the budget-setting process. On the other hand, you say that you do not see the integration of primary and secondary care as the method by which you should achieve it.

Professor Mathers: Budgets. That is the next stage. If we can get integration of health and social care budgets to deliver better quality care in the community, that is the first step. The second step, obviously, would be to engage secondary care, but it is such a difficult subject that to do it at all once would be very difficult. But if there is a flow of resources from secondary to primary care and there is the integration funding, then here is a great opportunity for us to transform the care of people with long-term conditions in the community.

Q211 Andrew George: But you will still be left with a tariff-based payment which will be tempted to kind of suck patients into secondary care in order to achieve their payment by results.

Professor Mathers: Exactly, and that is why we have called for an urgent review.

Q212 Andrew George: What we have in this desire to achieve better integration is a lot of timidity and a lot of advocating that we need to find solutions. Given that you are, after all, the Royal College of GPs, and it has been suggested that you are now centre placed in the commissioning and shaping of the NHS, do you not think that you have a central role in designing a method by which long-term care can be better integrated? I am surprised that you are so timid in suggesting that secondary care integration with primary care is a second—way over the horizon—step that you are not prepared to propose at this stage.

Professor Mathers: We have to be realistic and we dooes, and a lot of advocating that we need to find solutions. Given that you are, after all, the Royal College of GPs, and it has been suggested that you are now centre placed in the commissioning and shaping of the NHS, do you not think that you have a central role in designing a method by which long-term care can be better integrated? I am surprised that you are so timid in suggesting that secondary care integration with primary care is a second—way over the horizon—step that you are not prepared to propose at this stage.

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Chair: Emily Holzhausen wants to come in as well.

Q213 Valerie Vaz: You mentioned the “action” and then the “alliance” “for Long-term Conditions”. What is its proper title and who is in it?

Professor Mathers: I am sorry. It is the “Action for Long-term Conditions”. It is an alliance of various stakeholders with a common narrative.

Q214 Valerie Vaz: Could you give us the examples of who is in it?

Professor Mathers: There are the Health Foundation, the King’s Fund, the Royal College of GPs and some of the Richmond Group of Charities. I think there are 15 different organisations and I am sorry I cannot remember all of them just at the moment. We are practitioners set to transform the delivery of care for long-term conditions because we are the people who are going to have to deliver it by developing four work-streams: one is developing the metrics, “How do you measure it?”; one is developing the models, “How do you deliver it?”; one is looking at the finance, “How do you pay for it?”; and one, of course, is the engagement of people with long-term conditions. So we have these work-streams to try and tackle some of the issues. But it is, as I say, a big job.

Q215 Valerie Vaz: Yes, I am not quick to talk about something you mentioned in your evidence about section 75 regulations. Do you feel inhibited by them at all?

Professor Mathers: I will pass on that question; I am sorry. I will have to have a look.

Emily Holzhausen: I want to quickly mention this. We have been talking about integration and different funding models and I want to recognise the different pressures on the supply side of funding if we are talking about closer integrated services in that in the present day and social care funding in particular makes it an unequal balance because of the different entitlements there. It is an opportunity, with the Care Bill coming along, to look at where funding goes into that, where the Government look at where they set their eligibility criteria and whether, in the future, for the management of long-term conditions and people living with long-term conditions in the community, it makes better economic sense to invest in the lower eligibility criteria, bringing in more people. I realise there is a price tag attached to that, but, at the moment, it is an unequal conversation around integration of the two sources of funding.

Q216 Chair: The proposition of rebalancing funding within the system implies that the price tag is paid by decommissioning services, the demand for which should not arise if we had proper services in the community. That is the challenge.

Emily Holzhausen: Indeed. That is the challenge.

Q217 Chair: Does anyone want to comment on the challenge? Then I am going to Graham next. Do you want to come back on section 75? It is the politician’s code for competition policies.

Professor Mathers: Yes, absolutely. I wanted to check what we had said in our evidence. We think that there is a risk of fragmentation of care. It makes it very difficult for CCGs if there are so many competing providers and the selection needs to be done on quality. As I say, we have received assurances that that is not going to inhibit the introduction of integrated care for people with long-term conditions.

Q218 Grahame M. Morris: This is building on what Emily told us a little earlier. Time is quite short and
we are looking for your opinions and evidence to help us formulate this report. There is a consensus that it is preferable to manage long-term conditions, where it is practical to do so, in the community, but what we are interested in currently is, “What are the barriers?” You mentioned a positive thing that could be done there in terms of the eligibility criteria for the Care Bill, but currently what are the barriers to transferring existing longer term care, integrated care, from the hospital setting into the community? I am just asking Emily now. Maybe you can quickly give us your thoughts.

Emily Holzhausen: If we look towards Northern Ireland, for example, there are important cultural barriers between health disciplines and social care disciplines, between a clinical model and a social model of disability that need to be brought together. Some of the training for some of the new health professionals coming through is starting to unpick that slightly. Of course, the different funding mechanisms are structurally complicated. We know that co-locating teams makes a huge amount of difference. The health and wellbeing boards are being seen as a reality check for getting joint work together. Certainly, the clinical commissioning groups are just finding their feet with commissioning and learning what to do there. I do still think it is an issue. Even though we have to repurpose the finances within the system, the demographic pressures are such that what we have in the system will not be enough to sustain things going forward even if we only do things more efficient in the way that we use services. The simple things could make a huge difference. If we do, for example, identify carers and give people the right information and advice earlier on, helping people self-manage quicker just like with dementia, if we diagnose people earlier to help the families to care quicker, not just be dealing with the one, not the other, and things more efficient in the way that we use services.

The simple things could make an enormous difference. If we do, for example, identify carers and give people the right information and advice earlier on, helping people self-manage quicker just like with dementia, if we diagnose people earlier to help the families to care quicker, not just be dealing with the one, not the other, and things more efficient in the way that we use services.

Q220 Chair: You also, if I may say so, need your colleague on your right to join you at the party.

Professor Mathers: Yes. We have worked very closely with the Royal Pharmaceutical Society to produce a document called “Working Together”, which looks at practical options for GPs and pharmacists to work much more closely together, because this is part of the integrated care agenda.

Q221 Chair: So you come with a single view, in answer to somebody’s question, as to what happens next—Grahame’s question, “What is it that is standing in the way?” It is inadequate information. Pharmacy and general practice comes with one view of the right answer, does it?

Professor Mathers: We come to the Committee with an agreement, not necessarily talking to each other. There is a devil in the detail and it is for local arrangements to be agreed and made.

Alastair Buxton: I would suggest that we have the agreement in principle but there is work that needs to be done nationally on the standards for IT, because you do not want to be defining standards for intra-operability at a local level. That is where I really believe that NHS England now is the new organisation that is going to hold the ring on that particularly and needs to take action to bring everybody into one room and bang heads together to ensure we do start to make progress.

Q222 Valerie Vaz: But you can only do that on certain conditions. You are only taking a few things, like hypertension. You are not looking at the patient and their other conditions.

Alastair Buxton: I am talking about general access. If we have the Government’s commitment—and rightly so—to give patients access to their own GP records, I would hope that, where the patient consents, a pharmacist would have full access where there is a need for that. It could be a simple query about a prescription they are dispensing, that they need to check something. If they are dispensing Warfarin, an anticoagulant, they may want to be able to look at the latest test results in the patient’s record, if the patient does not have their hand-held record, for example, to ensure it is safe to dispense that medicine and that the dose is appropriate. It is that we simply cannot do at the moment.

Q223 Valerie Vaz: I understand that. It is kind of complex, isn’t it, and there are many conditions so you would only be looking at one part? Your patient X has hypertension but also has diabetes. You would only be able to deal with the one, not the other, and they would still have multiple people to deal with, would they not?

Alastair Buxton: That, of course, depends on how the service is commissioned. My comments earlier on...
were suggesting where we believe we need to start. Our GP and practice nurse colleagues need to learn to work with us in community pharmacy and that is why some of my GP colleagues are suggesting, “Start with hypertension. That would be good for us. We can build up confidence in your competence as professionals.” Indeed, so can the patients as well, which is going to be critical within this. So start with single conditions but absolutely recognise that is not the way to go long term. We need to have a holistic approach and I would want to see people with multiple morbidities being supported with optimising their use of medicines by the pharmacy team. It may be that there is a specialist nurse providing the expertise for one disease and the pharmacist is dealing with another, but, yes, I would definitely like to see a more holistic approach taken in pharmacy. But it is about how we start and start simple.

Professor Mathers: In our practice—

Chair: With respect, we have 10 minutes left. Grahame has been interrupted and a GP wants to come in. Dr Wollaston, could you be very brief and then I am going back to Grahame. Is that okay?

Q224 Dr Wollaston: Going back to the issue of notes, is it time we had something a bit more radical and that patients own their notes rather than the Secretary of State? Therefore, they can have their notes accessible to whomever they would like them accessible to, can correct the very many errors that we find in patients’ notes and some of the commentary that are inaccurate and certainly prescribing errors, and also that whole principle of self-management. What is the panel’s view on that?

Professor Mathers: Patient-held records are a very good idea. We have had them for 30 years in Sheffield for mothers holding the records of their children. The notes never get lost and they always come to surgery with them. As an example of patient-held records, that is a very good one that has worked over many years and I see no reason why that should not be extended.

Emily Holzhausen: From the point of view of family, where consent is given, it certainly smooths their journey, though confidentiality is an important issue to discuss properly and well. I have to say, from the family point of view, that if we can get expert views from community pharmacists on perhaps a complex medication regime, that is brilliant. That is brilliant integrated care that gives families confidence from people who spend four years training to be experts in their field.

Q225 Grahame M. Morris: I quickly want to ask Victoria to answer a question. I know earlier you said that the key concern of the RCN and nurses is lack of specialist nurses. A number of us have been putting the case for more nurses, for numbers to be published and minimum standards laid down. For example, for hepatitis C nurses, NICE says we should have one specialist nurse for 20 patients in the community and one specialist nurse for 20 patients in a hospital setting. What is the problem? Are the specialist nurses being drawn into the hospital setting? Is that a barrier to treating some of these complex conditions in a community setting?

Victoria Mathews: It is a dilemma, in that it is a barrier and, to some extent, a need because they need to be current and up to date in terms of treatments, as treatments become increasingly complex.

Q226 Grahame M. Morris: So it is numbers and training.

Victoria Mathews: Yes. It is a dilemma, but I think there is also a risk that you end up with silos of specialist nurses in these centres and I would like to see them reaching out more. Probably their key relationship is with their GPs.

Chair: Grahame, can I interrupt you to let Barbara in before she goes and then come back to you?

Q227 Barbara Keeley: It is about personal health budgets that I specifically wanted to ask. We heard about some aspects of this earlier, but in terms of carers being involved in that situation, what contribution can personal health budgets make to that and are there any services that are relevant and that are possibly being used to manage long-term conditions at a moment that will not be available with personal health budgets, or is it a positive step?

Emily Holzhausen: It is a positive step. Our learning from direct payments within social care is that, on the whole, about 85% of carers say that the services to the person that they care for are better and they prefer them. We have seen a slight fall-off in the last couple of years, down to 57%, for satisfaction rate, which is starting to worry me, and an increase in the number of carers who say that administration has increased. So, overall, it is better.

The natural transition is to continuing healthcare. If you imagine you are employing this team around you who are supporting you, then you get continuing healthcare funding and you cannot employ them any more, that is a real transition issue for families who have got used to certain workers. So we can really celebrate the fact that it moves across into continuing healthcare. What we need to guard against is a tendency to over-prescribe, “You cannot use that for that and you cannot use that.” It is all about choice, outcomes and a certain level of trust and, on the clinical side, good quality clinical input to help people make choices. What I do not want to see is it transferring across to families again, where you almost get the unpaid care manager who is at home managing this huge, complex number of direct payments and financial returns and all those sorts of things and they are effectively managing that full time and on income support. That is not a healthy way for a family to be. We need to guard against the administrative side while really recognising the enormous positives that it can bring as well.

Chair: Grahame.

Grahame M. Morris: I am happy with the answers I got and time is short.

Chair: In that case, we will go to Valerie on obesity.

Q228 Valerie Vaz: We have been told that obesity is a contributory factor for long-term conditions such as diabetes and arthritis. What role do you think primary and community care would play in preventing this?

Alastair Buxton: Shall I kick off on that?
Valerie Vaz: Answers in five minutes, or less actually, because there is a vote shortly.

Alastair Buxton: All of us in primary care need to make every contact count, as has been said previously, and within community pharmacy it is really important that we make use of our wider teams. We have the opportunity to do that via public health campaigns. We are currently contracted to NHS England to provide six of those that are organised by the area teams at the moment. We proposed to Public Health England that we ought to ensure we have national topics, so every pharmacy in the country would be promoting “Stoptober”, this last month, for example, so that we get more bang for the buck out of what has been invested there.

Making use of support staff is another thing. They often live locally within the community and we have seen some fantastic examples from the Healthy Living Pharmacy approach that started in Portsmouth. Following the White Paper on pharmacy, we now have over 700 accredited Healthy Living Pharmacies. A key difference between them and a normal pharmacy is that the staff have been trained to be health trainer champions and are being taught the techniques of behaviour change. They are getting on and doing that both within the pharmacy and sometimes outside the pharmacy. I saw an example of a pharmacy that was organising a walking group for people locally to get them out and exercising, which obviously has much wider benefits as well. But we need to do that collaboratively across primary care, I would say.

Professor Mathers: Those three things are making every contact count, being a pointer to additional help and services, and supporting public health campaigns and legislation to reduce the amount of sugar and salt in food.

Victoria Matthews: Work further upstream and invest in your school nurses. Start at the beginning.

Chair: Okay, thank you.

Q229 Valerie Vaz: Emily, do you want to—
Emily Holzhausen: We know that families neglect their own health when they are caring, so I would say equal access to services is really important for families who are caring full time.

Chair: We should exercise this time pressure more often. Do you want to come in on training, Sarah?

Q230 Dr Wollaston: Having read the Cavendish review—the recommendations about bringing in the healthcare assistant workforce and helping with their continuing professional development, and indeed initial training—what role do you feel that has in the future of long-term care?

Victoria Matthews: A very significant role. The regulation, training and development of healthcare support workers is a critical issue for the RCN.

Professor Mathers: I think it is essential to, and a key component of, care planning.

Emily Holzhausen: Absolutely—backing for the Cavendish review.

Chair: This is evidence in 140 characters, for which we are very grateful. Thank you very much.
Tuesday 12 November 2013

Members present:
Mr Stephen Dorrell (Chair)
Rosie Cooper
Andrew George
Charlotte Leslie
Andrew Percy
Mr Virendra Sharma
David Tredinnick
Valerie Vaz
Dr Sarah Wollaston

Examination of Witnesses

Witnesses: Norman Lamb MP, Minister of State for Care and Support, Department of Health, and Dr Martin McShane, Director, Improving the quality of life for people with long-term conditions, NHS England, gave evidence.

Q231 Chair: Minister, thank you very much for joining us.
Norman Lamb: It is a pleasure. Am I allowed to take my jacket off?
Chair: Please do.
Valerie Vaz: Just the jacket.
Norman Lamb: Don’t worry, Valerie.
Chair: Dr McShane, you are extremely welcome as well. I would like, if I may, to lead off by asking where we are in the process of preparing a policy for dealing with long-term conditions. Our understanding was that this was being followed up within the Department of Health, that there was a commitment to publish a policy for how we deliver improved services for people with long-term conditions, and that has now been transferred as a responsibility from the Department of Health to NHS England. What effect has that had on the process? Is the team being transferred or is NHS England starting again? How is this—to long-term conditions next year.

Norman Lamb: Perhaps I can start and then hand over to Martin. There are two things I would say first of all. To be honest, the work that was under way was slightly out of sync with the changing architecture of the way the system works, and a conclusion was reached that it was properly the responsibility of NHS England. So all of the information that had been gathered as part of the process building up to the strategy has been passed to NHS England. None of that is lost, but it does more sensibly sit under the responsibility of NHS England to map out the way forward. Along with that, the Secretary of State has made it clear that he wants his personal focus next year to be on long-term conditions. As you will be aware, he has focused very much on the “Vulnerable older people’s plan”, which is primarily looking at people over the age of 75. But the view that the Secretary of State took was that, if you can try and get things right for frail elderly people, you can learn important lessons for all other people who might have similar complex health needs, and whose care is often at the moment, as you said, as we have discussed many times, a fragmented system where people fall through the gaps, breaking up the continuity of their care. These things will, ultimately, all move in the same direction of policy, with the idea of an accountable, named clinician and the idea of a pretty fundamental shift towards a model of care, which is joined up and integrated around the needs of the patient. Whether you are talking about long-term conditions for people of any age or frail elderly people, the policy and the care solutions are rather similar, I think.

Dr McShane: Just to build on that, if I can contextualise it, there are the two big changes that we need to understand. One is that, as I would put it, we are almost a victim of our own success. We have seen huge improvements in health, life expectancy and longevity across the UK and in England. The problem that that has created is that, as people live longer, they are also developing both long-term conditions and frailty. Now we are trying to create an understanding that frailty is a diagnosis, not an adjective—that you can be frail because of your age without it necessarily being accompanied by long-term conditions. So it is a “both and” issue. It is quite right that the definition of “vulnerable” is both people with long-term conditions and people with frailty.

The other big context change is that we have done very well on health and planned care, but the system we have created does not really address long-term conditions and these are now dominating the consumption of resources in both health and care, of which I am sure you are fully aware.

From my perspective, long-term condition management needs to be integrated with everything else that we are doing. That is why, as one of the domain directors, we have started to model the way we work in the way that the system should work so that we are working as a team. If we take the proposition that the vision for NHS England is to deliver high quality care for all, we have the legacy of the Darzi definition of quality, which is safe, the sort of scope of the “Vulnerable older people’s plan”, which is primarily looking at people over the age of 75. But the view that the Secretary of State took was that, if you can try and get things right for frail elderly people, you can learn important lessons for all other people who might have similar complex health needs, and whose care is often at the moment, as you said, as we have discussed many times, a fragmented system where people fall through the gaps, breaking up the continuity of their care. These things will, ultimately, all move in the same direction of policy, with the idea of an accountable, named clinician and the idea of a pretty fundamental shift towards a model of care, which is joined up and integrated around the needs of the patient. Whether you are talking about long-term conditions for people of any age or frail elderly people, the policy and the care solutions are rather similar, I think.

Q232 Chair: What is the difference between a vulnerable older person and an older person who suffers from long-term conditions?
Norman Lamb: There is clearly an overlap, isn’t there?
Chair: You have accurately predicted my thought process.
Norman Lamb: Clearly, there are lots of people who live with long-term conditions who are younger than...
effective care, which gives a positive patient experience.

Effective care has been divided into three components: preventing premature mortality or avoidable deaths; enhancing the quality of life for people with long-term conditions; and helping people to recover from acute care or episodes of trauma. These components are three of the five domains that lead to high-quality care for all and form the NHS Outcomes Framework. My role is to provide leadership and a narrative, and to look at the system levers and enablers that will enhance the quality of life for people with long-term conditions. But I am also dependent on the work that is being done in Domain 1 on reducing premature mortality and working closely with Keith Willett—I am sure you are aware that there is an “urgent care” review going on—because everything that happens in long-term conditions has an impact on emergency care as well. We have to try and create a system that looks at a system, not just its different components. We have had a system that has focused very much on hospitals and we have had this mantra about moving care out of the hospital. I do not think it is about moving care out of the hospital. It is about creating the right care in the community so that people do not need to go into hospital. That is the agenda we are facing and which we need to tackle. To do that requires a huge cultural change, which is the biggest change.

Q233 Chair: Can I bring you back to my original question, which was a relatively narrow process question? Are you supported by a team that was previously in the Department? Are you seeing any? We have been talking about the need to remodel services for people with long-term conditions since I was Secretary of State and that is a very long time ago.

Dr McShane: We have taken a very different approach. When I came into this job I discovered three different teams in the Department of Health addressing long-term conditions. We have set up the five domains and we have created cross-cutting programmes across each of the domains to support improving quality of care for people across the whole context, as I have described. If you like, my team is very small but my resources are very large. So I work in a cross-cutting way with all the other directorates in NHS England—patients and information, finance, commissioning development and operations—to make sure we have a clarity of purpose, a clarity of direction and we are focused on making those system changes.

Q234 Chair: I will have one more go. When are you going to publish an outcome from this process?

Dr McShane: We already have published a number of documents. On the NHS England website there is the narrative around quality. We have published the narratives for each of the domains and have already started to publish some of the tools. But the traditional “Let’s publish one strategy which says how we are going to deliver long-term condition management” is not our approach. It is about how we move the whole system to ensure that people with long-term conditions get high-quality care as well as delivering changes to premature mortality and hospital care.

Q235 Charlotte Leslie: Dr McShane, the overarching objective in Domain 2 of the mandate, for which you are responsible, is that the NHS should “make measurable progress towards making the NHS among the best in Europe at supporting people with ongoing health problems to live healthily and independently, with much better control over the care they receive.” What is your assessment of progress against that and how on earth are you measuring it?

Dr McShane: First of all, I think we have made good progress, and let me give you one example of where the new system might differ from the old system. We have recently had the national audit report for diabetes published, which says that, in terms of care processes, we could do better. The “Global burden of disease”, which was published in the autumn last year, with follow-up articles in The Lancet and a Canadian study, show that, benchmarked against the rest of Europe, we deliver the best outcomes for people with diabetes. When we look at the change in premature mortality for people with diabetes, only one country has done better than us, and that is Canada. So process is really important, but it too long we have completely disconnected it from purpose. We have not understood what the outcomes we are trying to deliver are and the measures of progress we are making. That is a huge step forward and we are probably the first country in the world to make that step. Other countries are looking at us to see how we do with it. There is a great deal of interest around it.

We are now working with the analysts to look at a whole range of new analytical measures. For instance, in the survey that is done annually for GP practices on patient experience, we have the EQ-5D. Don’t ask me to explain it. It is a measure of what quality of life people have and I think it goes from 0 to 5. The 0 means dead, but I discovered that there is a negative measure as well.

Dr Wollastor: Worse than dead?

Dr McShane: Yes, working for the—no.

Charlotte Leslie: Being on a Select Committee.

Dr McShane: Anyway, measuring that, we are starting to understand what those factors are that correlate with improved quality of life for people with long-term conditions, because 52% of the people who responded to that survey self-declared that they have a long-term condition or conditions, which is becoming more prevalent. We are now starting to tease out what the measures are that we can put in place that show that doing this improves someone’s health and care.

Q236 Charlotte Leslie: So it is a sort of “work begun but very much a work in progress”.

Dr McShane: It is absolutely a work in progress because it is a fundamental change in the way that we tackle improving health, given that the nature of the challenge to health care has so fundamentally changed itself.

Q237 Charlotte Leslie: Moving on, the mandate also requires particular progress in four key areas for long-term conditions. They are involving people in
their own care, better use of technology, better integration of services and better diagnosis, treatment and care of dementia by March 2015. What is your assessment of progress in those specific areas and what do you think they will have delivered by March 2015?

Dr McShane: If I take those in reverse order—so I do not forget them—with dementia, the issue is that we have a national clinical director for dementia, Alistair Burns, who has provided continuity of care through the transition. We have, over the last two to three years, vastly increased the number of people who receive a timely diagnosis. It is a bit of an uphill struggle because the more people we diagnose, the more our estimated prevalence goes up at the same time. The denominator is changing almost as fast as the numerator. If we look at absolute percentage changes, we are seeing 10% or 8% changes year on year in absolute numbers diagnosed, but that is not being reflected in the ratio because of the change in prevalence.

Also, we are now working with the Alzheimer’s Society on what is critically important for long-term condition management—all four components. Traditionally, we have just looked at the person and the professional. It is critical that we also look at the carers because the carers suffer a huge burden where people have long-term conditions, yet the culture and, as a medic, I can say it—is kind of, “Oh, well, everybody knows who their boss is. I used to work for Sherwood and we started off with a hierarchical system that everybody understood and we did very well. Then a managing director came in who believed in matrix management, which is a little bit like what you have just reflected, in that everybody worked up and down as well as across. The organisation froze and nobody knew whose boss was who and who did what. I have to say that is how the health service feels to me today.

The fourth component is communication. We work that the Alzheimer’s Society and the Prime Minister’s Challenge on Dementia—are funding on dementia-friendly communities is incredibly important—that we change the stigma and perception relating to that. So in dementia we have made good progress. On personalisation I would warmly commend—and, if it has not been submitted as evidence, perhaps we can have a late submission—“Transforming Participation in Health and Care”, the document published by NHS England a few weeks ago. One of my ambitions is to make sure that people have much more control of their own care and ownership of it. That is not abandoning people but giving them authority to inform and influence their care.

There were four things, but I can only remember three now. The other one was integration and the Minister has led the push, which I am quite willing to surf, on integration and integrated pioneers.

Q238 Charlotte Leslie: Great. I have another quick one and you have semi-answered some of it. Have you set out any other measures of progress against other indicators in Domain 2 of the mandate—the proportion of people, for example, feeling supported to manage their own care?

Dr McShane: Yes. Fortuitously, I was able to influence the GP Survey this year.

Chair: It was more than fortuitous.

Dr McShane: They had dropped the question on care planning and we went back and said, “Actually, we need to have this reinstated,” because I truly believe that people being involved in the decision making about their care is incredibly important.

Norman Lamb: Can I quickly add, in terms of measurement, that you will be aware as part of the Prime Minister’s Challenge on Dementia that one of the focuses is on the health and care system, and part of that is about diagnosis, as Martin has said? The overall position is still under 50%. So we have made progress, but we are still massively behind. By going to all parts of the country, all CCGs, and getting them to determine what they want to achieve by 2015, we have come up with an objective to get to two thirds of people with dementia diagnosed by 2015. There is a very clear measurable objective there. Progress being made, but there is a long way to go still on it.

Q239 Rosie Cooper: Can I make some general observations, Dr McShane, on that which you have talked about? As somebody who is close to this currently, you talked about operating as a team, yet out on the front line the NHS is fragmented and nobody knows whose boss is. I used to work for Sherwood and we started off with a hierarchical system that everybody understood and we did very well. Then a managing director came in who believed in matrix management, which is a little bit like what you have just reflected, in that everybody worked up and down as well as across. The organisation froze and nobody knew whose boss was who and who did what. I have to say that is how the health service feels to me today.

A lot of people in the health and social care system talk often about care in the community—and I noted you used different words “the right care in the community”—but the truth is that, when you are out there and that system is fragmented, what you are actually saying is, “You are on your own.” You get somebody who will dip in every now and again, but the reality is that you and your family are on your own. Of course, that is so tragic. To make an observation, in terms of cost, the cheapest patient is a dead patient, and talk is even cheaper. All I hear so often is people in senior positions talking. The Chairman talked about integration, and I hear it; I hear it; I hear it. The people out there want it if it delivers, but you actually do not see much change.

If I might give you an example—and I will put it to the Minister as well—for me, what is going on is that we are all being kept busy talking while, using figures the Treasury have issued, the NHS will be bust in three or four years. It is just not affordable. On those Treasury figures we are bust. Last week Sir David Nicholson was here and he agreed. He told us that the Integration Transformation Fund, using existing money stripped out from the health service and from social care, would be the cliff edge to reform. How is all that going on, when you are redesigning and you have got domains everywhere?

On the front line, let me tell you, my father has just been diagnosed as terminally ill and I am told that nurses will come and see him every fortnight, but they cannot possibly tell me when they are going to come
other than “sometime on Thursday”. What am I to do—sit around? What are all these families supposed to do? Are we to sit around waiting for somebody to come today? It is all talk. You are not delivering on the front line.

How do you change? All this is grand and keeping us busy, but I still do not know what integration is. I absolutely do not know what it is because I cannot see it. As hard as I look for it, I cannot find it. How do you make it different for the people who really matter—the patients?

**Dr McShane:** Okay, I think that sums up the problem and the challenges we face, so let me tell you how people are doing that in places. We need to learn from them and make sure we spread it and create the right infrastructure and national levers to give people permission to do that. We need to have tried to direct the solution from the centre with a one-size-fits-all approach, which does not recognise that Barnsley, Basingstoke and Birmingham are completely different places and require different solutions depending on their populations, health needs and also the type of infrastructure that they have.

If I talk about accountability, one of the things that are absolutely right is having a buck stop. When I was a practising clinician working in the field—and I have worked for over two decades as both a surgeon and a GP—I felt that accountability for my patients. There has been some sense of dilution of that, and the current proposals to create accountability for a named person who is responsible for ensuring that care is co-ordinated and planned well—is a step in the right direction.

On the second point and your statement about matrix management, what I described, [John] intended to describe, was programme and project management. My insight and understanding of that is, if you want to make change happen, if you have good programme and project management, then it happens. That is what we have set up. We have set up these programmes of work and they have clear accountability. For instance, we have just established the parity of esteem programme board within NHS England. Lord Victor Adebowale has kindly agreed to chair that, and I, as the domain director, am responsible and have a clear-felt responsibility for making sure we deliver in that area.

One of the things to recognise is what Chris Ham described in the health system as the inverted pyramid of power in that we are dealing with a professional system. It is the professionals on the front line who make the decisions on a day-to-day basis. We have tried to overprescribe how they should do things, rather than trusting to their professional experience, knowledge and skills, and focusing on outcomes.

I will give examples of places I have visited in the last seven months since this organisation was established—and we have been going for only seven months. I would like to point out. Tower Hamlets a few years ago introduced a model, which I have nicked from them, called the House of Care, which took them from being the worst performing in terms of long-term condition management to the best, audited, in the UK within three to five years. I have been to Liverpool where the CCG there set out a new form of GP specification which meant that, in terms of being benchmarked against other areas, they are seeing reduced emergency admissions. I have been to Newark and Sherwood where the integration between general practice and the community and mental health team, end-of-life care, social care and the third sector is there. I spoke to a GP and asked, “What difference does this make to you?” and she said, “It means that when I go in and see someone in their house I do not say, ‘I am sending in a social worker and a district nurse to see you some time in the future,’ but rather, ‘I have rung Jane and Jack and they are coming to see you this afternoon,’” because they work as a team. So, yes, we are not there, but that is the direction of travel. That is why we need to make the changes that are being proposed and included in all the levers that we have.

**Q240 Rosie Cooper:** Okay, I hear that. You mentioned Liverpool. That is where my dad is. Let me tell you—I will truncate this dramatically—that he is falling; he is taken to hospital; he goes in to ward 2A, which is in the community ward, and falls in the hospital. Useless. And I say, “Why is he falling? I need to speak to the ward doctor,” and they say, “No, this is a community ward. You do not get it in a community ward.” So I say, “No, why is he falling down? Is he in the appropriate place?” Then they say, “This is a community ward,” and then I say, “The Secretary of State says there must be a named doctor.” The response from those professionals you have just talked about was, “Even in the community?” If Liverpool is somewhere you are proud of, you need to get back there pretty darned quick and stay there because it is useless.

**Norman Lamb:** First of all, the example you give from your own family is an example of very poor care. We have to be very open about that and there is too much of it. We have ended up with a completely fragmented system, as you describe. Over the years, and I made the point, we have managed to institutionalise fragment mental health from physical health, which, from the patient’s point of view, often makes no sense at all. Primary care is separated institutionally from secondary care—and health care from social care. So it is a horribly fragmented system, and the principle of integrated care does not have to involve organisational change. It is about the model of care. It is about meeting the needs of the patient and shaping the care and the needs of that patient. I was in Barnsley last Thursday and I would encourage you to go somewhere like that just to see it on the ground if you say, “Where is it?” “I do not understand it,” and so forth. There are these places where they have really got it. I met with the chair of the CCG, together with the leader of the council, the chief executive of the acute trust and someone from the mental health trust, all working together achieving a sort of system-wide, joined-up approach to patient care. It is quite inspiring when you see it, but it is the exception, not the rule.

We have identified—we may well come on to it—and announced two weeks ago 14 pioneers around the country who will push the boundaries of what is possible. I think everyone recognises that there are too
many failures of care, and the way the health system is designed does not meet well the needs of people with long-term chronic conditions—often quite complex, often a mix of mental and physical health—and it has to change.

**Chair:** I think that is it.

**Q241 Rosie Cooper:** I very much welcome that but we have to do less talking and more doing.

**Norman Lamb:** That is why, in a sense, I got on and did. The interesting thing is that, when I invited expressions of interest for the pioneer programme, 99 local health systems came forward wanting to be part of it. We have identified 14, which I think are the real exemplars. They have been through quite an exhaustive process with an international panel, but they are getting on with it and doing it. I want these people to be leaders of change, not for the rest of the system to stand back and wait for five years to see what the result of a pilot is. We are going to constantly evaluate this. There is going to be a proper scientific evaluation from the start so that we can learn lessons all the way through the programme.

**Q242 Andrew Percy:** That segues nicely into my questions that relate to these pioneers, who the Department says are going to be “exemplars to support the rapid dissemination and uptake of lessons learned across the country,” which, in English, I think means we are going to see how they do it and then try and copy them and do it quickly. Very accessible ambition of the Department in terms of scale and pace of learning from these pioneers.” By 2015, what percentage of the public, of patients, do we expect to be in receipt of proper integrated services?

**Norman Lamb:** The first thing I would say is that there is now very much a shared vision across the health and care system, the Department and NHS England. The players, I think, recognise that we have to change this model of care to meet this particular growing need of people with chronic conditions. It is happening internationally; this is not something that is unique to the UK. I went to the States and saw some brilliant integrated care organisations at the end of May. There are great leaders all over the world changing and adapting the way their health systems work to meet this 21st century challenge. There is a momentum now to make things happen quite fast. So you have the pioneers out in front, but at the same time we have announced this £3.8 billion transformation fund, which Rosie—what am I supposed to—Rosie Cooper: “Rosie” will do fine.

**Norman Lamb:**—has referred to. That comes into effect in 2015–16, but we are asking every area—the local NHS, the CCG and the local authority through the health and wellbeing board—to draw up their plans now. The plans will have to be finalised by, I think, February next year, and the idea then is that they start to implement this new approach ideally now, but we want it really in place by 2014–15. Then the transformation fund applies from 2015–16. This is a sort of whole-system change, and it will require every area to draw up a plan of how they will use their share of the £3.8 billion fund. The interesting thing is that, when I met with some directors of adult social care a couple of weeks ago, they were all saying, “We are looking at pooling the whole of our budget, not just that 3% element that the £3.8 billion represents.” You need to have the CCG to share that ambition, but it was fascinating that that is what they were thinking about—that the sort of catalyst appears to be driving some quite radical thinking about how you can pool resource locally, and I totally welcome that.

**Q243 Andrew Percy:** It would be interesting to see this scientific study of the pioneers, but the one thing that concerns me is this. We have been down this path in the past before in my local area when we tried to do it through mental health services in about 2008 and there was a push to community care. In my area the beds went, mental health wards were closed and it was all focused on care in the community. However, what we still find is that everybody talks about integration and about proper community services, but, at the end of the day, the only 24/7 services that are there 24/7 are the local hospital A and E department and the ambulance service to get you there. I am interested to hear this is all going to work out, because if we are going to have proper community services—and we have this going on in my area at the moment, where we are trying to put an intermediate care centre in my constituency, costing £3 million, and it is very welcome—it means that social care has to be there 24/7. It also means that GPs have to be there and accessible, whether that is weekends, evenings or whatever. But of course whenever we get to the point of saying, “This is what we need,” it then comes to a question of, “Who is going to provide the money for it?” So we are having a debate at the moment about trying to extend GP services in my area, but it instantly turns into an argument, “But we want more money to do that.” How do we avoid that? The hospital is not going to need less money, and social care still needs the same funding, yet the doctors and GPs are saying, “We want more money as well to remain open longer.” How do we deliver proper community care services when they still end up with the problem of people arguing over their individual budgets?

**Norman Lamb:** The truth is that too many people end up in hospital inappropriately and unnecessarily—frail elderly people. About a third of people in a hospital these days are frail elderly people, often with dementia. Often they are there because of failures of care. If you can get the response much better in the community, supporting people in their own homes, then you can prevent those crises from occurring. Kaiser Permanente in California, for example, whose hospital in San Francisco we visited, has something like 200 beds occupied. Their bed utilisation is massively lower than we have here because they are much better at preventing crises from occurring in the first place. That has to be, I think, the focus of our minds. Ultimately, by shifting the investment from the sort of repair end to the prevention end—and there does have to be a shift—

**Q244 Andrew Percy:** With respect, that is what we are always told. That is what we were told when we
had this with mental health services, but when people are in crisis the burden then ends up falling on the family because that has not happened. We have not seen that shift. It is great, and I buy into the concept and absolutely accept that we need to see it, but too many examples of where we have tried to do this locally in my area have resulted in—we have not had the shift—beds going and services being taken from the hospitals but not being replaced with community wrap-around care. Instead, it is the family who ends up bearing the burden.

**Norman Lamb:** I agree and I am not claiming that this is easy, but first of all you have to agree what the vision should be and I think we are probably agreed on that. The £3.8 billion does represent a real shift—not talked about, but a real shift—from repair to prevention. It is shifting resources to prevent deterioration of health.

If you go to Hertfordshire, for example, within their existing resource I visited a 24/7 care response team that responds to crises in the community to make sure that someone does not have to be rushed into a remote hospital but can be looked after and supported at home to prevent crises from happening. There are examples all over the country. This is an early stage in the development of this but there is lots of evidence. Stephen, we were on a panel together last week and you made the point that Torbay always gets mentioned. That is because they are good.

**Chair:** It was 29 minutes today.

**Norman Lamb:** Yes, and that is probably something that people have been trying to avoid it but I cannot—they have demonstrated on their statistics reduced crises, emergency admissions and bed utilisation and so on.

**Q245 Andrew Percy:** I understand all that. I just wonder, given the pace and scale of this, how do you achieve that in such a short period of time? Hospitals have many of those places that we always quote, such as Greenwich, another of the pioneers, they reckon they have saved 2,000 admissions to hospital in their first two and a half years of operation. The local authority has saved £1 million just by co-ordinating things and also making very significant use of the voluntary sector. Voluntary sector and people—communities—have to be partners in this. We will not do it without the power of the wider community.

**Norman Lamb:** In Greenwich, another of the pioneers, they reckon they have saved 2,000 admissions to hospital in their first two and a half years of operation. The local authority has saved £1 million just by co-ordinating things and also making very significant use of the voluntary sector. Voluntary sector and people—communities—have to be partners in this. We will not do it without the power of the wider community.

**Chair:** Lots of people want to make very short interventions. We will have Andrew and then Rosie very quickly.

**Dr McShane:** You are right about the overlap and people are looking at what sort of transition funding might facilitate that sort of change. I have had to think about this as the £2,000 per head on average that we have to invest in health for people. So you have a certain pot of money—there is not extra cash really—and we almost need to run both systems alongside each other, because there is not this cut-off point where people suddenly stop presenting at the hospital and there are fantastic community care services and all the rest of it. To provide one you need to take money from the other, but that does not end the pressure there. So I am not seeing where the money is going to come from in my local health system to move from one to the other seamlessly. You almost need an overlap.

**Q246 Andrew Percy:** I have a final question on this. As to “the golden years”, I am not sure we would consider them as such locally when we were losing lots of services. Similarly, surely that was the time when this should have been done, when there were bigger increases, and it is a shame it was not. But just to go back to the start of the question, what percentage of patients do we expect to be in receipt of proper integrated services by the end of 2015?

**Norman Lamb:** We set an ambition to get the whole system fully integrated by 2017. That was when we published the shared ambition or whatever it was
called—I cannot remember the title of it—when we launched the pioneer programme back in May. That was the sort of ambition we set. This has been given quite a turbo charge by the £3.8 billion transformation fund, so by 2015 the whole country will be starting to see a significant change. It does not all happen overnight, but there will be significant changes happening by then.

Q247 Chair: Dr McShane, did you want to come in?
Dr McShane: In terms of integration, the common thread that comes out time and again is the fact that the places that are successful share information about the person and the person also knows that is happening. One of the things that in the NHS we should be able to do—and it seems to be quite difficult to achieve—is to share. We have the most computerised GP records in the world. We have the ability to share care records. We need to move that.

What truly creates integration for people is the fact that the professionals and the person know what is supposed to be happening to them, there is a care plan and they can understand it. In London, for people who are terminally ill there is a process called “Coordinate My Care”, where, with the patient’s sanction and agreement, their care plan is loaded on to a web portal that can be accessed by services that they may require.

Norman Lamb: Including the ambulance.

Dr McShane: That includes the ambulance, doctors and so on. The number of people who receive their preferred place of death in the “Coordinate My Care” programme is 77%. The national average is less than 50%. So it can be done.

Q248 Rosie Cooper: I have a very quick question to the Minister. The ITF is currently standing at £3.8 billion. I am delighted to hear, or I heard you say, that the professionals and the person know what is supposed to be happening to them, there is a care plan and they can understand it. In London, for people who are terminally ill there is a process called “Coordinate My Care”, where, with the patient’s sanction and agreement, their care plan is loaded on to a web portal that can be accessed by services that they may require.

Norman Lamb: Including the ambulance.

Dr McShane: That includes the ambulance, doctors and so on. The number of people who receive their preferred place of death in the “Coordinate My Care” programme is 77%. The national average is less than 50%. So it can be done.

Norman Lamb: Including the ambulance.

Dr McShane: That includes the ambulance, doctors and so on. The number of people who receive their preferred place of death in the “Coordinate My Care” programme is 77%. The national average is less than 50%. So it can be done.

Q249 Rosie Cooper: May I write to you and show you the documents and figures?

Norman Lamb: Yes, absolutely. I know that the “total place” or “community budgets”, or whatever they are called now—the DCLG plan—have some quite dramatic figures about the savings they believe they can achieve by pooling the resource that they have locally to use it in a more rational way. The trouble is that the evidence about savings from integrated care—a joined-up approach—is still emerging. That is why the evaluation of the pioneers is really important. But the starting point is that it provides better care. At the end of the day, all of us ought to be interested in that joined-up care that your dad clearly is not receiving.

Rosie Cooper: Forgive me, just to make it clear, the nurses were wonderful. The organisation and the management are absolutely awful.

Q250 Valerie Vaz: I have a quick point on pioneers. Minister, welcome. I think this is the first time you have come before the committee.

Norman Lamb: It is. It is the first time I have been before an all-party committee.

Valerie Vaz: I have to say that. Anyway, we are not as bad as people make out.

Norman Lamb: So far so good.

Q251 Valerie Vaz: We just try to get to the truth on behalf of the public. I want to ask you about the pioneers. It may be in some written documentation somewhere, but could you tell me what considerations you took into account when you picked these pioneers, and did they get any money for it?

Norman Lamb: The fascinating thing was that we were not offering any extra money and yet 99 areas of the country came forward wanting to do it, which is quite instructive. The way I see it is that you have a lot of great people doing amazing things around the country despite the system rather than because of it. They often have to fight through endless barriers to join up services, and it frustrates a lot of people and a lot of them do not get there. These are the people who have managed to do it despite everything.

We set a number of criteria—which I will try to identify, but if I cannot find them before we finish I will make sure we send you the criteria about whole-system integration, ensuring that there was a commitment for the whole of that system through the health and wellbeing board to demonstrate how you can join up care in a more effective way.

We invited expressions of interest. We were not offering any extra money and yet 99 areas of the country came forward wanting to do it, which is quite instructive. The way I see it is that you have a lot of great people doing amazing things around the country despite the system rather than because of it. They often have to fight through endless barriers to join up services, and it frustrates a lot of people and a lot of them do not get there. These are the people who have managed to do it despite everything.

We invited expressions of interest. We managed to narrow it down to 28 as a sort of long short-list. We then had a panel, which included international representatives. We had someone from Kaiser Permanente, someone from Sweden and someone from New Zealand—there is great stuff going on in Christchurch, New Zealand. Every area came forward and did a two-hour session with panel members in London, and it was a pretty robust process, which ended up with unanimity, including the international contributors, as to the 15 originally. Unfortunately, they had set a criterion that, if there was a hospital in special measures, it was not credible to have that area as a pioneer. So, very sadly from my point of view, west Norfolk, my own county, did not make it because
of the Queen Elizabeth Hospital in King’s Lynn having difficulties. But we now have 14 that have gone through that pretty exhaustive process and they, as I say, can hopefully lead the way in trying to demonstrate to the rest of the country. There will be a centre of excellence based in NHS IQ.

I was very insistent that there must be experts in that centre who were there to remove the barriers to integration. Martin has talked about sharing information. There are horrific problems across the system with bureaucratic rules all over the place, which prevent rational sharing of information between professionals caring for someone. They need to be removed; we need to get rid of them. We need to redesign the financial incentives so that we do not incentivise activity in hospitals but rather get the hospitals to have a stake in keeping people out of hospital, keeping people healthier. We need to ensure that procurement rules do not get in the way of sensible joined-up care. The centre of excellence will be there to remove these barriers and to provide guidance on how to do it.

Q252 Valerie Vaz: Great; thank you. Were there any patients’ or carers’ voices on this international panel?

Norman Lamb: We had outside organisations. We had Nuffield—Jennifer Dixon chaired the panel—and also National Voices was very much involved in the document that we drew up about setting our ambition for what we are trying to achieve, and the whole thing has to be completely focused on the patient. This is all about—

Q253 Valerie Vaz: But none on the Panel?

Norman Lamb: I do not think there were any involved on the panel itself, but they had been involved very much in the document that we drew up about what we are trying to achieve.

Q254 Valerie Vaz: We have all mentioned Torbay, but we do so because it exists, it has worked and we have been to see it and they love it in Sweden, Denmark and everywhere else. So I was wondering why, if it exists, it is taking so long to have this integrated service put through everywhere else. You have the good practice and it works. I would just add the section 78 regulations for you to look at, which I think they are finding very difficult. I know you have been to the House to put through the new regulations, but I think they are finding them difficult to operate.

Norman Lamb: Do you mean these competition—

Valerie Vaz: Yes, with integration and competition.

Norman Lamb: Okay. First of all, it is a bit of a paradox, in a way, that one might imagine that in a state system like the NHS everyone would be doing exactly the same thing and following best practice and so forth, but actually it is a bit anarchic. You have fantastic practice, but you also have people who just fail to follow the best practice. It is often quite difficult to translate brilliant practice like Torbay across the system. In a way, I go back to what I said earlier. The people in Torbay achieved it despite everything placed in their way—all these barriers. They worked their way through it. They created a care trust and made it happen. These were pioneering people and I have enormous admiration for them, but we have to make it easier to experiment and to develop models locally. My ambition, in a way, is to change it from a culture where you do great things despite the system, to the system encouraging experimentation. We also have to be prepared to take some risks. If you never take risks in trying new ways of doing things, you will always end up with mediocrity. We have to be prepared to experiment. There is a lot of diversity among these pioneers. In Cornwall, for instance, they have a very substantial involvement of the voluntary sector in addressing the problems of loneliness, helping with people’s wellbeing and keeping them out of the formal system altogether.

Q255 Valerie Vaz: That comes on to my next very short question before we move on, but I think Sarah needs to talk about this point. They seem to have a different population. The population coverage is quite wide and I am wondering what mechanism you are going to use to pull together the best practice for each one because they all seem to be doing different things.

Norman Lamb: That is very deliberate. I expressly wanted diversity. I did not want us to impose a model to say, “This is the way to do it,” and, “Who is interested in doing it this way?” I wanted people to say, “This is the way to do it,” and, “Who is interested in doing it this way?” I wanted people to empower clinicians and managers at a local level to develop their thinking. They are the ones who know how to run services. Sarah will know this very well from all of her practice. The richness in that diversity will be of enormous value because we will be able to see what is working better and what is not working so well.

Q256 Valerie Vaz: You will be able to pull out consistent themes from it.

Norman Lamb: Yes, I think so, because there will be this evaluation from the start. It will not be a question of us publishing a report in five years. There will be a constant dissemination.

Q257 Valerie Vaz: When is the first lot of dissemination of information?

Norman Lamb: Exactly.

Valerie Vaz: No, when is it? When is it likely to be?

Norman Lamb: I want it to be constant. I want to create a sort of virtual network. We are having a launch event on 3 December, bringing all the pioneers together. I want them linked up virtually, but I want all of those who failed to get to the final 14 to be linked in as well. The fascinating thing is that all of those who failed to get there all say, “We are doing it anyway. The fact that we have not made it to the final 14 is not going to stop us. This encouraged us to get
on and have the conversation locally. We are doing it.” So it has generated a great deal of action; that is Rosie’s point about actually doing something. It has generated that activity locally because they have been given permission to do it.

Q258 Rosie Cooper: If I may say so, Kaiser Permanente is working with Southport and Ormskirk Hospital Trust to set up an integrated care organisation. I have not noticed the difference in three years. I say that on the record.

Norman Lamb: Rosie, I do not know about the leadership in that area, but if you went to Kaiser you would see how it could be done really well.

Q259 Dr Wollaston: I am delighted that we are having a “Torbayfest” today, as that is my patch, and I share your tribute to the enthusiasm of the pioneers there. Dr McShane, you mentioned that the successful places share information about their patients, but you will probably be aware that they have a specific problem in Torbay. They have had to stop doing their virtual ward rounds because of the issue of patient confidential data flows, so they appear to be going backwards in some ways. Despite numerous letters and conversations about this, we are no further on. Could you, Minister, perhaps set out what is being done, because it is not just affecting patient confidential flow? It means that the GPs and the CCG cannot talk to each other on things like sharing information with alcohol teams in very many areas. This is causing real difficulties across the NHS, but, particularly when we look at what is happening in Torbay, who are renowned for their data sharing, it is going backwards. Is there anything that is being done actively to put this right?

Norman Lamb: This drives me crazy. We had some events as we were developing the “Vulnerable older people’s plan”, and I attended and spoke at a conference in London and wanted to test it. I asked people in the Q and A section—these were a whole load of people from the health and care system—“Is information sharing a problem?” You would have loved the reaction; it was just overwhelming. So I went straight back to the Department and set about finding a way of removing this barrier.

My starting point was, is it legislative or cultural? Is it people being overcautious because they fear that they might be doing something wrong? I have the latest advice today, because I said I wanted it before the session today, on this issue about sharing between commissioner and provider. If a commissioner wants to do risk stratification, for example, or wants to commission well for people with learning disabilities or mental health, there needs to be some sharing of data, information. The advice I have had today—and we can copy it to the Committee—is that there is no legislative barrier; this is a sort of cultural thing where people are behaving overcautiously. What we need is very clear advice. The Caldicott review, which was published earlier in the year, was supposed, in a way, to give permission to share, but it has not had that effect. That is the honest truth of it.

Q260 Dr Wollaston: In fact, people have actively been told that there is a problem. You are saying there is not a problem but they are being told there is a problem. This has been going on now for many months and directly impacting on patient care. It would be helpful to set out for the Committee exactly what is the problem and how it is going to be fixed.

Norman Lamb: I was told first of all that it was the Health and Social Care Information Centre that was responsible for issuing advice. I am now advised that that is not the case. They will be providing high-level advice for large-scale organisations using data, but, for the purpose of advice to the system to practitioners and provider organisations, it is the Department and NHS England that have to collaborate to do this. I have made it very clear to officials that we have to publish advice as quickly as possible—this is an urgent priority—which will make it absolutely clear that there is a sort of option to share but that there is a duty to share. To get good, co-ordinated care you have to share. Indeed, commissioners have to have the capacity to do the risk stratification that is central to any integrated care approach for a whole population.

Q261 Chair: You did offer to share your advice with the Committee, to which I think, if we may, we would like to say “snap”, just in case anybody missed it in the transcript.

Norman Lamb: Thank you for leaping on that.

Q262 Dr Wollaston: I am sorry to press the point, but it is directly there in the update to Dame Caldicott’s guidance that there is a duty to share in the patient’s interests and that there is just as much harm by failing to share. But that was some time ago and is still not happening. Could, for example, the virtual ward round be confident that they could re-open tomorrow without a penalty, or are we going to have to wait for more guidance specifically?

Norman Lamb: On the basis of what I have been advised, I absolutely understand that that should be perfectly possible. What appears to happen is that local areas end up, because of a fear of breaching confidentiality rules—data protection rules—creating their own bureaucracy around the sharing of data, which puts impediments in the way, whereas it is not needed.

Q263 Dr Wollaston: But they were directly told to stop doing the ward round, so it was not just that they feared it; they received instructions that they could not do it.

Norman Lamb: Who gave the instructions that they couldn’t do it?

Q264 Dr Wollaston: The CCG were told that they could not carry on doing this.

Norman Lamb: By whom—NHS England?

Q265 Dr Wollaston: I understand it was from the information, from Chris Outram’s office.

Norman Lamb: I would love to get to the bottom of this. In a way, dealing with an example like that is a good way of perhaps addressing the problem. The centre of excellence that I referred to earlier for the
pioneers, which will be available to Torbay, will be there precisely to unlock this sort of problem. But there is an urgency about this because it is, as you say, affecting patient care all over the place.

Dr Wollaston: Thank you.

Q266 Chair: Can I deal with another specific example, because I would like to turn, if I may, to the process of who is going to do all this? You have described, and we have been in many evidence sessions where we have heard, a verbal picture painted of how services would be better if they were more patient-focused, more integrated and so forth. I did a thought experiment in my own county of Leicestershire the other day going through the commissioners, all of whom have to co-operate to make this happen. We have three CCGs, two local authorities, NHS England as the holder of the primary care contract and NHS England as the specialist services commissioner. Those are the obvious candidates; no doubt there are other small players as well. Who moves the system from where it is to where it is going to be, and what are the constraints on them doing it?

Norman Lamb: The reality is that leadership in any area—are you talking particularly about how you achieve the change at a local level or are you talking about—

Q267 Chair: I am talking about one health economy, and I think I listed seven commissioners, all of whom will tell you they have resource constraints and all of whom have different accountability mechanisms and so forth. The purpose of commissioning surely ought to be to achieve the kind of change that you describe, but each one of those commissioners is working in a silo with legal constraints on their ability to move resource from one silo to another. Ever mind the accountability constraints. My challenge to you is that we all embrace the picture but who holds the monkey?

Norman Lamb: At the local level, the CCG can, and in a way the health and wellbeing board has the potential to do so. The potential does not mean it is necessarily there yet, but it has the potential to bring people together, and the various commissioners that you talk about in your thought process in Leicestershire have the potential to pool their resource, expertise and ambition to work together to achieve that.

Q268 Chair: To interrupt you for a second, take one element of this. Primary care, we all agree, is an important contributor to this process. NHS England is bound by a national contract with the BMA. How does NHS England as the commissioner of primary care play its part in refashioning community health? That is difficult enough on its own, never mind co-ordinating all the other commissioners on this landscape.

Norman Lamb: I agree.

Dr McShane: There are a number of points there which I will try and answer. The first is that clinical commissioning groups bring together clinical leadership and membership at a local level of people who are at the front, if you like, and they can make or break the system in their behaviour.

The second point is that we have always had a problem over the last 20 years. I was a fund-holding GP and, unfortunately, the reputation of giving finance to GPs to commission a system was tarnished by a few rogues in the system. We then had a situation where the 2004 contract came along and devolved, creating a business contract rather than a professional contract. So there has always been a bit of a problem about the governance of investment in primary care. Currently, there is work ongoing in NHS England around our primary care strategy and the way that we work with CCGs. The legislation has one key clause, which is really important—that both NHS England and CCGs have a duty to the quality of primary care. It is about NHS England and the CCGs working shoulder to shoulder on that, but it also creates an opportunity to ensure that the governance of investment does not become tarred in the way that it has in the past.

Then you have the specialisation commissioning. I have worked in specialised commissioning for 10 years and it ain’t easy. We are now beginning to see what bringing together can do for specialised commissioning across England. There is still work to be done about reconnecting the levels of commissioning and, if you like, the skin in the game between specialisation commissioning and commissioning done by CCGs, and then linked back to primary care. This comes back to some of the stuff that we are doing around changing the national, community and personal approaches towards long-term condition management, which we are talking about here, so that we create enablers at the national level, use the community resources, insight, intelligence and understanding, to work with NHS England and the CCG side by side, so unified on commissioning in that part of the system, but also then, as the Minister has mentioned, the potential of health and wellbeing boards. Certainly, having been involved in commissioning for a long time, one of the big changes for me was a few years ago when we were told we had to commission some social care from health. That brought us to the table, made us talk to each other and think about how we could make sure we both got value for that. I think the Integration Transformation Fund will support that as well, and the accountability is for the clinical commissioning group. There is an accountable officer; there is an area director in each of those areas who will be responsible for making sure that they work with the CCGs and with the health and wellbeing board; and then there is the local authority, which has social care and all the other pertinent parts of a community that contribute to health and care.

I was talking to a CCG accountable officer this morning, who has done a lot of work on integration in the last few years, and they are now exploring what role housing has to play in improving care and how they can align their purpose with the local authority to make sure that supports better care. If you want a “command and control system” we could have that, but we have been there and done that, and the nature
of the challenge and the context have changed and we need to do things differently.

Q269 Chair: I agree with that, but I want somebody who is actually going to change things.

Norman Lamb: Can I add two quick points? In Barnsley last week the local authority leadership was saying to me that their collaboration with the CCG, with the doctors leading the CCG, was much richer and more effective than the old PCT because there was the clinical leadership there, which was encouraging and positive. But I have also been struck by some of the leading innovative CCGs saying, “We want to do things to primary care and we are frustrated by the fact that it is commissioned by NHS England.” I raised that with the leadership of NHS England, and they appear to be very much up for their area teams working—as Martin says, because there is that duty to do so—collaboratively with a CCG that wants to do things differently, to be able jointly, in effect, to commission primary care, for instance, to extend access or to improve out-of-hours support in that area, or whatever it might be. So there are mechanisms to achieve the change that you and I both desire.

Q270 Valerie Vaz: The Chair has asked the questions around commissioning generally, but I want to push you on the dialogue you are having. I know you want to bang heads together, but what dialogue are you having with the CCGs to support them in the whole-system approach?

Dr McShane: It is massive. It is a very, very dynamic and, as I say and I will reiterate, it has only been going seven months so we have been through the storming of the transition and we are now in the forming. We have a commissioning assembly. It meets once a year but that brings together NHS England and all the CCG leads, and there was one held a couple of months ago, which we attended. But the most important thing about this is that the commissioning assembly is a virtual entity that exists for the rest of the year. In the last few weeks, when I have been trying to work out how I can get delivery done, I have used the rapid reference process with the CCG chairs and accountable officers. So I can posit a question, send it out through that network and get a response within hours or days, and that then informs decision making within NHS England. At the moment I am doing work on the House of Care model and iterating that with colleagues in CCGs—and not just CCGs, but in the colleges, with National Voices, NESTA, the Health Foundation and other people—to build a model that people understand and have helped create, rather than sitting here coming up with a model and saying, “Right, everyone go away and apply this because I think it is a good idea.” We have a really strong interrelationship with the CCGs.

Q271 Valerie Vaz: Everyone knows where they are going. Do you have any examples where NHS England has supported a whole-system approach? Can you give any examples of that?

Dr McShane: Yes. It is partly through NHS IQ. NHS IQ is “improving quality”. As the Minister has said, they are supporting the whole integrated transformation movement. The other example I would give, for instance, is as to some of the enablers we are trying to get the money out of the system and into the ground to support commissioning development for mental health. The national clinical director for mental health, Geraldine Strathdee, worked in London previously and established a commissioning development course for mental health, which ran with the CCGs. That has had an impact already in London where the CCG leaders who have been through that development course really understand the potential, the purpose and the wherewithal to commission mental health better on a whole system, both in primary care, community and specialist as well. Is that the sort of example you were looking for?

Q272 Valerie Vaz: Yes. I do not know. You have to give the example; I do not know the example.

Dr McShane: Off the top of my head, that would be a clear example. We are taking that, and, as you said about the early adopters, when I sat down with Geraldine earlier this year, one of our objectives was to try and ensure that that programme gets rolled out nationally and that we have one person in every CCG involved in mental health commissioning. We are making progress on that.

Q273 Valerie Vaz: One thing I need clarification on—and it is partly probably me—is that NHS England has commissioned specialist services. Is there an impact already in London where the CCG leaders are saying to me that they are working with the CCGs to support them in the whole system, both in primary care, community and mental health?

Dr McShane: Absolutely. Let me give you another clear example if I can find it. If you give me a second to shuffle through my papers, I wrote down the details this morning. If we can think about obesity, this straddles all three domains in effectiveness. The guys from safety and patient experience will kill me now. In Rotherham they established a service to address obesity. Obesity, we know, leads to a fivefold increase in diabetes, a triple increase in cancer risk and osteoarthritis and all the other problems. They set up a tiered system, with primary care interventions, and then GP’s could make referrals according to certain criteria. Then, of course, there is the specialised commissioning service, which is bariatric surgery where you put constraints around someone’s stomach. They launched this two or three years ago. They have had over 7,000 referrals now and I think the cumulative weight loss was 14.7 tonnes.

Norman Lamb: What an awful thought.

Dr McShane: But, seriously, they predicted on their model, on their trajectory, that 67 people in 2010–11 would require bariatric surgery. They predicted that would be 78 in 2011–12. The actual numbers fulfilling the criteria for bariatric surgery were 33 in 2010–11, so there were 67 predicted and 33 actual. It was 78 predicted in 2011–12, 28 actual, and in 2012–13 they had 15 people go through for bariatric surgery. That shows why we need to take that whole-system approach. In fact, the commissioning group for bariatric surgery has said that every CCG must have a level 3 intervention in place. The fact of the matter is that the reduction in bariatric surgery funds the...
level, and it is again this matter of shifting the money around and making sure the investment is there. But we have had 40 clinical reference groups set up in the specialised commissioning service, with lay representation on every single one of them. They have been doing the specifications, but they are clearly linking to and trying to forge better links with the CCGs about what the implications are, how there needs to be that connectivity and integration between specialised commissioning, and community and acute service commissioning.

Q274 Valerie Vaz: Finally—you might have touched on this earlier—what tools do the Department of Health and NHS England have to influence commissioning for long-term conditions?

Norman Lamb: First of all, from my side, and then to Martin, we have the mandate. This is the set of Government priorities that we hand to NHS England and it has some legal force behind it. They are under a legal obligation to seek to deliver the mandate. We can hold them to account against that mandate through our formal sessions that we hold with them, and then it is refreshed. The refresh of the mandate has been published today. The mandate is very strong on long-term conditions about the need for everybody, for example, to have a personal care plan that they have been involved in drawing up, just to give one example. Then, as well as the mandate, we can hold on initiatives. On the pioneer programme, for example, we have worked collaboratively with NHS England. They have helped to design and deliver it. Then there is the £3.8 billion fund, which, as you know, stemmed from the spending review, but then it is refreshed. The refresh of the mandate has been published today. The mandate is very strong on long-term conditions about the need for everybody, for example, to have a personal care plan that they have been involved in drawing up, just to give one example. Then, as well as the mandate, we can hold on initiatives. On the pioneer programme, for example, we have worked collaboratively with NHS England. They have helped to design and deliver it.

Dr McShane: If I can, I would like to try and capture all of this. This is why we are using the metaphor of the House of Care at the centre of the domain narrative for Domain 2, the one I lead on, enhancing the quality of life for people with long-term conditions, because it has four components and all of them have to be built if you are going to create person-centred care. The first component is commissioning. For instance, the RCGP has been really helpful about his approach to trying to tackle the issues around risk stratification. When I went to Newark and Sherwood, they had used risk stratification not to identify individuals with problems, but to look at the total need of their population and then map what they were commissioning against that total need for the management of long-term conditions and see where the gaps were and what else they had to commission. So commissioning should be seen as a quality improvement cycle. Most people think of it as just procurement and contracting—and it is not. It is an art as well as a science.

The second point is the roof of the House of Care, which is clinical and organisational processes, such as NICE guidance. We are working very closely with NICE. For instance, again we had the opportunity to influence them and say, “The problem with your single-condition approach is that the nature of the challenge in the health system has completely changed. People do not pitch up with one long-term condition. They are hunting in packs now.” The second point is the two pillars that really hold this place up.

Q275 Valerie Vaz: It is the walls, isn’t it?

Dr McShane: It is the walls—empowered patients and carers. In the work that Tim Kelsey and his team are leading—and I am working on—one of our programmes is “Patients in control.” We identified that in the domains, but we have actually said that Patients and Information—they took it off us—are leading that and we are supporting them. As to carers, we have a big carers’ workshop coming up in the next few weeks because we want to know what it is we need to do to create this at a national level.

Finally, there is professional collaboration. Long-term condition management requires continuity of care and there are three components to that. One is informational continuity. “The information about me is available wherever I go.” We are now seeing with mobile technology the development of apps, which means people can take their information with them. There are a number of apps that are now available. I recently had a patient, an 80-year-old taken to A and E recently who handed over her iPad and said, “All my medical records are here. Would you like to use them?” which rather stunned the assessing clinician, but they did find it useful.

It is about professional collaboration. Continuity also requires that and management continuity, which we have talked about, but also relational continuity. This is where the named doctor comes in. Getting back to knowing who I can trust and turn to when I have problems with the care that is being delivered for me in the way that we have had so clearly articulated is not happening in places.

I also think that relational continuity is about relational continuity between professionals. When I was a GP, there was a coterie of incredibly useful specialists—not all of them doctors, some of them nurses—whom I would contact when I wanted help in managing the patients I was looking after in the community. It is about that team-working. In part, some of the incentives and financial incentives in the system, which are brilliant for planned care, just do not work for long-term condition management. Competition and choice is great for planned care, but long-term conditions demand integrated care and that requires a new dynamic.

That is the model. I think there are components we can deliver at a national level, which have already been articulated; there is some of that that has to be delivered. But the biggest transformation is at the personal level. That is why we are working with the Royal College of General Practitioners, NESTA, the Health Foundation and others, to create a narrative and an understanding of how we support professionals and change the culture right at the coalface. I know I did not behave that way in the past and it is a big ask. So we are working with Health Education England on how we change the training and the skills that professionals have coming up for the future challenges, not the past.

Valerie Vaz: Thank you very much.

Chair: That is a neat lead-in to Sarah’s question.
Q276 Dr Wollaston: You mentioned tariffs. That was going to be the next group of questions. You talked about levers quite a lot earlier. Dr McShane, and one of the problems in the NHS is that people tell me they pull the levers and nothing happens, be that a reconfiguration that is bogged down in bureaucratic and legal challenges at vast expense or something else. The other issue is tariffs and how we are ever going to shift this while hospitals can still hoover up the care through a tariff-based activity. Could you update us as to whether you agree that the tariff change is essential and what progress is being made?

Dr McShane: NHS England and Monitor recognise that tariff change is required to support the vision that has been set out by the Minister. We are already making progress on that. There has been a lot of work done on what we call the Year of Care tariff, which NHS England inherited and has continued. We are discovering some quite exciting information.

I was recently party to information from Somerset, which was an analysis done by York university, part of the Year of Care work, where they had analysed over 100,000 episode treatment groups, patients with long-term conditions. It illustrated two key points. One is they had 5,500 patients with diabetes in Somerset, and only 853 of them had diabetes alone, so multiple long-term conditions were the problem. Some of those are synergistic in medical terms, but some of them are non-synergistic. It makes it very difficult to interpret NICE guidance if you have someone who has, for instance, anxiety and hypertension and—

Norman Lamb: Depression.

Dr McShane: Yes, they will have depression, dealing with that. What they found in addition to the multimorbidity agenda, confirming the Scottish study, is that once you get above two or three conditions the average cost is dependent on the number of conditions, not the type of condition. So we are hoping we may get into a model that may be more useful and applicable. How we set a Year of Care tariff. But the evidence from elsewhere is that you need to set that across the whole system, linking the hospital, the community services and the general practice. Then it needs to be a proportionate risk for all those players. You cannot do it on an episodic, fragmented basis. The integration pioneers, the new planning guidance that will be coming out in December, and the joint announcement by the key national bodies will show the change in context for people, and the opportunity for people to experiment to use flexibilities locally to design different ways of incentivising the system. I think we are at a tipping point.

Q277 Dr Wollaston: Does it also highlight the issue that has come up several times about whether or not you split the NHS cake depending on age, which is, I understand, the greatest predictor of multiple-morbidity or whether you split it predominantly on the basis of deprivation? If we are looking at needs-based or prevention-based care, what is your view on that debate?

Dr McShane: It is complex and interesting. The York study would show that in fact it is the number of conditions you have that is the biggest predictor of cost, not age. It is just a fact that, as you get older, you get more conditions. You have to remember that there are an awful lot of older people living really well, and that is the way I would like to go as well. Quality of life into old age can be very good, but, if you are 55 and you have multiple conditions, your quality of life will be as poor as if you are 85.

Q278 Dr Wollaston: Do you see eventually the NHS moving to a model that predominantly recognises the number of conditions people have as the main way that you distribute the financial cake across the NHS?

Dr McShane: Possibly, and I think there is still a lot more work to be done on that. The other thing we have to recognise is the emergence of frailty as a diagnosis, so you can be elderly and frail without multiple long-term conditions. John Young, who is our national clinical director for frailty and integration, has defined this and there are measures for it. We can send you a note on it; it feels like a viva voce at the moment. One of the key determinants is how the person walks. You can measure that in a GP setting, your patient walks with a stopwatch.

Q279 Dr Wollaston: You can have a race with all your patients.

Dr McShane: But it will tell you the likelihood of something. That is a strong indicator of co-ordinated and substantive care being needed for that person. By the way, there are two things that drive huge cost into the system: one is dementia and the second is mental health. We have not really properly understood and tracked the importance of improving care for people with dementia.

Norman Lamb: The most expensive people of all in terms of their care costs are people with multiple chronic conditions, including mental health. That shoots up the cost and often the care they receive is very poor.

Q280 Dr Wollaston: So treating their mental health will improve costs across the system.

Dr McShane: Again, at Newark and Sherwood, when I talked to the team, they CPN commissioned, because of their analysis of what was required in the virtual ward, within six months they had already identified that it would be a good idea to commission more mental health input, because when the CPN was going in to deal with someone’s problems, often with long-term conditions and anxiety, they were also supporting the family’s problems and the carer’s problems. There is a huge impact on the mental health of carers as well.

Q281 Dr Wollaston: Returning to the tariff for a moment, when would you estimate that we are going to have the new system in place? When are we going to have the certainty for those who are trying to plan services as to how the reformed tariff will look?

Dr McShane: First of all, there is a raft of flexibilities within the current system that people can use. I have used them in the past myself.

Norman Lamb: We are actively encouraging the pioneers to do it with support from the central team.
Q282 Dr Wollaston: So to decide how they use the personal budget, you are going to support patients and carers in taking control of their care plan and managing their own care. The question I want to ask you to begin with is how that might be captured in the payments or services. Practitioners involved as patients ask for those services. You have already alluded to personal care plans, Minister and, Dr McShane, you talked about that. Do you think that all services users with a written submission that there is a “fundamental shift” in emphasis from a disease focused to a person centred system.” We are all agreed on that. It is interesting to me, as someone who has been closely involved in complementary and alternative medicine practitioners, if not all, have always put the patient's needs come first with that slightly complicated background? That is now coming into the mainstream and is something that you might want to mark, because, with personalised budgets, I suspect that there will be more complementary and alternative medicine practitioners, if not all, have always put the person first and the disease second. In that sense, that is something that you might want to mark, because, with personalised budgets, I expect that there will be more complementary and alternative medical practitioners involved as patients ask for those services.

The question I want to ask you to begin with is how are you going to support patients and carers in taking charge of their care plan and managing their own conditions?

Dr McShane: I think again—I am sorry—

Norman Lamb: Who were you asking?

David Tredinnick: I am always asking the Minister first, but I think, Dr McShane, if I may say so, you have done sterling work in support of your Minister in this session.

Norman Lamb: There are various things that you can do to help an individual manage their own care and take control, and we are often not very good at guiding and providing education for someone, for instance, with diabetes to be able to manage their condition much more effectively. We know that, if you do that, it makes a massive difference to well-being, but also helps to avoid crisis occurring in their care. Along with that, I want to make the point about personal health budgets, something that I am a passionate advocate of. When I came into post last September, there was a plan in place to legislate to provide a right to request a personal health budget for people on NHS continuing care. I feel that that does not do enough to change behaviour across the system. There will be some CCGs that are very good at encouraging and facilitating people taking control, but there will be others who do not tell people about it and do very little to change the traditional way of doing things. So I wanted a “right to have” a personal health budget, not just “a right to request”. That will come into force in October next year. In April next year there will be a legal right to request, ultimately for the CCG to say no, but from October it will be a right to have, obviously subject to some safeguards in cases where it proves impossible. It will be fundamentally a right to have a personal health budget, and I am very keen that we extend that beyond people with NHS continuing care. A prime area for me where I want to develop the concept is in mental health. If there is any area where we should be empowering people to take more control of their lives, surely it is in mental health.

Q284 David Tredinnick: I want to ask you further on about that, as you have learned from the pilots, on which I had a very interesting presentation a while back. Do you think that all services users with long-term conditions will welcome a shift to patient centred management? Have you done any—

Norman Lamb: I am quite sure.

Q285 David Tredinnick: Are they going to be frightened of the concept?

Norman Lamb: It was fascinating back in Barnsley again last week that they have pushed within social care the principle of personal budgets and direct payments further than many local authorities have done. The leader of Barnsley council was telling me that he was faced with lots of people saying, “This is the council abandoning older people and forcing them to take charge,” and everything, but he said that it was an amazing the extent to which older people, the very group who many people say will be resistant to being given the power, are just as enthusiastic and committed to it as anyone else. One of the big shifts that I talk about that needs to happen is from a paternalistic system, which I think the NHS fundamentally is, and indeed the local authority care system is, to one that is absolutely personal, where the objective is to give power to the individual to take control of their lives.

Q286 David Tredinnick: I will develop that in a moment, but I want to ask you first about primary and community care services which are being asked to manage models of care that are increasingly complicated and also individualised. How is it possible to design a service model that ensures that the patient’s needs come first with that slightly complicated background?

Norman Lamb: I do not think it is necessarily any more complicated involving the individual than imposing something on the individual as a passive recipient, ultimately. All of the evidence suggests that, if you engage and involve the patient, the person...
themselves, you end up with better results. You design that package of care to much better reflect their needs and what their priorities are than you do if you just impose it on them. I am not suggesting for one minute that this is easy, and some of the packages of care are highly complex—I absolutely accept that—but having a partnership between the patient and the professional must be the way to get the best results.

Q287 David Tredinnick: I put it to you that on personal health budgets the pilots that the Department ran were spectacularly successful. They showed, from the presentations I have seen, not only that the patients were empowered and costs reduced but also that carers were re-empowered. Would you like to expand on that, as I see Dr McShane nodding? If you would like to elaborate on that, the basic question was what have you learned from the pilots?

**Norman Lamb:** We have learned that exactly. I have learned the same lesson that you have learned. What was quite interesting was that there were a number of areas of the country that participated in this, and where the maximum power was given to the patient to take control, the best results emerged. Where it was highly constrained, where it was constrained empowerment, the results were more limited.

To give you an anecdote, I was talking to a man from the Kent pilot, a wheelchair-bound individual who had complex disabilities who had been in and out of hospital, like a revolving door in A and E. Once he had taken control and was able to determine what his priorities were about how his care was delivered and sorted, he had no longer been in and out of hospital. It had stopped. It was moving from health to social care.

Q288 David Tredinnick: One of the aspects of the pilots was that those offering the pilots were not judgmental about the type of treatments that the individuals asked for. They were not offered a rigid range of options. That is not understanding. Is that right?

**Norman Lamb:** Yes.

Q289 David Tredinnick: In one instance a presentation from an official in the Department was talking about piano therapy, tai chi and even sports therapy that had been selected and approved, because the patient can choose what they like, providing it is safe.

**Norman Lamb:** We have to open our minds.

**David Tredinnick:** Really open them.

**Norman Lamb:** Yes. Let’s focus on what is the central principle in the Care Bill, which is well-being. We should not always be asking, “What service do we need to deliver to this individual?” We should be asking the question, “How do we enable this person to lead a good life?”

Q290 David Tredinnick: We had Arthritis UK present a memorandum to this Committee. They published two reports on complementary and alternative medicine in which they found that the 20 they looked at, the whole range, were fundamentally safe; they were absolutely safe. I put it to you that we are going to move into a period here where these patients ask for, increasingly, what used to be seen as complementary and alternative medicine and that the legislation and this policy is almost automatically drawing them into mainstream health.

**Norman Lamb:** That may well be the case. For me, it is about what matters to the individual and focusing on their well-being. We know that in mental health, for example, exercise, good diet, sleep and engagement with the outside world are all incredibly important principles. So we should go with what is important to that individual as far as it is sensible to do so.

Q291 David Tredinnick: I have one more question on that theme. When Professor George Lewith, professor of health research at the university of Southampton primary care department, gave evidence a week or so ago—I quote from the transcript—he said: “We know with cancer that people who use complementary medicine on their cancer journey, which is between 20% and 40% of people with cancer, get a huge amount of ability to self-care and a lot of positive skills for life. Indeed some individuals can care for themselves.”

**Norman Lamb:** I note the evidence that has been presented. We have learned the same lesson that you have learned. What do we know? We know with cancer that people who use complementary medicine on their cancer journey, which is between 20% and 40% of people with cancer, get a huge amount of ability to self-care and a lot of positive skills for life. Indeed, some individuals can care for themselves.

Q292 David Tredinnick: What follows on from that is that we have to make sure that the resources for the different treatments that the people choose are readily available.

**Norman Lamb:** If you have personal health budgets for particular areas of care, such as NHS continuing care for those people with complex needs, I suspect that markets will develop for the sort of things that people want to use the money on. Where it is rational for the individual, we should not seek to overly constrain the way that money is used.

Q293 David Tredinnick: Chair, I have one last question. It has been suggested to us that personal health budgets could be joined up with local authority personal care budgets under certain circumstances, allowing integrated care at a personal level. Is this a funding option you are considering?

**Norman Lamb:** For me, in a way, the best integrator of care is the person themselves. If they are given some power in this, they will design what they need around their lives, making sure that it all fits together for them. The more we can move away from these awful silos that have existed—which in the past have been okay because the NHS, in a way, has focused particularly on episodic care for a particular problem, which is then sorted and the patient goes home—the
better. Now that we are dealing with this dramatic growth in chronic complex conditions and people living for many years with them, the model has to change. To have these silos makes no sense from that patient’s point of view. If we can use the resource through personal budgets, bringing the two sides of the divide together, that seems to me to make absolute sense.

David Tredinnick: Thank you very much.

Chair: Rosie wants to ask a question, I think, about the impact of all of this on the acute sector.

**Q294 Rosie Cooper:** Yes. In essence, I was going to suggest we went back to the shared vision, but lovely warm words—

**Norman Lamb:** That sounds almost cynical.

**Rosie Cooper:** It is. I am afraid—very. The treatment of long-term conditions in the acute sector should actually be reduced substantially. If that is the case and we get towards delivering that, what would the effect on the acute sector be and has anybody made an estimate of the number of beds that we would need to take out of the system if that move to community care was successful?

**Norman Lamb:** I have not seen any estimate of numbers of beds involved. I want the incentives in the whole system to be aligned—and they are not at the moment. You have an acute hospital that is incentivised to do more, and that is not aligned with what people in community care are trying to do for their patients. We have to change that fundamentally.

Under the last Government, the changes made to stroke care are a perfect example of how that was recognition, from the clinicians first of all, that the way we were dealing with it was not good. People were dying unnecessarily of ending up with permanent disability unnecessarily. A model was made to focus on fewer centres and probably hundreds of lives have been saved in London—just to take one place—as a result of that.

All this has to be driven by achieving better care. If we end up with fewer people going into hospital, as a result of keeping frail elderly people fitter and healthier at home because their care is managed better, and the voluntary sector is attacking the crisis of loneliness that we face in our communities, then that is great. That is a “good news” story and then the system needs to adapt too.

**Q295 Rosie Cooper:** As long as you are not home alone, of course.

**Norman Lamb:** That is what we need to tackle. That loneliness is what we need to absolutely tackle.

**Q296 Rosie Cooper:** Minister, it would be great to have a much longer conversation with you because there are things I could say that I should not say here, but that would be—

**Norman Lamb:** I am not sure what you are referring to there.

**Rosie Cooper:** The thing is that it is very difficult for people. The reason I used the example before of nurses not being able to say what time they were coming to see my dad is that he is deaf; he was born deaf. So without me or an interpreter, what is that visit about? He is one of those people who had a stroke who did not get the treatment. Although I got him into hospital within 40 minutes and I knew what should happen, he did not get a brain scan and thrombolysis was not given. In fact, the consultant on duty told me to my face that thrombolysis kills more than it cures. I asked him what his specialty was—he was in charge of the Royal Liverpool A and E that weekend—and it was diabetes. This was a few years ago, but it is an absolute disgrace and from there we move to today. I have a long front-line experience as well as—

**Norman Lamb:** I understand.

**Rosie Cooper:** So, when I hear all this, it is fantastic but it really has not changed a great deal.

**Norman Lamb:** I think stroke care has changed though; it really has.

**Q297 Rosie Cooper:** Yes. Stroke care has changed fantastically, but what I meant is that interface. I will have this conversation.

**Norman Lamb:** I have been in the job a year but I have a very clear vision of what I am trying to do.

**Rosie Cooper:** Okay, and that is really great, but what I would say, clearly, is that there is a big difference between what we think we are doing and what which we think we are doing and that which is being delivered on the front line.

**Q298 Chair:** I want to bring Dr McShane in, but I want to help Rosie. One of your predecessors, Mirror, Enoch Powell, when he was launching the hospital plan for the transformation of mental health services, was more direct in the effect on the old-fashioned mental health acute sector. He went to the contemporary equivalent of the NHS Confederation and told them to close 75,000 beds and not to err on the side of caution.

**Norman Lamb:** Wonderful. What year was that?

**Chair:** It was 1961.

**Norman Lamb:** Amazing.

**Q299 Rosie Cooper:** I cannot believe that you do not have in the Department of Health some idea of the numbers. Why do I say that? Because whenever you fashion a new hospital, with the PFI and all those numbers, you work out how many hospital beds you need. So you, the Department of Health or NHS England, will know how many trusts have to go and how many beds have to go.

**Norman Lamb:** I am not trying to be difficult, or I do not have a figure in my mind that in a new world it would be, but I do recognise that when you go and see Kaiser Permanente you see a much lower bed utilisation in hospital because they are keeping people healthier, and that is ultimately what our objective surely should be.

**Chair:** Dr McShane, I promised to bring you in.

**Dr McShane:** It was really as an example of what could happen. So, small scale, a GP in Gnosall—

**Norman Lamb:** This is fantastic.

**Dr McShane:** Sends out a birthday card to everyone over the age of 75, and it just happens to have a comprehensive geriatric assessment attached to it, which he asks them to return. Because he has lived and worked in that community for so long, they do. He risk-stratifies his population and has used a mobile
technology with the elderly and those with dementia to create a care plan with the carers and the community services, but he has also mobilised the community with volunteers going in and befriending people with dementia and supporting them. As a consequence, for just his one practice—benchmarked, again, against other areas—he has taken over £400,000 out of his spend for acute and social care.

It will have an impact on hospitals. I have worked in hospitals for over a decade. They are big places with lots of wards, and in each ward it is the staffing and the cost to the ward that has the biggest impact. So, if hospitals work with their communities and are part of the community rather than acting as if they are a community on their own, then we can shift these resources between those components to support the better care that people should be receiving.

Q300 Rosie Cooper: I hear that and think that is absolutely where we should be. But—of course there is a “but”—Dr McShane, you talked before of the elderly patient turning up with their notes on their iPad. Let me tell you what really goes on. In August my father fell; I am down south and he is taken to hospital. The Royal Liverpool A and E has no interpreter, so God knows how they made any sense of it. Anyway, I find he has been transferred to the community ward—fine. When I get there, I am very clear that no one—one—could have read his notes because they do not have a clue. After I asked to see the doctor—the bit you heard before, and it goes on and on—a locum doctor opens his notes and says, “Oh, they stop in 2007.” Can you tell me how good clinical care, in my A and E and on a community ward, can operate with nobody noticing that they do not have all his notes? It took three days to get those notes. How is that good clinical care? It is an outrage.

Dr McShane: We totally agree with you, and your particular case is—

Q301 Rosie Cooper: It cannot be unusual. They are not all lining up just to pick on my poor lovely dad. This is going on with all the people about whom you are talking in this lovely idealised situation. It is not happening.

Norman Lamb: The technology challenge is enormous. I have had a chap in Norfolk admitted on a weekend and they needed to see his medical notes, but they were locked up in the GP practice. They could not get hold of them. They gave him aspirin twice that weekend and he was allergic to it, and it ends up with awful care. But we need, as a priority, to get all of these different parts of the system linked up.

Rosie Cooper: These were paper notes.

Dr Wollaston: Rosie, is that the question I am coming on to.

Rosie Cooper: I am sorry, Sarah.

Q302 Dr Wollaston: I am just saying that I think it is very important, Rosie. What you say comes to the heart of this. What progress are we making towards patients holding their own records so that they are transferable across the whole system? We are told that it will be by 2015. Are we on target to deliver just this kind of thing so that we do not have these issues arising again and again?

Norman Lamb: Do you want to answer that from NHS England’s point of view?

Dr McShane: Yes, I will. In terms of the infrastructure, the opportunity to deliver that and the work that is being done by Tim Kelsey’s team on—I have to use the word—inafra- operability, notes can talk to each other and the deployment of the summary care record across the country covers 60% of the country now, I believe. We are making progress. I think, though this is a fundamental cultural shift that has to be addressed. We have to stop being scared of people having access to their own records. We have to realise that people with long-term conditions, especially, are partners in their care with professionals and need to be given that control. We are making progress to enable it. Are we on target to deliver it? I am not going to nail myself to that right here and now because it is a massive agenda.

Q303 Dr Wollaston: Do we need to have a fundamental shift in who owns a medical record so that the patient owns their record? It is not owned by the Secretary of State.

Norman Lamb: Exactly. Dr McShane: Yes, Sarah. There are two things. Where people are being given permission to do this, they are embracing it. As to the example I gave you, I know that people are trying to roll that out across whole CCG areas. I know that there is Patients Know Best and that there are areas where CCGs and local populations are embracing it. I cannot tell people to do this, because there are all sorts of problems and the reality is that, for some people, having access to and control of their own records may be dangerous if they are in abusive relationships or in circumstances where it could put them at risk. It is up to local areas to make the advances that are required to change the culture and to work with their local populations to do this. But are we giving out the signal from the centre and creating the levers and enablers to allow that to happen? Yes.

Norman Lamb: All I would add is that there does have to be an urgency and a sense from the centre that people have a right to have access to their records. It should not ultimately be down to a local area to deny that. There are other systems where on an iPhone you can get medical records, test results, book an appointment or have secure e-mail consultations with your doctor. This is what should be happening. In Seattle, Group Health—a fantastic not-for-profit integrated care organisation—by extending massively the number of patients who consult their GPs by e-mail, frees up the GPs’ time in order to deal with those really complex cases that need more than the ridiculous 10 minutes that many GPs have at the moment to try and resolve complex problems. The evaluation of this transformation in one clinic in their system was dramatic. It resulted in massive improvement in patient satisfaction, but, interestingly also, a very significant improvement in quality of life for the clinicians, because the pressure was taken off them, and they were able to work in a more rational way and devote more time to the complex cases.
Q304 Dr Wollaston: Do you think part of the problem is that we had our fingers burned by the cost of Connecting for Health and that it did not deliver?
Norman Lamb: Yes.

Q305 Dr Wollaston: How is that going to change?
How are we going to get a system that—
Norman Lamb: The national programme has been a disaster. We have spent billions of pounds on it. The NHS is caught in a time warp. When I hear that faxes are still flying around the NHS, I wonder what other sector of the economy that happens in.
Chair: The Inland Revenue.
Norman Lamb: Did you want to say something?
Dr McShane: Very briefly. It is already happening in places. We are at the bottom of the S-curve of change. All the patients of Amir Hannan—who I believe took over Shipman’s practice—have open access, where they want, to their records, and he can extol the virtues of that. Other people have involved people in their care planning and it is going on. We are at a tipping point where people are embracing it. The other thing I would say about e-mail consultation—the best description that I had of that—is from a doctor in The Veterans Administration, who said that, because they were doing e-mail consultations with their patients, they saw their patients less often but knew them better. When I said that to a British doctor, they pointed out why: because you cannot interrupt an e-mail.

Q306 Dr Wollaston: Very good. Chair, may I ask one separate point on the issue of healthcare assistants? We have talked a lot about the loneliness and isolation and improving long-term conditions. Are either of you able to say what is going to happen about the cavity of the really necessary changes?
Norman Lamb: I still find it amazing that, in essence, someone can get a job with a care agency and go out and do pretty intimate caring work without any training. There is no effective mechanism to stop that. Even though the Care Quality Commission sets an obligation on providers to ensure that their staff are properly trained, there is no mechanism to really hold them to account on that. The Cavendish report, which was really welcome, proposed the idea of a very clear care qualification. We are amending the Care Bill to facilitate that, and, obviously, there has to be a consideration about the mass of existing care workers. You could not expect the whole system—the very many skilled care workers who do not need to—to do a qualification, but new people coming in, in my view, should have a qualification.
I also make the point that statutory services cannot do it on their own—either statutory services or private providers commissioned by statutory commissioners. There has to be this collaboration with people in their communities. Is it “Better Lives” they have in Cornwall? There is a fantastic programme there that involves volunteers working alongside the GP practice, just giving some companionship to people living on their own and giving them a bit of a life again. I think some GPs are sometimes reluctant, instinctively, to work collaboratively with volunteers, but they have embraced it and the results are quite dramatic in terms of reduced admissions and reduced dependency. So this sort of collaboration is necessary as well.

Q307 Valerie Vaz: I know we have gone all over the place, but, just to go back, every newborn baby gets a little red book and you put in their height, weight and vaccinations. So it cannot be too difficult, I suppose, to do something similar for long-term conditions. I want to go back, Minister, to the personal budgets. I am not quite sure whether they are cash limited, where the money will come from for the individual person and whether it would reflect, for example, changes in long-term conditions—say, if someone gets another one—or what would happen.
Norman Lamb: The bottom line is that a CCG currently pays for the care of someone who has NHS continuing care. The budget is quite substantial, as we know, for NHS continuing care. Instead of the CCG just paying for a care team to provide care to that individual without that individual having any choice about what they do and how it is made up—and you could involve people with long-term conditions who have been receiving social care from the local authority, their housing detectives, they become entitled to NHS continuing care and the NHS continuing care people say, ‘You can’t keep your existing team of carers. We are going to impose our own team on you and you have to take it’—this changes it so that the money that is currently being spent, in a sense, is put at the disposal of the patient. The patient is asked, “How do you want this resource that we are spending on your care spent?” It is not, in a sense, a new pot of money. It is spending the existing money that we are spending on people with chronic conditions—but spending it in a more effective way that meets their needs and their priorities.

Q308 Valerie Vaz: But the individual patients do not hold their own little budget, do they?
Norman Lamb: Right. There are two alternatives. You can have the personal health budget where the patient has a say but the money is deployed by the CCG, or you could have it as a direct payment, so they actually receive the budget and you have an agreed care plan, which is what happened in the pilots that we were talking about earlier with David. That choice is there. If someone’s care needs develop and another condition develops—depression, for example—then they could be reassessed and their budget could be increased.

Q309 Andrew George: I am sorry that I missed the earlier part, but following on from Sarah’s excellent question earlier about care assistants, when you consider all of the pressures in relation to home care workers in particular, there is a bottom—a floor—which I am afraid there may be a race to. If you consider that all of the policy, the mantra, the logic and the budgets are pushing patients out to their homes—and in the most extreme cases clearly they require some form of home care, some kind of home assistance—unless the Government step in with the minimum wage, as you were suggesting, Minister,
with no training being required and minimal visit times in a very competitive environment with budget pressures from both the NHS and also local authorities, one can envisage this race to the bottom carrying on, at the very time when all of the policy logic is suggesting that is where a great deal more work needs to be done in terms of service delivery. Do you not agree that something needs to be done to raise the floor by suggesting regulations in relation to, for example, the living wage, minimum training and minimum visiting times in order to avoid the race to the bottom?

Norman Lamb: First of all, it is imperative that employers meet their obligations under the minimum wage.

Andrew George: Yes, of course.

Norman Lamb: I am extremely uncomfortable with this practice of not paying someone when they are travelling from one home to another. If there is a zero-hours contract, it might be that technically they can get around the normal understanding of the law in that way and we are looking at that. I have met with Vince Cable, who is undertaking a review of the rules on zero-hours contracts. There is this interplay between zero-hours contracts and the minimum wage that needs to be looked at. You referred to minimum training, and this is what we are seeking to do through the Cavendish recommendations and the amendment to the Care Bill.

The other issue here is the commissioning of home care. This practice of commissioning for some of the poorest possible standards is hopeless, in my view, and there is an urgent need to improve the quality of commissioning in social care. At the moment you might have a tendering exercise to deliver a home care service and the lowest bidder wins the contract, and it is that race to the bottom that you described.

In Wiltshire they have introduced commissioning to achieve outcomes, to achieve other sorts for people, to focus on quality. I was hearing from Paul Burstow in fact, who has visited there, that the care workers are receiving a salary. It is really interesting and a complete change of approach. If you incentivise the provider to improve someone’s mobility, to do introduce, for instance, telehealth and telecare into their provision, if you incentivise them to improve the person’s well-being, or perhaps work collaboratively with the voluntary organisation locally, and if the result of all of that is that dependency reduces, then there is a gain for the local authority. Most important of all, there is a gain to the person who is receiving the care.

We have worked with ADASS—the Association of Directors of Adult Social Services—to develop much better quality commissioning, a sort of template for commissioning for outcomes, for results for people, and that is the change that I think we have to make.

Q310 Chair: I am conscious that we are very close to the end, but when it was announced that you were coming to give evidence to us, Minister, a number of people wrote in to the Committee expressing concern about prosthetic services for limbless patients, which has been transferred, as I understand it, to NHS England. There is a belief in that community that those services, since 1 April, have been the subject of significant reductions. I do not know whether either of you are able to answer that question, but, if you are not, I would be grateful if you could write to us and set out the position.

Norman Lamb: I am concerned to hear that view expressed, because there is the potential, with NHS England commissioning it across the country, to introduce a common standard that should raise standards across the country to avoid the variability that has been there. If that is happening, it needs to be addressed, and we need to look at it. I do not know whether Martin has any thoughts to add.

Dr McShane: With the specialised commissioning, it may have been a dip—I do not know—but, prior to the creation of NHS England, there were about 30 specialist centres across England with no national commissioning, no standards and no coherence to that. There was variation in commissioning and funding and inequitable access. We have set up a clinical reference group to look for complex disability equipment. The work has commenced on that. We are working with 12 of the prosthetic centres to identify clear guidance and study the potential number of patients that would benefit from, for instance, microprocessor limbs for the future as well. So it is not about taking a step back. It is about bringing about some equity, some standardisation and then some quality improvement into the future. That is my understanding of the situation.

Q311 Chair: Obviously it is a view that is not entirely shared in the affected community, so I think if either you, Dr McShane, or the Minister were prepared to meet people from that community, it may—

Dr McShane: NHS England would be delighted to.

Q312 David Tredinnick: I have one final question. We have been talking about personal budgets in the context of long-term care. Unless I missed something earlier on, are you looking towards taking personal budgets out to a wider health community—younger people?

Norman Lamb: Yes. As you may know, the first group that we have looked at is people who are on NHS continuing care. From October next year, they will have a right to have a personal health budget. I am very keen to expand this. There are some parts of the health service where it does not work, but for people with long-term conditions of various sorts it is a highly attractive proposition, from my point of view. I mentioned earlier that I think mental health is the area that I would most like to focus on next, because that capacity to give some power to the individual to determine their priorities is particularly strong in mental health.

David Tredinnick: Now one really last question.

Chair: Just one more.

Q313 David Tredinnick: I keep thinking of new questions to ask. Have you given any thought to whether there might be any conflict through personal budgets when a patient says, ‘Well, I want to do this,
doctor.” and the doctor says, “Oh, no, you don’t. I know best!”
Norman Lamb: There is potential conflict there. The interesting thing was that the pilots did not demonstrate that there was any great problem in reality. Probably the clinicians go on a bit of a journey as well in that they may start off from a position where they feel reluctant to lose control, as it were, but this idea of a partnership—and I am sure that Martin as a clinician absolutely sees that that is the way to do it—delivers better results for people.
Dr McShane: We underestimate the intelligence of the population. There is the evidence from Dartmouth, engaging people in managing and understanding their own needs, starting with the person rather than the condition, and then looking at what are their life goals—what do they want? We had a fabulous conference a few weeks ago, “Future of Health”, where we had a people’s panel. We had 14 people with a variety of long-term conditions who sat in front of every speaker and they were the first to get to ask the speaker questions. I do not know why that came to mind today, but one of them, Jonathan, really resonated with me in what he said. He had had renal failure from the age of 16. He is now in his 50s. He said it took 20 years before anyone asked him his opinion. If you have had renal failure and been through the sort of management that he has had, who is the expert? I would have seen him as a clinician for maybe five hours a year. He lives with it for 24 hours a day; his carers are with him probably seven days a week, and I am there.
I think we need to respect the knowledge, insight and experience of the person with the long-term condition, and that is part of the culture change that I am trying to champion, but I am under no illusions about how difficult this is going to be.
Norman Lamb: The fascinating thing also is that people tend to be pretty good custodians of the money as well. They do not choose to go out and rashly spend it. They realise it is a scarce resource and use it to achieve their objectives but not in a—
Dr McShane: They are often harder than the medical profession.
Chair: This is the point in this evidence session where everybody has just one last question and I am going to draw it to a close. Thank you very much.
Q314 Rosie Cooper: Forgive me, though, I need to take advantage of the fact that I have got a Minister and NHS England here and ask you a question from left field, if I may. Does choice still exist in the NHS? Are patients able to choose their consultants as well as hospital, or are we using “Choose and Book” to make sure you cannot choose your consultant?
Norman Lamb: For me, choice absolutely exists.
Q315 Rosie Cooper: Consultants as well?
Norman Lamb: Yes, and in a way the whole discussion about personal budgets is completely about that. It is about power or choice. It is about putting the person in control, and that must always be the mantra.
Rosie Cooper: Thank you. I have evidence in Liverpool where again “Choose and Book” is used to not get you to the consultant you wish.
Chair: No more questions from left field, right field or centre field. Thank you very much.
Written evidence from the Department of Health, NHS England and Health Education England (LTC 01)

Summary of the Evidence

— The Government is committed to improving care for people with Long-Term Conditions so that they are able to enjoy an independent, fulfilling life, and have the support needed to manage their health. The Secretary of State for Health has identified this as a particular priority area for action, so welcomes the Health Select Committees focus on this important area.

— Currently, approximately 70% of the health spend in England is on 30% of the population who have long term conditions (LTCs). The number of people with long term conditions is rising significantly and by 2016 there will be an additional cost pressure on the NHS of around £4 billion p.a. (2010 baseline). The majority of this cost pressure comes from continued unplanned use of acute hospital services. NHS England will need to work with partners to shift spend to support more primary and community based care and prevention.

— The mandate from the Government to NHS England sets specific objectives related to LTCs that NHS England must meet. Domain 2 of the NHS Outcomes Framework sets out an overarching indicator on LTC: “Health-related quality of life for people with long term conditions”.

— NHS England will work closely with Local Government as well as with other partners (including CQC, Monitor, Public Health England) to support Health and Wellbeing Boards, and Clinical Commissioning Groups in focussing on improving health related quality of life for people with long term conditions.

— There are good examples of best practice in commissioning person-centred coordinated (integrated) care for people with long term conditions, which are being shared through mechanisms in both health and social care.

— NHS England will focus on parity of esteem for mental and physical health services, whilst promoting service improvement that benefits people with long term conditions and multiple morbidities. Preventative strategies for long term conditions (including reduction in obesity, smoking, and alcohol consumption and increasing physical activity) are priorities.

— Personalised services, including care planning, along with patient education, shared decision-making, and personal health budgets improve the participation of people with long term conditions in planning their care in partnership with health professionals.

— Together with our national partners in care and support the Department of Health is working to break down barriers to delivering integrated care and support that offers the potential to make measurable improvements in patient and service user experience, outcomes and system efficiency.

The Challenge of Long Term Conditions

1. It is estimated that over 15 million children, adults and older people in England live with at least one long term condition (LTC).1 This figure is set to increase to around 18 million by 2025.2,3 People with LTCs are high users of health services. They account for 55% of all GP appointments, 68% of all outpatient and A&E appointments, and 77% of all inpatient bed days.4 Around 70% of the total health and care spend in England is associated with caring for people with LTCs.5

2. Overall prevalence is strongly linked to age. Only 14% of those under 40 report having an LTC compared to 58% of aged over 60, including 25% of over 60s having two or more. There is also a strong link to inequalities; compared to the highest social class (1), people in the lowest social class (5) have 60% higher prevalence of LTCs and 30% higher severity of conditions.6

3. The annual health and social care cost per person per year for a person without a LTC is £1,000, this rises to £3,000 for those with one LTC, and £8,000 for those with three.7

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3 Ready for Ageing? Select Committee on Public Services and Demographic Change Published 14 March 2013


4. Without changes to services, the costs of delivering care to people with LTCs will continue to increase. If there is failure to improve the prevention and management of care for people with LTCs it is estimated that by 2016 there will be an additional cost pressure on the NHS of around £4 billion p.a. (2010 baseline). The majority of this cost pressure comes from continued inappropriate and unplanned use of expensive acute hospital services.

**The New Health Structure, Mandate and Outcomes Framework**

5. The Department will work with NHS England, Local Authorities, Public Health England, Monitor, Health Education England and the Care Quality Commission to support continuous improvement in outcomes for people living with LTCs. The mandate from the Government to NHS England sets specific objectives related to LTCs that NHS England must meet. The NHS will work to support all people with LTC and their carers by:

   - Helping people feel supported to manage their own LTCs in partnership with their healthcare professionals to optimise their functional abilities and quality of life;
   - Reduce the time people with LTCs spend in hospital by promoting the co-ordination and continuity of care between local health care providers, local councils, community and carers organisations;
   - Lead the drive for a “parity of esteem” between mental and physical health services by ensuring more effective and equitable commissioning of services, including for people with mental ill health, those with learning disabilities and for people with dementia.

6. During 2012–13, Clinical Commissioning Groups (CCGs) set ambitions for 4 improvements they intend to deliver locally, including how best to support people with long term conditions. They will be held to account for the outcomes they achieve through the CCG Outcomes Indicator Set. Improving commissioning for people with LTCs will therefore form a vital element of CCGs work to secure efficiency and value for money and better outcomes for their patients.

7. Local public health services also have a major role to play in improving LTCs through actions such as reducing rates of smoking and obesity, and in tackling alcohol and substance misuse problems. These preventative activities are the responsibility of Health and Wellbeing boards and other partners such as Public Health England.

8. Health Education England is responsible for ensuring that the health sector has the right numbers of appropriately educated and trained staff to meet and care for the growing numbers of patients with LTCs in order to deliver high quality services. This will be reflected in the approaches to workforce planning as well as workforce development, education and training adopted by Health Education England.

9. Health Education England will be focusing specifically at the impact of the growing numbers of people with dementia and the provision of training for existing staff, not just the training of newly registered professionals. Training will need to affect providing support for families and patients to manage dementia, as well as preparing NHS staff to diagnose, treat and care for those with dementia. Training and development will need to focus on early diagnosis of symptoms and this will include training for staff to enable them to spot the early signs of dementia.

**Evidence on the Specific Issues Raised by the Committee**

The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness

10. NHS England will encourage CCGs to commission a broad range of services in order to manage people with an LTC outside hospitals.

11. Best practice supports early diagnosis of LTCs. This can help avoid patients presenting late as emergency attendances or admissions. Many of these admissions or attendances could be avoided with improvements to simple early recognition and response models, opportunistic and systematic identification of risk, and appropriate assessment, diagnosis and support for those with conditions sensitive to ambulatory care. Early diagnosis can also lead to better treatment and management and halt or slow progression of disease.

12. There is also accumulating evidence that properly coordinated and integrated care management can reduce use of acute services, especially for urgent care which is a major driver of cost. Pilots in Torbay, Greenwich, and Gnosall (Staffordshire) showed reductions in acute and/or social care usage. This mirrors the international experience with North American healthcare organisations which operate vertically and horizontally integrated care models, such as Kaiser Permanente and The Veterans Administration.

13. Integration of services will also require integration of records, either through patient-controlled records or through streamlined data-sharing in different care contexts. NHS England is prioritising the use of information technology and patient controlled records to enable patients to better experience coordinated care. Medicines
optimisation and increased involvement of the pharmaceutical profession in the delivery of services will also act to provide better community-based care. The innovation of risk stratification and “virtual wards” aims to identify patients before unnecessary admissions and provide appropriate assessment and treatment in the community.

14. To deliver this will require the right skills and capacity in community based health and social care services.

The readiness of local NHS and social care services to treat patients with long term conditions (including multiple conditions) within the community

15. Addressing the challenges presented by LTCs will require major changes in professional mindsets and behaviours and public attitudes.

16. Many patients with long term conditions can largely manage themselves with the right support and a few hours of contact each year from primary and specialist care. Self-management and education is encouraged as best practice in LTCs, working alongside assistive technology and practical support. For all, renal units in England now provide the option of home dialysis, allowing patients and carers greater flexibility in managing their treatment as well as reducing transport costs and reliance on health care providers.

17. The NHS will build on past and current work in order to promote good practice such as “Right Care” and enhanced recovery programmes which place the emphasis on patients’ health results (rather than the volume of services) and support clinical leaders to identify unexplained variation. These new models of commissioning and contracting can be used to facilitate a population-based integrated approach to commissioning services.

The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long term conditions

18. The 2010 Spending Review set out substantial funding, up to £1 billion per annum by 2014–15, which would be transferred from the NHS to local authorities to specifically benefit social care and improve health outcomes. The Government have made additional investments in priority services such as £300 million per annum between 2012–15 for reablement services and a £100 million one-off allocation to Primary Care Trusts in December 2012, for transfer to Local Authorities to help reduce delayed transfers of care. Whilst some of this funding has been used to maintain eligibility for social care, the majority has been used to support preventative measures, including integrated services, reablement and early discharge from hospital.

19. The national partners have formed an Integrated Care and Support Working Group including: the Department of Health, NHS England, Monitor, Public Health England, the Association of Directors of Adult Social Services, the Association of Directors of Children’s Services and the Local Government Association. The national partners are working together to co-produce a framework document on integration for publication in May 2013. The framework will include a focus on improving outcomes and experiences for individuals, the challenges facing localities, the national offer of support, and how we will monitor progress.

20. As part of this collaboration, the national partners are working to enable and encourage localities to innovate and experiment in ways that will deliver integrated and joined-up care and support at pace and scale. Together the national partners are developing the concept of “pioneers” who will act as exemplars to support the rapid dissemination and uptake of lessons learned across the country.

21. The NHS will have a clear focus on supporting integration and addressing the challenge of co-morbidities by using policy and commissioning levers to support management continuity and building on the GP practice to support relational continuity. The publication of the Common Purpose Framework and the development of NICE quality standards support this new approach.

22. The NHS will support the effective local commissioning of LTCs by:

— Working with Monitor to develop currencies and prices that support improved outcomes for people with long term conditions;
— Establishing successful networks and partnerships with the third sector, social care and user organisations;
— Supporting CCGs and other partners at local Health and Well Being Boards (HWB) to address the prevention of LTCs in partnership with Local Authorities and local community action.

23. Further, NHS England (with NHS Improving Quality) will work with commissioners and providers to spread existing best practice.
24. By way of example, in the Wirral 52% of urgent admissions were deemed inappropriate, and data indicated that GP referrals to hospital for urgent care and admission rates to residential care from hospital were high. An admissions prevention service was therefore initiated. Benefits of the service included:

- Improved service user assessment with goals and outcomes agreed with providers;
- A shift from bed-based services to supporting people at home;
- Better value for money by making better use of existing partnership resources.

25. In Lancashire, elderly people with mental health problems have access to intensive short term support to older people. This service dramatically reduced use of acute services and supported early discharge. The key feature of the model is that specialist staff from mental health work alongside care staff to role model best practice care.

26. A practice in Gnosall, Staffordshire, serving a population of 8,500, by taking a proactive approach to care of the elderly, has reduced predicted costs by £450,000 with fewer people admitted to hospital and those that were having reduced length of stay. This was attributed to the practice having implemented a comprehensive assessment and simple, agreed and person centred care plan confirmed in a letter shared with the patient and family.

The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions

27. Patients should not be seen as diagnoses or collections of conditions but as people living with these conditions. Increasingly people have co-morbidities, requiring input from a number of different health and care professionals; the health and care system needs to be geared up to support the whole person, considering their needs within an holistic context. This approach requires support from a whole range of stakeholders as it is a fundamental shift in emphasis from a disease focussed to a person centred system.

28. Clinical decision-making is more difficult in people with multi-morbidity because clinicians and patients often struggle to balance the benefits and risks of multiple recommended treatments (the use of polypharmacy in people with long term conditions brings accordant risk of medication errors and resulting injury or death), and also because patient preference rightly influences the application of clinical and economic evidence. The majority of people with an LTC have more than one, and individual levels of disability may vary irrespective of the number of co-morbidities identified (or the severity of illness). Recognising this variation in need is key to the delivery of personalised care.

29. The NHS will promote and support:

- The use of evidence-based assessment and holistic care planning across multi-disciplinary teams;
- Proactive identification of people at risk, or with additional LTCs, to encourage improved management;
- The deployment of staff skilled in motivational interviewing, shared decision making and the promotion of effective self-care, and the use of technology where appropriate such as telehealth and telecare;
- Integrated teams that work effectively together without the constraints of professional or organisational boundaries;
- The use of advanced care planning as a tool to reduce avoidable admissions and to enable more people to die at home.

30. NHS England will support the piloting of personalised, participative care planning, and learning from these pilots will be shared with CCGs and will contribute to the evidence base regarding the management of people living with multi-morbidities.

Obesity as a contributory factor to conditions including diabetes, heart failure and coronary heart disease and how it might be addressed

31. Obesity prevalence in England remains high. Approximately one in four adults and 1 in 5 children aged 10 to 11 are now obese. Obesity is a major risk factor, for example in men the risk in Type 2 diabetes (5 times relative risk), cancer (eg 3 times relative risk for colon cancer) and heart disease (2.5 times relative risk).

32. Tackling obesity requires a multi-agency approach at a national level and across local health communities. In October 2011 the Government published Healthy Lives, Healthy People: A call to action on obesity in England which sets out a national approach to tackling obesity and the role of key partners. The Call to action includes new national ambitions for a downward trend in excess weight in adults and children by 2020 and includes a commitment to help people improve their diet and to be more active, through key initiatives such as the Change4Life campaign and the Public Health Responsibility Deal.

33. Through the Public Health Responsibility Deal, businesses have signed up to pledges to reduce and cap calories, salt and trans-fats, and increase uptake of fruit and vegetables, as well as label calories when eating out. In addition, the Government is working with the devolved administrations to finalise details of the new
Front of Pack labelling system. This approach to front of pack nutrition labelling will help achieve greater consistency and clarity and help consumers make healthier food choices.

34. Other national programs for early identification of obesity include the National Child Measurement Programme and NHS Health Checks. Local Authorities have new powers and funding to help them meet their public health responsibilities. These include commissioning weight management services so that people receive the support they need to maintain a healthy weight and reduce their risk of developing long term conditions. Public Health England will support Local Authorities with their new role.

35. The NHS will contribute to tackling obesity and its associated inequalities by “making every contact count” and seeking to support healthcare users in making the necessary lifestyle changes. Primary care will play a central role in providing and signposting a range of integrated interventions, from purely preventative, through brief advice on weight loss, through to weight management services and ultimately surgery. Specialist commissioning for severe and complex obesity will enable appropriate and equitable access to bariatric surgery.

Current examples of effective integration of services across health, social care and other services which treat and manage long term conditions

36. Where localities have succeeded in integrating care and support, too often it has been despite the national system rather than because of it. This is why the national partners are coming together to tackle those barriers and allow locally-led integration to flourish. There are no “one size fits all” blueprints for integrated care and support models. Each locality needs to develop the right solution for their local population and circumstances. There are however a number of great examples of integrated care and support across the country:

37. One example is Torbay. Torbay was one of the first areas in the country to become a Care Trust and benefit from full structural integration of health and social care. “The Torbay model” is an early example of excellence, and of genuine innovation.

38. The Care Trust was created to remove the barriers that existed between health and social care services, and to deliver better and more coordinated outcomes for older people who are heavy users of local services. For each health and social care team, the focus is on knowing their population, concentrating on the most vulnerable, and managing their care in a proactive and multi-agency manner. This was achieved by co-locating staff and enabling them to work together, improving communication and arrange timely patient/client care. GPs became the single point of contact for all services. With a single assessment process created to reduce fragmentation, avoid unnecessary appointments and streamline access to health and care services. This enabled GPs to plan care packages for the most complex and vulnerable patients and coordinate discharge from hospital. Joint budgets were created which pooled funding between adult social care and NHS Community Services. This simplified decision-making, overcoming the issue about which service provider pays and “buck passing”.

39. Torbay adopted a unique approach by developing a notional/fictional character called “Mrs Smith”, a typical user of health and social care in Torbay. This helped professionals and managers to focus on how resources and services are being used to meet her needs.

40. The results of integration have had a significant impact in the local health and social care community. There is now strong evidence from a range of commentators, including the King’s Fund and Nuffield Trust, of improved performance over a range of indicators in the Torbay area, including:

- Reductions in emergency bed day use in the over 65s and over 75s.
- Delayed transfers of care from hospital have been reduced to negligible levels and this has been sustained over a number of years.
- Increase in the use of home care services and a decrease of people in social care funded residential and nursing home placements.

41. Torbay is widely regarded as one of a limited number of sites that have managed to implement whole system integration at pace and scale. This has been supported by innovative use of IT/information as well as multi-disciplinary team working and co-location.

42. In Lancashire, two local Clinical Commissioning Groups, a Community Trust, an Acute Trust and the County Council are working together to deliver integrated care and support and is based around four key themes:

- Risk Profiling of whole populations.
- Integrated Neighbourhood Care Teams that are multi-disciplinary and multi-agency.
- Self-Care/Shared decision making.
- Rehabilitation—whole system review and remodelling.

43. Based on national and international evidence the ambition is that this approach will lead to a 20% reduction in unscheduled admissions for people with long term conditions.

44. Dudley Council, working in partnership with Dudley Clinical Commissioning Group, has developed an innovative, integrated approach to the diagnosis, care and support offered to people with dementia (as well as to their carers and families). They have developed three “dementia gateways” located across the borough which
provide care and support for those affected by dementia, throughout all stages of the illness. Through attention to the individual needs and wishes of the individual the gateways ensure tailored care, as well as providing extensive support and advice for families and carers. The gateways aim to ensure those affected by dementia enjoy life to the full, and offer a wide range of sessions and therapies, from crafts and memory exercises to gardening. There are also day sessions available to provide a break for family and carers.

45. Essex is another one of the 4 national Whole Place community budget sites to be implementing at pace and scale. They are seeking to develop a Greater Essex integrated, commissioning approach across public services based on CCG boundaries.

46. The programme will focus on four key service cohorts:
- Long term conditions.
- Learning Disabilities.
- Dementia and Older People.
- Right to Control.

47. The ambition is to implement a single integrated approach that supports new commissioning entities across Essex and seven CCGs in the County. This will deliver an integrated service model which will reduce demand, improve care outcomes and share risk and benefit across the whole system.

48. Further examples of effective integration of services can be provided on request.

The implications of an ageing population for the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand

49. The House of Lords Select committee report on Public Services and Demographic changes—Ready for Ageing (published March 2013) comprehensively sets out the scale:
- The number of people aged over 75 is expected to grow from 5.4 million in 2015 to 8.8 million in 2035.
- The demand for hospital and community service spending by those aged 75 and over is in general more than three times the demand from those aged 30–40.
- It is estimated that under current funding arrangements total spending (public and private) on long term care for older people will need to more than double in real terms by 2030 to sustain standards.

50. The NHS reforms place clinicians at the heart of the new NHS system and provide them with the flexibility to focus on solutions which meet the needs of local populations. The QIPP challenge is on target to save £15 billion to £20 billion from 2011–14, and whilst there are difficult decisions ahead, the experience of service reconfiguration (such as stroke services) suggests that there is scope to free up resources to provide care in more efficient and more effective ways. Further, the sorts of local innovations in integrating services (detailed above) demonstrating how clinical communities, effectively empowered, can find ways to meet this challenge.

The interaction between mental health conditions and long term physical health conditions

51. People with a physical long term condition are two to three times more likely to experience mental health problems than the rest of the population. When people live with depression and another long term condition, this can reduce their ability to manage their conditions, and lead to poorer physical and mental health outcomes. Therefore, it is essential that an individual’s mental health needs are considered alongside other support.

52. The NHS is working towards more people with long term conditions and psychological comorbidities being able to access NICE recommended services and treatments.

53. The Improving access to psychological therapies (IAPT) programme, aims to improve public access to a range of psychological therapies for depression and anxiety disorders for people with LTCs. It includes psychological approaches to assist patients to increase their ability to undertake treatment and rehabilitation programmes, as well as promoting medicines and treatment adherence and self-management.

54. NHS England will promote parity of esteem for mental health (in line with No Health Without Mental Health) in all its mental health work streams, including the management of people with long term conditions.

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11 The Economic Case and Return on Investment for Stroke Reconfiguration. NHS Midlands and East Stroke Review—Compiled December 2012. Available at: www.eoe.nhs.uk/FdownloadFile.php?%3Fdoc_url%3D1335911136_VkbV_return_on_investment_generic_presentation.pdf&ei=nt4IfmIalAfi0afIqCQ&img=AFQjCN GyhMrW2ZKm6KmK65hr_2Fhj5g&sig2=a_TY0HrscOOGS9OnZgJyQ&bvm=bv.45645796,d.22k
55. People with long term conditions need support to understand and manage their health and wellbeing, to share decisions with professionals, and to self-manage. There is increasing evidence that when patients are involved in managing and deciding about their own care and treatment, they have better outcomes, are less likely to be hospitalised, follow appropriate drug treatments and avoid over-treatment. This requires a more personalised approach to care: one where people with long term conditions have more control of their health, and share decisions with health and social care professionals.

56. A range of tools are available to help individuals and their clinicians have a conversation where both understand what is important to and for the individual. Health literacy programmes help people understand more about their health and healthcare, and empower them to ask questions. A range of shared decision aids help people think through different treatment options and make informed decisions about difficult healthcare options (eg NHS Right Care shared decision-making tools). NICE guidelines recommend a “Rehabilitation Prescription” after episodes of critical illness, taking into account person-centred, measurable goals.

57. Personal health budgets are another way of giving people more control over how their long term health needs are met. They build on personalised care planning, knowing how much money is available to meet agreed health outcomes, and enables people to meet their needs in ways that work for the individual. They allow people to take a holistic, whole-life approach to planning, and facilitate integration across health and social care (personal budgets have been available for much longer in social care).

58. Personal health budgets are new to the NHS and early implementation is focused on people receiving NHS Continuing Healthcare (the majority of who will have at least one long term condition), who will have a right to ask for one by April 2014. CCGs will be able to offer them more widely on a voluntary basis to other patients who could benefit. One method of managing a personal health budget (direct—cash—payments) requires Parliamentary scrutiny before they become more widely available (The National Health Service (Direct Payments) (Repeal Of Pilot Schemes Limitation) Order 2013 was laid in Parliament on 22 April and will be debated in both Houses in due course).

59. Patient-accessible records, which are an NHS England priority, will allow greater personalisation of treatment plans and for patients to better understand their treatment and have a say in how their care is personalised.

Additional written evidence from Department of Health (LTC0114)

I gave oral evidence to the House of Commons Health Committee on Management of Long Term Conditions on Tuesday 12 November. During the session I offered to let the Committee see the advice I received on sharing information between commissioners and providers.

I have heard concerns about data sharing directly, for example at meetings to discuss the “Vulnerable Older People’s Plan”. I am also aware that commissioners cannot use information that identifies people and that this restriction is preventing them from commissioning and undertaking case management for people with learning disabilities or mental health, especially where there are concerns about the quality of care provided. These issues are also preventing risk assessment, risk stratification and case reviews by multi-disciplinary teams.

We have sought legal advice and the annex provides an overview of the advice we were given. My officials are working with NHS England on interim measures to allow commissioners to continue to work within the law and also on longer term solutions. NHS England is providing guidance as soon as the short-term solutions are agreed. We will be looking to publish guidance aimed at the wider service before the end of this financial year.

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13 Hibbard JH Green J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. Health Affairs 2013;32:2207–14
14 “Self-care reduces costs and improves health: the evidence”, Expert Patients Programme 2010
17 http://www.nice.org.uk/CG83
18 http://www.personalhealthbudgets.england.nhs.uk
19 Details of the personal health budget evaluation, can be found at https://www.phbe.org.uk/
OVERVIEW OF LEGAL ADVICE ON RISK STRATIFICATION AND CASE MANAGEMENT

The Department has worked with NHS England and others to identify and investigate the most pressing problems relating to use of data for commissioners including risk stratification and case management.

As indicated by Dame Fiona Caldicott in her report “Information to share or not to share: The Information Governance Review”, these activities can already be carried out within the current legislative framework, and neither primary nor secondary legislation are required at the current time to enable these commissioning activities to be carried out.

Working with commissioners, we have identified interim solutions for the immediate pressure points relying upon Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to provide temporary support for commissioners to access fully identifiable data.

The Department has taken leadership of this area and will be working with NHS England to ensure that long term solutions for these and other problems relating to data sharing are identified and implemented.

For risk stratification, commissioners should use information at population level to identify those who may benefit from intervention. It is for the GP or other direct care professional, rather than a commissioner, to make contact and access the relevant confidential patient data. NHS England has provided very detailed guidance on this and a revised version is expected to be made available shortly.

We have identified a number of options that deliver a long term solution for risk stratification. We are exploring with NHS England whether these and the solutions already being used successfully by some commissioners are transferable to other commissioning organisations. We will carry out further work to investigate the concerns about possible variations in access to information between health commissioners and social care commissioners.

For case management, consent is the best route to enable commissioners to receive personal confidential information. Where that is not possible (or may not be practicable), interim support under Regulation 5 to set aside the common law of confidentiality is required and NHS England is seeking this support for ex-Winterbourne View patients. Further applications for other patient groups will follow. It is also possible to use contracts to require providers to disclose information and NHS England will be leading work in this area.

We are seeking information and intelligence on case management from policy colleagues, NHS England and other stakeholders to explore options for permanent solutions.

28 November 2013

Supplementary follow up written evidence from NHS England (LTC0116)

I gave oral evidence to the House of Commons Health Committee hearing on Management of Long Term Conditions on 12 November 2013. During that session I offered to send the committee a note on the definition of frailty in patients. The National Clinical Director for Integration and Frailty, John Young, has kindly drafted a note. That note is attached.

NHS England will be continuing to work to ensure that there is greater understanding of the nature and importance of frailty and ways of addressing it proactively.

DESCRIPTION OF FRAILTY

Frailty is a distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves. This means the person is vulnerable to dramatic, sudden changes in health triggered by seemingly small events such as a minor infection or a change in medication. A person with frailty therefore typically presents in crisis with the “classic” frailty syndromes of delirium (acute confusion); sudden immobility (stuck in a chair or in bed); or a fall (and subsequent unsafe walking). There is a strong evidence base that rapid (within two hours) medical assessment, followed by specific treatment and a period of supportive and rehabilitation care, is associated with improved outcomes (lower mortality; greater independence; and reduced need for long-term care). Much of this urgent care response to frailty is currently done in hospitals by Geriatric Medicine departments (Geriatric Medicine is now the largest medical speciality in England). For example, there are over 640,000 hospital admissions for older people with frailty related falls each year. Increasingly, crisis assessment and management of older people with frailty is being done in the person’s home (“admission avoidance”). This requires the provision of dedicated, well led, multi-disciplinary community teams.

Frailty develops slowly over five to 10 years: so could more be done to help older people with frailty before a health crisis occurs? Older people with frailty can be readily identified and are usually well known to local health and social care professionals. They usually have weak muscles and also often have other conditions like arthritis, poor eyesight, deafness and memory problems. This means that frail older people typically walk slowly, get exhausted easily and struggle to get out of a chair or climb stairs. They are therefore more likely to become dependent on others for day-to-day cares and are at higher risk of future admission to a care home.
At present, however, we do not formally “diagnose” frailty or identify it with a specific “code”. This means systematic case finding and proactive care is difficult. Slow walking speed is a simple test that could readily help identify people who are frail. Taking more than 5 seconds to walk 4 metres is highly indicative of frailty. The primary care electronic health record contains large amounts of health data from which selected existing items could be readily brought together to form a “Frailty Index” to identify the sub-group of older people who have frailty, and to grade the frailty state. This would allow a structured self-management plan for people with mild/moderate frailty and case management (multi-disciplinary assessment and individualised care planning) for people with moderate/severe frailty.

5 December 2013

Written evidence from Dr Peter Fisher, Royal London Hospital for Integrated Medicine and Professor George Lewith, University of Southampton (LTC 07)

SUMMARY

— The rising prevalence of long term conditions (LTCs) is the greatest single challenge to public health in the UK. The main categories are psychological (including depression, anxiety and insomnia), musculoskeletal (including back pain and osteoarthritis), chronic pain (various conditions) and metabolic conditions (including diabetes). With advances in treatment, formerly life-limiting conditions including coronary heart disease and cancer are increasingly becoming LTCs.

— The most important correlates of LTCs are age and socio-economic deprivation. The most important complicating factors are multimorbidity (many people with LTCs have more than one) and polypharmacy (the use of five or more drugs at once with some drugs given to counteract the adverse reactions of other medicines). Polypharmacy is common in people with LTCs and associated with greatly increased risk of adverse drug reactions. Antibiotic resistance is often a consequence of polypharmacy.

— LTCs, multimorbidity and polypharmacy challenge the single disease model on which most current health care, best practice, research, and education is based.

— The effectiveness and cost-effectiveness of care for LTCs could be greatly enhanced by integrating Complementary Medicine (CM) and other patient-centred self-care and enabling approaches alongside conventional therapy. This is termed Integrated or Integrative Medicine (IM), defined by the Consortium of Academic Health Centers (53 centres in North America, including some of the most prestigious) as: “the practice of medicine that reaffirms the importance of the relationship between practitioner and patient, focuses on the whole person, is informed by evidence, and makes use of all appropriate therapeutic approaches, healthcare professionals and disciplines to achieve optimal health and healing”.

— There are a range of therapies and service models, but these approaches have in common that they are safe, increasingly of proven effectiveness, attractive to patients and cost effective in the community. They empower people with LTCs, improve symptoms, underlying disease processes and quality of life while reducing requirement for secondary care and drugs. We cite examples of successful NHS implementation of IM.

— There is a need for research and development on these interventions including their safety, effectiveness, modes of delivery and integration into NHS services.

The scope for varying the current mix of service responsibilities so that more people are treated outside hospital...

1. IM enhances individualised care of patients and facilitates therapeutic relationships centred on individual need. There is good evidence that it enhances the quality of both primary and secondary care, improves adherence to treatment, reduces emergency admissions and improves outcomes.

2. It is important that care is truly integrated so that secondary care, investigation or intervention is available if required, and to meet the needs of those have complex problems. Training, supervision and support of service providers are essential to ensure high-quality services and require a degree of centralisation.

3. A number of UK healthcare providers are fostering such initiatives. The Royal London Hospital for Integrated Medicine (RLHIM) is a centre of excellence and has developed a number of safe, evidence-based IM service models for LTCs in the NHS.

4. Service models include:

   (a) High volume group acupuncture clinics for various painful conditions have proven benefits including pain relief, reduced need for knee replacement surgery and cost savings to the NHS in both primary and secondary care.

   (b) Integrated services for chronic back pain, chronic fatigue syndrome and insomnia.

   (c) Programmes using mindfulness, relaxation, cognitive behaviour therapy, hypnotherapy and related approaches for variety of clinical conditions including cancer, anxiety, depression and
pre-clinical distress are of proven effectiveness. Many such programmes can be delivered through internet-based applications or DVDs/CDs with limited face to face contact. They enhance self-care, reduce polypharmacy and demand for NHS services.

5. There are many other areas of potential interest, for example:
   (a) Tai Chi appears to reduce falls in the elderly and improve symptoms of Parkinson’s Disease.
   (b) Aromatherapy may be helpful for behavioural and psychological symptoms of dementia. Antipsychotic drugs, sometimes used to treat such symptoms are associated with increased mortality.
   (c) Antibiotic resistance is now a major threat: herbal remedies may have potential to replace the need for antibiotics while homeopathy is associated with reduced use of antibiotics in children’s upper respiratory tract infections, an important source of inappropriate use of antibiotics.

The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions)....

6. Divisions between primary, secondary and social care are reflected in treatment of LTCs and multimorbidity. Expert assessment requiring specialised facilities is most effectively provided in secondary care, but treatment generally involves long term management and medical, social and self-care, most appropriately provided locally.

7. Even when there is clear evidence of cost effectiveness (as for acupuncture in a variety of chronic painful conditions) it is often not “heard” by commissioners.

8. Other examples include
   (a) An insomnia service incorporating online education and treatment resources, group and individual consultation provided by the RLHIM. Specialist back up is required for patients who have complex problems (for instance sleeping tablet dependency).
   (b) Penny Brohn Cancer Care has developed a Treatment Support Clinic for cancer patients undergoing chemotherapy and radiotherapy at the Bristol Haematology and Oncology Centre. This provides emotional and physical support and lifestyle advice. Evaluation shows an improvement in survivorship and self-help skills.

The practical assistance offered to commissioners to support the design of services....

9. NHS contracting arrangements can result in a lack of cooperation between commissioners, primary and secondary care providers. Limited, available information on IM is available to the commissioners and preference for existing local and conventionally based services makes it difficult for those offering an IM approach to LTCs.

10. The report of the recent EU research collaboration CAMbrella highlights the need for more comparative effectiveness research into IM. If we are to provide sustainable solutions to healthcare provision for an aging population suffering from LTCs we must examine the potential of IM rather than continuing to invest in specialised secondary care and increasing polypharmacy. There is promising preliminary data on the potential of IM, but without more detailed evidence expensive and inappropriate ‘managed’ choices for patients with LTCs will continue. Evidence must include informed patients’ perspective. Commissioners and patients should become active and informed stakeholders in the development of research strategy.

11. The RLHIM is has many years of experience and could be an important agent in supporting and advising on the design and implementation of IM, including training and Continuing Professional Development.

12. The cost-effectiveness of such services is greatly enhanced by close integration with NHS and social care. Difficulties in agreeing contracting arrangements between commissioners and care providers and lack of familiarity with IM have constrained wider provision of such services.

The ability of NHS and social care providers to treat multi-morbidities and the patient as a person...

13. The NHS is weak in the treatment of multimorbidity, which is now highly prevalent. NHS secondary care services are often specialised so there may be little holistic overview of the patient. Multimorbidity is frequently compounded by polypharmacy which, in turn, is frequently associated with adverse drug reactions. Fragmentation of clinical care through specialist services may result in lack of awareness of drugs prescribed by different doctors. 50% of UK care home residents take six or more drugs daily; this is associated with a very high risk of adverse drug reactions.

14. While attention has been given to reducing drug consumption (for instance by regular review of medicines, an area in which the UK is weak); much less attention has been given to developing and implementing effective non-drug treatments with long term safety and high patient acceptability.

15. Most complementary therapies treat patients rather than diseases. This means that several, nominally separate, conditions coexisting in one patient, may be targeted by a single treatment. This may be the result of
the patient centred approach or specific effects of treatment, or both. High quality clinical studies and qualitative research suggests that it is powerful and effective.

16. For instance a large study of acupuncture (18,000 patients) showed it to 50% more clinically effective than conventional care for painful musculo-skeletal conditions and headache and. Other studies show it to be cost effective.20

Obesity as a contributory factor to conditions including diabetes, heart disease...

17. Obesity is a very major contributor to these and other conditions such as arthritis and back pain. Obesity is best tackled in an integrated manner including dietary advice, lifestyle and psychological support across health and social care, combined with appropriate backup including bariatric surgery in extreme and intractable cases.

18. Specific dietary interventions are of proven value for various conditions including high cholesterol. Unlike drugs, their collateral effects are positive. Type 2 diabetes is associated with consumption of sweetened beverages (including “diet” drinks). Dietary interventions should be more widely used in the NHS.

Current examples of effective integration...

19. The College of Medicine supports, encourages and disseminates good practice this area.21 Examples of IM included in their innovations network include:

20. “Altogether Better” an evidence-based approach to engaging, training and supporting individuals in communities to become volunteer Community Health Champions. A preliminary evaluation of this approach suggested substantial social return on investment (SROI).

21. Wester Hailes Health Agency works within a disadvantaged community in Edinburgh. It offers a range of integrative services including green gyms, exercise, community gardening, time banking, complementary therapies and counselling.

22. Freshwinds Integrated Medicine Programme, based in the community in Birmingham provides integrative care for adults and children with life-threatening and life-limiting conditions. The multi-disciplinary team includes doctors, complementary therapists and researchers. Programmes include outreach CM for adults receiving end of life care and a “Personal Budgets” complementary therapies project for people living with LTCs. Interim analysis suggests a reduction in hospital admissions.

23. The Bromley By Bow Centre (London) and the Calm Valley Integrated Centre for Health (Devon) use Health Trainers and Facilitators. These programmes provide a wide range of activities from cooking classes to gym and dance sessions. The programmes also include IM approaches and specialist Health Trainer to support individuals with mental health needs.

24. A project led by Newcastle West CCG is moving away from a disease specific view of LTCs and is developing a social prescribing project. Social prescribing supports GPs to refer and encourage people to take up activities, instead of, or alongside their medical prescription, to improve the quality of life. This initiative should result in substantial cost savings in terms of prescription drugs, outpatients and hospital admissions).

25. Stockport Council is working with Pennine Care NHS Trust to redesign mental health services to discharge people from specialist services to supportive community alternatives. The new pathway is expected to reduce referrals to secondary care by 65%, discharge by 25% and re-presentation rates by 60%, with savings of £1,320–1,880 per patient.

26. Several charities have developed community programmes, for instance Age UK’s Fit as a Fiddle project is designed by older people for older people to help improve their physical health and mental well being. Savings to NHS have been calculated as £3.50–7.00 for every £1 spent.

The implications of an ageing population for the prevalence and type of long term conditions...

27. An influential paper published in The Lancet in 2012 showed that 23% of the population of Scotland is multimorbid, on average those aged 65 or over have two morbidities, those over 75, three. It concluded “Our findings challenge the single-disease framework by which most health care, medical research, and medical education is configured”.22 The single disease framework has delivered dramatic improvements in health care, so much so that it has become a victim of its own success, it has eliminated or controlled large swathes of human suffering. But applying it uncritically in the context of LTCs and multimorbidity may aggravate the situation.


28. There is a strong correlation between ageing, LTCs, multimorbidity and polypharmacy, the problem is compounded because older people are more susceptible to adverse drug reactions. Existing services will struggle to cope, segmentation of services, particularly when it results in excessive use of drugs, may aggravate the situation.

29. The CAMbrella report shows that IM provision within the EU is widespread but provision at best patchy and regulation poor. This is the case in the UK. Up to 50% of the UK population suffering from LTCs use CM. This has encouraged charities such as Arthritis Research UK to commission reports for patients on CAM as the majority of patients with arthritis are using CAMS in conjunction with their conventional care to self-manage their LTCs.

The interaction between mental health conditions and long-term physical health conditions

30. Poor mental health is strongly associated with physical LTCs, particularly in socio-economically deprived groups. Whole person approaches which do not view physical and psychosocial problems as independent and integration between health and social care an important in dealing with this. Psychological techniques including mindfulness, relaxation, cognitive behavioural therapy and hypnotherapy-based outpatients have been evaluated for various stages of chronic pain, irritable bowel syndrome, headache, asthma and several other conditions. These non-pharmacological self-care approaches have major and sustainable impacts. These techniques are simple to deliver through a combination of web-based interventions with minimal (but vitally important for adherence) face to face contact.

31. Application of such approaches to asthma is supported by preliminary evidence and is now the subject of a large NIHR-supported clinical trial.

The extent to which patients are being offered personalised services...

32. Individualisation, choice, respect for patient preference, cultural appropriateness and understanding of the bio-psycho-social factors that underlie chronic illness are key to successful management of LTCs, including cost and the quality of life of sufferers. A large volume of qualitative research shows the central role that IM can play. The value patients place on it is demonstrated by the high proportion of patients with LTCs who pay out of pocket for CAM. They are, in effect, creating their own models of IM. These could be provided more effectively if the models used were evidence-informed and in cooperation of health professionals. Regrettably many patients do not tell health professionals about their use of CAM as they believe them to be poorly informed and sceptical.

33. Apart from reflecting a regrettable lack of trust between patients and health professionals, this could be dangerous: for instance St John’s Wort, an effective and widely available herbal antidepressant, interacts with many drugs. The value that patients place on an open and supportive attitude from health professionals is highlighted by the fact that the RLHIM has among the most positive patient feedback of all NHS hospitals.

3 May 2013

Written evidence from Dr Sue Roberts (LTC 11)

ON BEHALF OF “DELIVERY SYSTEM GROUP”23 AND YEAR OF CARE PARTNERSHIPS

SUMMARY

This submission describes an unique opportunity to bring together all the ideas and expertise about Long term conditions (LTCs) around a practical, reproducible and transferable approach to providing better services and better support for people and their families who live day to day with these conditions. This is outlined in a Delivery System designed around personalised care planning and integrated care which focuses on culture change as the driver for system change.

1. LTCs are now the commonest cause of death and disability in England and people who live with LTCs are the biggest users of services and greatest generator of costs. Despite a robust evidence base, and compelling economic case, there has been little improvement over the last 10 years.

2. Many of the elements needed to support change have been developed but are fragmented.

3. On 19 March 2013, 44 individuals and organisations working on various components of the LTC agenda came together at the Kings Fund in an event co-sponsored by Anna Dixon (Director of Policy at the Kings Fund) with Martin McShane (Director of Domain 2, NHS England) to review current activity and pledge to work together to support a joined up “Delivery System” (DS)24 as a starting point for local communities to design “a better way of working”.25

23 The Delivery System convening group: Alf Collins, Simon Eaton, Jim Phillips, Sue Roberts

24 Convening document: “Delivering better services for people with LTCs—getting on with it!” (attached);

25 The Kings Fund event is being written up as a Report.
4. A convening group is developing a “hub” for this “coalition of the determined” to act as a source of consistent messages, and practical support, including training, to enable local commissioners and providers “to get on with it”. This group includes the People Powered Health (PPH) Programme led by NESTA which has similar aims; that all people with LTCs gain the knowledge, skills and confidence and receive the coordinated support they need to live more comfortably and effectively with their condition/s; and the NHS can benefit from the financial savings associated with this new way of working.26

5. A unique feature of the DS is that while it provides a common framework this delivers a tailored, personalised package of care and support for each of the 15 million people with one or more LTCs.

6. The barriers to be overcome in making this widely available include changing attitudes amongst health care professionals, which can be addressed by the training and support included within the DS itself; and fragmented commissioning for LTCs which would benefit from coordinated national policy.

**BACKGROUND**

7. It is important to recognise that LTCs which at present cannot be cured can be prevented and ameliorated by changes in behaviour and community support as well as by drugs and traditional therapies.

8. Organisations which represent service users emphasise five key issues. These are coordinated (integrated) care, patients engaged in decisions about their care, support for self management (SSM) linked to better prevention, early diagnosis and clinical care with emotional, psychological and practical support. These elements need to be wrapped up in a culture which places equal value on the lived experience of the person with the condition/s and the technical expertise of the health/social care professional.

9. Despite a strong evidence base for supporting personalisation services, people are not involved in their own care as much as they want to be. Less than half of those with diabetes report discussing their own goals or developing a plan;29 less than 40% with multimorbidity, feel confident to manage their own condition.30

10. Current service configuration is designed around the traditional need to treat, cure or palliate and has been too slow to accommodate change.

11. Nearly half of all those with LTCs have more than one condition (multimorbidity). In the recent past the focus for delivery has been on those (5–10%) who are individually at highest risk of emergency admission and greatest NHS spend. However the greatest number of emergency admissions comes from the much larger pool of those with multimorbidity who are at an earlier stages of their condition/s, where prevention of complications and deterioration may be possible through care planning and by effective self management. It is short sighted as well as inefficient to concentrate effort on these individuals at highest risk; a common approach will benefit everyone with the added potential of increased penetration and sustainability of system wide culture change.

**THE DELIVERY SYSTEM**

12. The DS is built on the learning from the Year of Care (YOC) programme, sponsored by the Department of Health, and using diabetes as an exemplar for all LTCs. The approach puts people with LTCs firmly in the driving seat of their care and supports them to self manage. It transforms what is often “tick box” care encouraged by the QOF system into a constructive and meaningful dialogue between the healthcare professional and the person with diabetes. Adapting this to other LTCs, the DS includes:

   — A collaborative care planning consultation for everyone including shared decision-making, which brings together the individual’s and the professional’s perspectives and expertise, encompasses all the individuals’ health issues and supports the individual to identify their own information needs, goals and action plans.

   — Sign posting to a range of local services, including telehealth, that people need to support their goals and actions via social prescribing, described by PPH as “more than medicine”.33

   — Coordination/integration of any additional clinical and social input required from integrated multidisciplinary teams (MDTs).

26 http://www.nesta.org.uk/areas_of_work/public_services_lab/health_and_ageing/people_powered_health/assets/features/the_business_case_for_people_powered_health


30 QIPP LTC Programme 2011 : Personal Communication

31 Roland M and Abel G. Reducing Emergency admissions; are we on the right track? BMJ 2012;345:e6017 doi: 10.1136/bmj.e6017


13. The YOC sites recognised that this new way of working cannot happen within the current constraints of time, clinic organisation and workforce design. They arranged the issues that need to be addressed in a “House of Care” as a guide for those that wish to introduce this new way of working.

— The “walls”, “roof” and “foundations” act a checklist of what needs to be in place. The left wall emphasises the informed and empowered patient and the right wall the health care professional committed to partnership working. The roof indicates the local processes that need to be included and the foundation is formed by commissioning tasks.

— The “house” also acts as a metaphor emphasising that all components need to be in place if care planning is to be embedded and sustained. This was recognised in the training programme, now delivered to over 3,000 professionals via quality assured trainers, which challenges attitudes, and develops new skills while encouraging participants to “build their own house”.

This has enabled the basic intervention (personalised care planning) to be transferred to other health communities, and other single or multiple LTCs in a reproducible way.

14. This approach works for people with low health and language literacy thus reducing inequalities, acknowledging that those with poor “activation” may need additional support. It provides a generic approach adaptable to prevention (“Health checks”), to people with complex bio psychosocial needs or Personal Health Budgets, who are frail or are approaching the end of life. This common way of working and training leads to economies of scale for practices and teams.

AN EXAMPLE FROM DIABETES

15. In Tower Hamlets (TH), an area of high deprivation and ethnic diversity, the indices for diabetes care were amongst the worst 10% of PCTs in 2005. By March 2012 TH reported the best in England.

16. Care planning became the norm for people with Type 2 diabetes (March 2012). Ninety five per cent had had at least one annual care planning consultation and 40% more than one. Uptake of the nine key elements assessed in the National Diabetes Audit improved dramatically. Ninety six per cent of people had the three “traditional” components of diabetes care (HbA1c, BP and cholesterol) measured and 74.2% had all nine components recorded. This value is the highest reported in England (average 54.3%). Clinical indicators also improved; the proportion of people with good control of all three indicators for development of diabetes complications increased from 24% to 35% (England average 20%).

17. Improvements in patient experience, job satisfaction, and practice organisation were directly observed. Positive answers to the question “I have had about the right amount of involvement in my care” rose from 52% in 2006 to 82% in 2009.

18. Patients and staff reported shifts in behaviours; “Each time I get a greater understanding of my condition and understand more about how I can get about maintaining and improving it”. (Person with diabetes). “YOC is a great idea because it is focused on the individual. I'm happy that I get more of a say in my care.” (Person with diabetes from Bengali community); “Care planning has made me look at patients differently. I understand more about how I can go about maintaining and improving it”.

19. The Public Accounts Committee recently reported that the processes and outcomes of care in diabetes are not consistently provided to an adequate standard. The example from TH demonstrates that this can change. It also illustrates that providing improved clinical care for people with diabetes is not a separate challenge from providing tailored support to self manage for each individual. They are part and parcel of the same approach, with economies of scale for practices, teams and training.

OBESITY, MENTAL HEALTH AND AGEING

20. While there is a large literature supporting a multipronged approach to reducing obesity which ranges from addressing the obesogenic environment to surgical solutions, obesity is essentially a behavioural issue.

— Care planning ensures that the opportunities to address individual behaviour during routine contacts with the health service by people who are obese, at risk of becoming obese or already have complications are used in the most effective way.

21. Physical and mental health conditions are inextricably linked for people with LTCs.

— People with enduring mental illness carry an enormous burden of physical ill health. Currently care is fragmented and poor. Care planning provides systematic, regular review mirroring the principles of “recovery” pioneered in mental health services, but which could be carried out by primary care teams already trained to provide this for their registered population.

34 Health and Social Care Information Centre. National Diabetes Audit 2010-11
35 House of Commons: Public Accounts Committee; 17th Report—Department of Health: The management of adult diabetes services in the NHS. HC 289. 6 November 2012
— When physical health issues are the primary diagnosis depression is two to three times more common compared to those with no health issues as a consequence of their condition/s and the therapeutic challenges this poses for themselves and those they live with. This can be exacerbated by lack of information, or the way information is provided at diagnosis or routinely, but it can be ameliorated by appropriate skills and behaviour on the part of clinical staff and the way services are organised. Care planning ensures that care from diagnosis onwards is provided in such a way as to prevent mental health issues developing or at the very least avoids exacerbating them.

22. **Aging:** The current focus on “multiple LTCs” and “co morbidities” can lead to confusion with specific issues of ageing.

— Ageing needs to be seen as a process. People pass through stages of “preparation” for old age, “active” old age, and “vulnerable” old age and “dependant” old age. Regular care planning for people with LTCs as they enter the phases of “preparation” and “active old age” can help to emphasise prevention. For instance if the onset of dementia can be delayed by five years (by physical activity) the prevalence is halved. \(^{37}\)

— A LTCs strategy should incorporate a systematic approach to these stages, with better prediction tools for each stage as part of local end to end pathways.

**CAN THIS NEW APPROACH BE IMPLEMENTED AT SCALE?**

23. The learning from the YOC Programme suggests that making change needs a whole system approach. Two main issues (health professional attitudes and joined up commissioning) both need to be addressed to enable the service to capitalise on the opportunities the DS provides.

24. The YOC team found repeatedly that new skills and ways of working cannot be embedded or sustained without new ways of thinking.

— Working with “patients”: Sixty percent of GPs do not endorse people being independent decision makers, \(^{38}\) still seeing their role as “doing to” rather than “doing with”. These attitudes can be challenged and changed by quality assured training with positive outcomes for all. Links with the Royal Colleges and Health Education England provide an avenue to review training capacity.

— Working with colleagues: Overcoming the concerns of specialists about the quality of primary care is essential for progress. YOC sites found that local care planning training identified the need for closer work with specialists which could be commissioned and built confidence. Practice nurses, currently doing the majority of care for people with LTCs, had no basic training in consultation skills and nurses and social workers in integrated MDTs remained uncomfortable about working across professional boundaries.

25. **Commissioning and resources:**

— Care planning stimulating new ways of working within GP practices. Overall the changes in skill mix and roles were cost neutral. But there were transition costs and extra resources needed for disadvantaged populations.

— New ways of working by specialists are equally important to support primary care in their new roles. The current configuration of consultant job plans and inflexible use of the tariff were major barriers to this.

— There is little incentive to change while commissioning for LTCs remains fragmented at local and national level.

— The main services that people with LTCs need are commissioned by different routes; care planning in primary care via NHS England (NHSE) using the GP contract; better use of community services to SSM via Health and Wellbeing sBoards; and specialist care when necessary by Clinical Commissioning Groups. The lack of integration of Health and Social care is recognised.

— Centrally, the main components of a LTC Strategy are the responsibility of different parts of NHSE and Public Health England.


**Conclusion**

26. The DS provides a starting point for a “new deal” for people with LTCs built on a new relationship between the individual and the healthcare professional and better use of primary care and community resources. There is willingness by senior leaders to endorse this. This needs to be matched by a coordinated national policy which understands the issues and the importance of integration and service and workforce redesign to support this new way of working.

27. I would welcome the opportunity to describe this important new initiative to the HSC in person.

7 May 2013

**Annex**

**DELIVERING BETTER SERVICES FOR PEOPLE WITH LONG TERM CONDITIONS (LTC) — GETTING ON WITH IT!**

The aim of the current initiative is to bring together all the expertise across the “LTC Landscape” (a coalition of the willing) around a Delivery System as a starting point for comprehensive change; led by the people involved (service users, policy makers, academics, practitioners, Colleges, trainers, service providers etc) and offering those “on high” a chance to help to make it happen more easily.

**Background**

Chronic diseases are now the commonest cause of death and disability in England and people who live with long term conditions (LTCs) are the biggest users of services and greatest generator of costs. It is now recognised that the care and support needed to live with a LTC is fundamentally different to that for acute episodic conditions, and that this will require services for people with long-term conditions to be radically redesigned. However, despite exhortation from people who live with LTCs, consistent health policy, a robust evidence base and a compelling economic case, progress on the ground has been painfully slow with little improvement over the last 10 years.

Many of the elements needed to support change in England have been developed, drawing on international best practice, but they remain fragmented. Top down exhortation and targets have failed to influence change and clinical behaviour at the grassroots. The missing component, which is a practical, robust, reproducible and transferable delivery system developed by practitioners and service users in England is now available.

**Key Issues**

The Delivery System is described below. Some of the key issues it addresses include:

- **People who live with long term conditions are central** to the process. They are involved in articulating their own needs and deciding on their own priorities, supported by health and social care professionals through a process of information sharing, shared decision making and action planning.

- **Support self management (SSM)** and the development of **partnership relationships** between people who live with LTCs and health care professionals is at the heart of service delivery. This shifts the focus onto the roles and responsibilities of both, and the systems that are needed to support them. The ultimate aim is that people should have the knowledge, skills and confidence to manage their condition effectively in the context of their everyday life.

- The Delivery System can help to **reduce inequalities**. The number of LTCs and their burden falls disproportionately on those with poor health literacy and in lower socioeconomic groups. Tools, skills training and ongoing support in a variety of formats are available to identify both those who find it harder to engage with health issues (low levels of “activation”) for whatever reason, and who will need extra support.

- The Delivery System not only brings together well planned and coordinated specialist support but is based on a generic approach. This ensures that each individual is involved in a **single, holistic care planning process** with a single care plan. The common set of relevant skills and processes involved also reduces the burden of training.

- **Quality assurance** of the philosophy, core approach and skills is essential to ensure that implementation both builds on relevant evidence and experiential knowledge and ensures that the intervention is delivered consistently increasing the likelihood that it will lead to the impact expected. “While the case for SSM is strong not all reported SSM interventions are effective.”

- Care planning is the **gateway to personalisation** and/or personal health budgets.
THE COORDINATED DELIVERY SYSTEM FOR LONG TERMS CONDITIONS

The delivery system provides a robust, systematic and reproducible approach, transferable to any setting and for people with any single or multiple LTCs, including multi morbidity which ensures that each person receives a uniquely personalised service bringing together support for self management with high quality clinical and social care, delivered in a systematic, coordinated and high quality manner.

The two part delivery system includes a guide to the components and a quality assured approach to implementation:

THE COMPONENTS

— A collaborative care planning consultation for everyone including shared decision-making, which brings together the individual’s and the professional’s perspectives (agendas) and expertise, encompasses all the individual’s health issues and supports the individual to identify their own information needs, goals and action plans.

— Access to a range of local services people need to support the goals and actions they identify, including social prescribing.39

— Coordination of any additional clinical and social input/support required from integrated multidisciplinary teams.

CARE PLANNING

— Care planning is a proactive intervention with the frequency of care planning consultations being determined by the interaction between systematic interrogation of practice and disease registers (“population risk stratification”), and individual needs (agenda) identified in dialogue between the person, the health professional and relevant carers. The frequency, style, intensity, place, person and finances for follow up (in intervals between care planning consultations) are determined during the care planning process itself.

— Individual care planning is a three step process of preparation (reflection by the individual on relevant test results and/or prompts—collation of health issues by the professional), the consultation itself (identifying information needs, goals and action plans, and explicit arrangements for follow up), with summarising and recording.

— This usually cannot be carried out without changes to the culture and infrastructure of care, thus driving change.

39 Social prescribing is an “unfortunate” term in common use for referral to non traditional community services to support self management such as exercise “on prescription”.
The Year of Care “House” model describes the issues which each team will need to address to make care planning possible.

The “House” model reinforces the whole-system approach and acts as both a metaphor and an implementation checklist.

As metaphor, it emphasises the interdependence of each of the elements, protecting and enabling the new clinical consultation. If one “wall” is weak, the structure is not fit for purpose.

As a checklist, it provides a reproducible and flexible mechanism to identify the essential processes and systems which promote engagement and clarity across clinical teams, stimulating reflection on the “building blocks” available locally and areas that may need prioritisation for improvement.

Implementation

The delivery system invites local services to work through the “house” for the particular health/social care setting relevant to their particular population, ensuring that attitudes, skills and infrastructure are all addressed together by using a quality assured approach leading to culture and system change. Importantly, the care planning consultation is in the centre of the house; local services need to ensure that all of the elements of the house are reliably in place for every care planning consultation.

This will involve:

— Acknowledging the philosophy and principles of systematic support for self management (the driver of the delivery system).
— Identifying accountable leadership
— Identifying the population involved (“risk stratification”).
— Identifying the capacity of individuals to engage in the processes; supporting them to do so.
— Identifying the multidisciplinary/integrated delivery teams involved and the roles and responsibilities of team members in order to ensure that care is co-ordinated.
— Using available evidence-based and quality assured interventions.
— Identifying metrics, methods of collection, analysis and feedback; to drive improvement.

Alf Collins, Simon Eaton, Jim Phillips, Sue Roberts: with thanks to all those who have contributed
Written evidence from Pharmaceutical Services Negotiating Committee (LTC 43)

Pharmaceutical Services Negotiating Committee (PSNC) promotes and supports the interests of all NHS community pharmacies in England. We are recognised by the Secretary of State for Health as the body that represents NHS pharmacy contractors. Our goal is to develop the NHS community pharmacy service, and to enable community pharmacies to offer an increased range of high quality and fully funded services; services that meet the needs of local communities, provide good value for the NHS and deliver excellent health outcomes for patients.

PSNC is pleased to be able to submit a response to the Health Committee’s inquiry into the management of long-term conditions. In summary PSNC believes that:

- To cope with the ongoing pressures on the health service such as the increasing number of patients with long-term conditions, the NHS requires a third pillar to support the pillars of secondary care and GP-based primary care, and community pharmacy must be at the heart of this third pillar.
- Community pharmacies already play a key role in helping patients with long-term conditions to get the most from their medications.
- There is more that community pharmacy can do, and the routine care of many patients with long-term conditions should shift to pharmacies, freeing up GPs to manage patients with more complicated or multiple conditions.
- Through the provision of healthy living advice and public health services, community pharmacies can help patients with long-term conditions to live healthier lifestyles and so reduce the risk of further health complications.
- To enable community pharmacy to extend its role, key barriers such as territorialism between professions and pharmacies’ limited access to patient records must be overcome.
- The use of national service templates and specifications could be a useful tool to support commissioners as they plan care for patients with long-term conditions.

The Ageing Population

1. NHS services are stretched more than ever before at the moment under the combined pressures of financial constraints and increasing demand for services. And with the patient base only set to expand further as the population ages and long-term conditions become related to unhealthy lifestyles, increase in prevalence, the challenges are not set to go away.

2. The scale of the challenge is clearly illustrated by a report by the Nuffield Trust published last year (A Decade of Austerity), which estimated that unless health funding could increase beyond inflation the NHS is set to face a funding gap, by 2021–22 of around £50 billion. Improved productivity of 4% per annum across the NHS reduces the deficit by around 40%, but that is a massive demand and still leaves a large funding hole.

3. PSNC believes that the NHS can, and must, meet these challenges. But it will not happen without radical thinking and a commitment from all healthcare professionals to play their part. And PSNC believes that it will not happen unless community pharmacy is used effectively to play a key role in supporting patients to lead healthy lifestyles and take the most of their prescribed medicines and the care available to them. By reshaping the community pharmacy service, large savings in NHS resources and improvements in health outcomes can be made.

4. GPs are fully employed dealing with ill-health and the administration that surrounds it. We therefore urgently need a new, 3rd pillar, to support the pillars of secondary care and GP-led primary care, and the community pharmacy network is the foundation of that pillar. In the 3rd Pillar model the community pharmacist and their team supports the patient in self care. For long-term conditions centrality of supply of medication gives way to taking responsibility for ensuring the patient uses medication appropriately and effectively. The GP will normally diagnose and initiate therapy, but the community pharmacist takes responsibility for ensuring the patient gets the best outcomes and identifies any changes to therapy that may be needed.

5. The routine care of millions of patients shifts to the pharmacy, where it can be accessed more conveniently, and more cheaply, and patients have a range of providers from whom they can choose. The “bricks and mortar” pharmacy service is supplemented by telephone, internet and where necessary, domiciliary support.

Treating People in the Community: Exploring the Role of Community Pharmacy

6. For most patients with long-term conditions, medication plays a key role in the management of their condition and in maintaining their quality of life. Community pharmacies can play a key role here through medicines optimisation services such as the Medicines Use Review (MUR). The role of the MUR in helping people understand their medication and its effects is an important contributor to the goal of having people fully engaged with their own health—the Wanless objective. But lack of engagement by PCTs and GPs with the MUR service and the absence of effective targeting combined with lack of robust data capture and outcomes research has been problematic. The introduction last year of nationally agreed target groups and data capture requirements have started to help address these shortcomings. Research into respiratory MURs conducted on
the South Coast provided strong evidence of improved control of patients’ conditions and the correlation between the service and reduced hospital admissions.

7. In future iterations of medicines optimisation services we should focus on the patient groups for which medication problems lead to expensive episodes, primarily hospitalisation. This is where the pharmacy service, properly used, can achieve real cost savings for the NHS, and convenient care for patients with long-term conditions. Ensuring blood pressure levels are monitored, ensuring inhalers are being used properly, ensuring that, so far as possible, patients do not give up on medication regimens prematurely but get optimal health outcomes.

8. These groups—those with high hospitalisation rates—form the eligibility cohort for the New Medicine Service, and its’ introduction has been far smoother: through implementation of MURs pharmacists had gained the skills and confidence to offer the service, and we worked with GPs in advance, to get their support.

9. The gains from these services will come from improved adherence to people’s medication regimen, leading to reduced numbers of complications for patients and to fewer avoidable costs from GP consultations and hospital admissions. Early analysis of the NMS recorded using the PharmOutcomes platform shows significant gains in adherence, as indicated by the initial research that underpinned the development of the service.

10. PSNC believes that there is great potential for community pharmacy to extend services like these, which enable pharmacists to deliver interventions at certain points in patients’ care, and move from delivering episodic care to providing more longitudinal care for patients. Some areas have piloted this sort of ongoing care very successfully, such as the respiratory MUR programme which saw pharmacies offering asthma patients follow-up MURs to improve their management of their conditions.

11. There is much more that pharmacy could do beyond asthma, but a key barrier to the extension of pharmacy’s role has been resistance from other healthcare professionals and we believe focusing on one disease area like this could serve a dual purpose in boosting the sector’s confidence in dealing with patients on a regular and long-term basis, but also in giving other professionals confidence in pharmacy’s ability to manage patients on this basis working in collaboration with other healthcare professionals.

**Multi-morbidities and other Contributory Factors**

12. In this response we have focused on the role the community pharmacies could play in providing the ongoing routine care for patients with single or uncomplicated long-term conditions. However, this would have implications for those with more complicated conditions as it would free up GP time enabling doctors to deal more effectively with those patients with multiple conditions.

13. Where other lifestyle factors are having an influence on patients with long-term conditions, community pharmacies are also well positioned to help. Many community pharmacies are routinely offering healthy living advice and services to help patients with a range of issues such as managing their weight, stopping smoking, or understanding alcohol consumption. Community pharmacies were involved in the regular care and management of patients with long-term conditions they would tie this healthy living advice in to their patient consultations to help patients to live healthier lives and so reduce the chance of further complications with their conditions.

14. Some pharmacies are also offering this support through the Healthy Living Pharmacy (HLP) framework which was developed and launched in Portsmouth in December 2009 and led to quality and productivity improvements in community pharmacy with better access to health and wellbeing services for the public. As well as committing to and promoting a healthy living ethos, one of the distinctive features of a HLP is having health trainer champions (specially trained pharmacy staff, who are trained in behaviour change techniques and giving healthy living advice)) on site. HLP community pharmacies in Portsmouth exceeded the PCT’s stop smoking quit target by 138%, achieving 664 quits at four weeks for the year 2010–11. Evaluation results indicate that a person walking into an HLP in Portsmouth is twice as likely to set a quit date and give up compared with a person walking into a pharmacy which is not an HLP. Twenty sites have recently been evaluated to see if the outcomes from Portsmouth could be replicated in different demographics and geographies and the evidence that they could was extremely positive. Today there are over 400 HLPs and 1000 healthy living champions in place. Expanding this type of service could make a very real difference to the health of both the general population and those patients with long-term conditions.

15. For patients with multiple conditions, a range of care delivered by a range of healthcare professionals is likely to be required, and this will be a challenge for the NHS as many patients still do not receive consistent and efficient care when they have to deal with more than one health organisation. Patients going into and out of hospital often end up with duplications in their medicines, with primary care professionals unaware of any care they have received in hospital.

16. To address this and other problems, NHS care pathways need to be designed to ensure seamless care across organisations—the patient journey must be at the heart of these pathways, and they must promote the use of the most appropriate providers and facilitate the transfer of information between health organisations. The radical changes currently being made to commissioning and the provision of health services may provide a good opportunity to examine local care pathways more closely to ensure this across all commissioned services.
17. We have set out here a vision in which community pharmacy could take on the routine management of many patients with long-term conditions. If this vision is to be achieved, several barriers will need to be overcome.

18. A key barrier preventing pharmacy from improving patient outcomes across long-term and other conditions has been the limitations of local service commissioning—this has been patchy and inconsistent meaning patients in some areas have not been able to benefit from high quality pharmacy services. The NHS reforms and emergence of new commissioners present a chance to rectify this, but we believe commissioners will need national direction and support.

19. PSNC believes national service specifications and agreements improve efficiency in the health service by preventing duplication of work, and they improve the outlook for all patients by reducing the chance for inequalities in services to develop. For local commissioners, having national systems and directions in place to inform the services they should commission can have a similar effect. PSNC has previously worked with the Department of Health on such specifications and hopes to do so in with the new commissioning organisations of the reformed NHS also.

20. Public Health England in particular could also play a key role in collating the evidence base for public health focussed services and the impact they can have to inform commissioning.

21. The PharmOutcomes system now being used by some commissioners in primary care could also a useful tool for some commissioners. This IT system enables community pharmacies to record the services they give to patients, noting any patient interventions and outcomes, so that commissioners can clearly see which services are being provided and what effect they are having. This could be a useful aid for those wanting to monitor the effectiveness of community pharmacy services or for people wanting to monitor the care being given to patients with long-term conditions.

22. The government and national health organisations also have a key role to play in the removal of regulatory barriers to better care and in tackling the territorialism that so often blights successful working relationships between professional groups. Tying contractual frameworks together to incentivise more efficient care and sharing of work is likely to be crucial to this. For example, by adjusting the General Medical Services contractual framework the NHS has the power to shift some patients with long-term conditions away from GPs and into pharmacies and self care. It could then also ensure that GPs are fairly rewarded for taking some of the secondary care workload away from hospitals.

23. Without this oversight and intervention from above, encouraging GPs to manage patients’ long-term conditions in partnership with community pharmacies, achieving our vision for the third pillar may always be a struggle.

24. Aspects of pharmacy practice are also in particular held back by regulations. Decriminalisation of dispensing errors could help to incentivise pharmacists to delegate certain tasks to staff, leaving the pharmacist time to deliver medicines optimisation and other services for patients with long-term conditions.

25. And pharmacy must be more effectively integrated into the rest of the health service—making patients the gatekeepers to their own medical records so that those being managed by community pharmacies could choose to make their information accessible to those pharmacies would ensure that pharmacies were aware of any other care being given to patients, and any potential health problems, and tailor their care to better meet their needs.

9 May 2013

Written evidence from Dr Karen Lowton, King’s College London (LTC 49)

1. This submission focuses on one of the issues the Committee wishes to examine: the implications of an ageing population for the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand. The submission gives evidence on:

— The rise of “new” ageing populations (NAPs) and associated long term conditions.
— Psychosocial needs of these populations.
— Professional careers and service provision for NAPs.
— Prescription charges.
— Research and recommendations.

INTRODUCTION

2. The notion that population is ageing is leading to an increase in long term conditions (LTCs) which are commonly experienced by older adults has been well rehearsed. However, there are “new” ageing populations
(NAPs) whose growth is mirroring that found in general population ageing: those born with serious health conditions who did not previously survive to adulthood and those developing previously life-limiting conditions in early or mid-life who are now more likely to reach mid- to late-adult life. These NAPs include adults with cystic fibrosis (CF), congenital heart disease (CHD), childhood liver disease (CLD), cerebral palsy (CP), human immunodeficiency virus (HIV), and Down syndrome. These populations are on average younger than those we traditionally conceptualise as the ageing population, yet as they age they are experiencing many of the LTCs found among the older population, but at a much earlier age.

3. The Department of Health’s definition of LTCs acknowledged that the life of an individual with a LTC “is forever altered—there is no return to ‘normal’”.40 Here the emphasis is on the more common conditions that are acquired in later life such as diabetes, coronary heart disease and stroke, and assume that there has been a period of “normality” in early life. For many NAPs, there is no earlier period of “normality”.

4. In 2010, the Chief Medical Officer emphasised that rare conditions (which underlie the health problems of many “new” ageing individuals) are an important cause of illness and death, yet do not currently receive the attention they need and deserve41. However, this terminology leads us to consider people with rare conditions separately from those with LTCs, even though the former are likely to experience both their underlying rare condition and acquired LTCs as they grow older.

### The Rise of NAPs

5. Better understanding of disease processes and progress in medical and surgical interventions has enabled NAPs to live longer lives. We are moving towards a society that contains more adults than children living with traditional diseases of childhood. For example, for the first time in history the number of adults with CF now exceeds the number of children with the condition. In 1938 the average survival age for those with CF was under one year;42 now 8% of patients are aged over 40.43 Furthermore, those born with CF in 2000 are predicted to live over 50 years.44 Similar growth is seen in children with severe CHD;45 before paediatric cardiac surgery programmes began in 1938 very few of these children survived46 yet in 2000 there were nearly equal numbers of adults and children.47 A US study death found that for those with Down Syndrome median age at death increased from 25 years in 1983 to 49 years in 1997, an average increase of 1.7 years per year over this period. By comparison, median age death in the general population increased by only three years during this entire period.48 Similarly, life expectancy for those with cerebral palsy is now approaching that of the general population.49

6. The epidemiology of many traditional conditions of childhood into mid-late adulthood is largely unknown.50 One exception is the European Cystic Fibrosis Society (ECFS) Patient Registry, which follows individuals through their lifetime.41 Many young people do not attend specialist clinics or are lost to follow-up after leaving paediatric care, leading to difficulties in understanding the size, diagnosis, treatment requirements, medical problems, complexity and speed of growth of these groups.52

7. Although numbers of individuals in a condition are relatively small when compared to those with more typical acquisition of LTCs in the general population, NAPs are growing significantly in terms of numbers of individuals and groups involved. For example, those with CLD also commonly died in early life.53 Following experimental childhood liver transplants which began in the UK in the mid-1980s, ten-year survival is now at least 80%, with clinicians predicting that “a significant learning curve” will fuel even longer survival.54 Today, around 100 children undergo liver transplant in the UK annually.55 It is likely therefore that these children will also eventually be outnumbered by adults with “childhood” liver disease, many of whom will experience LTCs at an early age.

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50 See 8
51 www.ecfs.eu/projects/ecfs-patient-registry/intro
8. These NAPs will potentially increase further through increasing survival of premature babies at lighter weights and earlier weeks. By analysing routine NHS datasets, Fraser et al.\(^{66}\) report an increase in prevalence of children aged 16–19 years with life-limiting conditions of 45% over the decade to 2009–10; the authors attribute this to increasing survival times rather than an increasing incidence of conditions.

**NAPs and Long Term Conditions**

9. Successful early intervention, ongoing treatment, and ageing processes for those with previously life-limiting conditions, has resulted in complex conditions, co-morbidities, and LTCs in NAPs. One prominent example of this phenomenon is highly active antiretroviral therapy (HAART) for those with HIV infection. This has turned a previously acute, fatal illness into a LTC, and as those with HIV age they are likely to experience more HIV-associated LTCs such as dementia; it is suggested that by 2030 the number of people of all ages living with HIV-related cognitive disorders will increase 5–10 fold.\(^{57}\) Another example is thalidomide impairment, where problems of ageing and the need for appropriate social care are now being recognised for a population that has yet to reach a traditional “old age”. There are many more examples of LTCs being found in NAPs as they grow into adulthood. For example, surgical repair is possible for many underlying congenital heart conditions, although few people have been “cured”, and for some the effects of their underlying genetic condition continue. Many adults with CHD have myocardial dysfunction, are exercise intolerant, and some have heart failure. As a group, these adults have neurohormonal activation levels similar to those found in a much older adult heart failure population with acquired heart disease, with the prevalence of acquired heart disease increasing as the CHD population ages.\(^{58}\) For people with Down syndrome, the risk of dementia is significantly higher, and is developed around 30–40 years earlier than for the general population.\(^{59}\) These individuals also develop LTCs including obesity and diabetes in early adulthood,\(^{60}\) as do those with CP.\(^{61}\)

**Psychosocial Needs**

10. Psychosocial needs including mental health needs are many and diverse for NAPs. Many individuals, for example adults with CHD, experience being different, externalised body image, effects of surgery, limitations and restrictions in the physical environment and in education and employment.\(^{62}\) Additionally, there is a psychological challenge of becoming an adult who is at higher risk of particular health problems than the general population, for example cancer (young women who have had a paediatric liver transplant undergo annual cervical smears due to the increased risk of cervical cancer). Many possess a heightened sense of their own mortality, for example young people with CP question regularly what their life expectancy will be;\(^{63}\) others with CHD live with the knowledge of heart problems and a limited life span.\(^{56}\) The prevalence of cognitive or intellectual impairment, long-standing due to underlying genetic or chromosomal syndromes, is also increasing in frequency due to a more active approach to treatment in childhood.\(^{64,65,66,67}\)

11. Additional psychosocial needs relate to missed education due to time spent in ill health or in hospital, and non-continuous employment records; many of these NAPs are not able to save for a pension to support them in later life. Many cannot obtain life, health or travel insurance, and experience difficulties in obtaining a mortgage. There may also be an ongoing need for education and counselling relevant to the underlying condition and its wider implications. Although some psychosocial issues around living with an underlying condition and its comorbidities have begun to be rehearsed, for example for survivors of childhood cancer, many needs still need to be defined before they can be met.\(^{68}\)


\(^{61}\) Bauman W A (2009). The potential metabolic consequences of cerebral palsy: inferences from the general population and disease increasing as the CHD population ages.\(^{58}\) For people with Down syndrome, the risk of dementia is significantly higher, and is developed around 30–40 years earlier than for the general population.\(^{59}\) These individuals also develop LTCs including obesity and diabetes in early adulthood,\(^{60}\) as do those with CP.\(^{61}\)


\(^{63}\) See 13.

\(^{64}\) See 13.


\(^{67}\) Schor N F (2013). Life at the interface: Adults with “pediatric” disorders of the nervous system. Annals of Neurology, DOI: 10.1002/ana.23910
PROFESSIONAL CAREERS AND SERVICE PROVISION FOR NAPs

12. Adult specialist and general physicians are not currently equipped for the range and complexity of adults growing older with traditional diseases of childhood and associated LTCs. Clinical expertise for NAPs has developed in an unplanned fashion, with training assuming relatively rigid transitions for individuals from child to adult, and from adult to old age. For example, in one Canadian survey half of adult neurologists sampled reported that they had not received enough child neurology training to treat the growing number of adults with child-onset neurological disorders. In cardiology, most general clinicians have very little understanding or experience of the management of adults with CHD. Similarly, paediatric specialists cannot manage within a paediatric environment the many adult conditions that these populations acquire. In one study, 60% of Canadian paediatric neurologists reporting difficulty finding an adult physician to take over care.

13. Health services have been developed around professional clinical career structures. For many NAPs, for example those with CHD, both specialist and generalist cardiology input are required as this “new” population of adults no longer fit within the traditional service divisions which split “adult and paediatric cardiology”. Most adult services for NAPs are based exclusively within secondary care, where multi-disciplinary teams have been developed to enable holistic care. Commonly, models are hierarchical, in a tertiary or specialist centre, with shared or outreach care delivered at district general hospitals; few receive care at local hospitals alone. One exception to secondary care provision is CF, where adults, largely an outpatient population, give hospital neurologists little exposure to this group in their training. Furthermore, many community-based clinicians, especially general practitioners (GPs), would not expect to see more than one patient with, for example, CF, during their career. When they do, there is a risk of their attributing any new symptom to the underlying condition, with patients acknowledging that a “specialist” patient may not always help educate their GP about their condition through their preference to contact specialist services. Although these adults have specialist needs that are met by specialist services in hospital, other needs of this ageing group mirror closely those with LTCs who are typically seen in adult or elderly care services. For example, urinary incontinence in women with CF and heart failure in those with CHD could potentially be treated in the community, although it is not clear how or when the relationship with community-based services should begin for NAPs who acquire LTCs at a relatively early age. Some examples exist of how specialist care can be moved out of hospitals into the community, for example hospital at home schemes for adults with CF with chest infection, yet studies suggest these may not be as effective as hospital-based care.

14. Aising from professional career and service structures, transition services act as a bridge to move children from paediatric to adult services. Established services for example CF demonstrate good outcomes although many others are less established with many patients having to travel significant distances to fit service provision. Transition services’ needs is on developing an “independent” adult able to manage their condition; transition clinics assume a lien progression through health services, although in practice many individuals find this difficult to achieve. There is little time to respond to wider health needs, for example the sexual health of those with CF. Additional outcomes rarely take into account ongoing family support or the strain on families who provide this. Despite ongoing improvements in life expectancy for NAPs, the emphasis remains on transition rather than adult health and social care services. Many young adults need supportive and palliative care services; these are not always addressed through the End of Life care strategy.

15. The absence of datasets for many rare and complex conditions makes planning difficult (both for precise numbers and size of growth) for future NAPs who will require health and social care services. Based on just one UK health region Wren predicted the need for adult follow up of CHD of over 1,600 extra cases every year in the UK. Adult services are playing “catch up” as many of these NAPs are pioneers; they are the first cohort to survive to adult age (for example adults living with paediatric liver transplant) and clinicians cannot easily predict what their future may hold.

16. An ageing society is not ageing solely at the “geriatric” end but there is no advocacy for adults in their 20s and 30s who may have lived with LTCs for as long as a 70 year old may have done, but with a wholly...

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69 See 13
70 See 30
72 See 13
73 See 33
74 See 13
75 See 30
79 See 30
different set of challenges. Charities, interest groups and health services see NAPs as having separate, disease specific conditions rather than acknowledging the common challenges of providing long-term care for these groups, and do not usually share their learning about training and organisational ways of working. In doing this, the voluntary sector is still to become effective advocates for NAPs navigating adult health and social care. Similarly, age-related voluntary sector advocacy on LTCs also misses NAPs.

**Prescription Charges**

17. The case has previously been made for exemption from prescription charges for people living with LTCs in England.\(^2\) The list of exemptions from prescription charges was drawn up when many individuals with childhood conditions did not survive to adulthood; these individuals were exempt from payment by virtue of their being children. People with traditional childhood conditions who are now surviving into adulthood must pay for their prescriptions; prepayment certificates are costly, especially for those who may not be able to work due to their condition. Anecdotally, some people with CF feel one benefit of the onset of CF-related diabetes is that it allows them to claim exemption from all their prescription charges. Despite not personally consenting to their surgery, adult survivors of childhood transplants also have to pay an adult lifetime’s charges for prescriptions that include the immunosuppressants that keep them alive. At the time the exemption list was compiled immunosuppressants had not been developed, yet they are now life saving for the vast majority of people who rely on them post transplant. This is at odds with people with diabetes who receive free prescriptions because insulin keeps them alive.

**In Conclusion**

18. In summary, NAPs are a significant growing part of our society for whom the experience, treatment and care of LTCs is becoming paramount; only a handful of examples have been given here. There is little evidence to clarify the extent to which existing services will have capacity to meet future demand. These NAPs are not included in long term care strategies, which situate health and social care issues within populations who typically acquire LTC at older ages, serving to further marginalise treatment and care for their younger counterparts.

**Research and Recommendations**

19. Extending lifespans has been one of the UK’s greatest achievements, but we must develop the epidemiology of traditional conditions of childhood into old age, and address workforce and service delivery issues to enhance the lives of “new” ageing individuals and their families as they grow older. To do this, we must reinterpret the “success” of medical and surgical interventions within a timeframe that incorporates the amelioration of underlying and acquired LTCs as NAPs age. Longitudinal studies that examine care delivery across the lifespan would allow us to understand what approaches and providers can deliver the best outcomes for these groups. Condition-specific research may miss the bigger picture of the challenges that NAPs face in respect of ageing with LTCs, and exempting individuals from prescription charges for immunosuppressants and other life-preserving drugs would meet one need felt by many of these “new” ageing individuals.

9 May 2013

**Written evidence from Professor Alan Maynard (LTC 56)**

Alan Maynard is a Professor of Health Economics, Department of Health Sciences and Hull-York Medical School, University of York. He was a Board member of York Hospitals NHS Foundation Trust from 1983–2010, and was Chairman from 1997–2010. He was appointed Lay Chair of NHS Vale of York Clinical Commissioning Group in 2012. He is a NHS patient with multiple morbidities, appreciating NHS long term care.

**Current Policy Assertions**

1. Patients with long term conditions could be “better managed” in the community with integrated pathways of care covering personal activity, primary care, local authority and NHS community support and hospitals.

2. Such care would offer better process quality, improved outcomes and the potential for cost savings.

**Policy Problems**

1. Commissioners are weak, compared to GP and hospital providers ie PCTs/CCGs are price and quality **takers** rather than price and quality **makers**. This problem is evident in both public-NHS and private health care systems ie private insurers also tend to be price and quality takers.

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2. Successive “re-disorganisations” of the NHS since 1974 have failed to remedy this power inequality as evidenced by the following quote from the Francis report on Mid-Staffordshire (2013):

“Commissioners—not providers—should decide what they want to be provided. They need to take into account what can be provided, and for that purpose will have to consult clinicians both from potential providers and elsewhere, and to be willing to receive proposals, but in the end it is the commissioner whose discretion must prevail.”

3. Why are commissioners weak? The answers to this question are quite simple: incentives and fragmented care delivery systems in practically all public and private health care systems:

(i) The policy “ideal” is that investment in community care is a substitute for care in acute hospital settings. For this to be so, hospital capacity has to be reduced and resources saved transferred, perhaps with economy, to fund community service development of good quality.

(ii) Sadly this policy ideal may not achievable in many cases. Investment in community care may become a complement and not a substitute for secondary care. The consequence is that service quality for patients may be enhanced but costs also rise.

(iii) PCTs/CCGs/commissioners can only downsize hospital facilities by mutual agreement with providers. Hospital providers can resist, maintain referrals from GPs and garner income via the PbR system of payment for activity. GPs can be similarly resistant to change. They will resist having to increase care for patients previously treated in hospital unless they are paid. Thus CCGs like their PCT predecessors have little or no leverage on providers other than “moral suasion”.

4. An additional clinical problem is that guidelines and pathway advice are based on evidence from trials exploring the best way to manage single morbidities. Many of the patients with long term conditions have multiple morbidities. The best treatment for one morbidity may deleteriously affect the best treatment for another condition. As a consequence clinical co-ordination among specialties is essential and has to be resourced. Clinicians have to exercise judgements in collaboration with their colleagues involved in the treatment of multiple morbidities. Thus they may not always follow evidence based guidelines for particular conditions.

5. As emphasised for decades (eg Barbara Castle’s “Priorities in Health and Social Care” 1976), and nicely re-iterated in the 2013 Health Select Committee report on Public Expenditure in the NHS, health and social care production is fragmented into the silos of primary care, acute care (now commissioned by two organisations, specialist care by NHS-England, and non-specialist acute care by CCGs), social care (provided by local authorities (LAs), CCGs and the voluntary sector) and public health (also provided by LAs and CCGs). These silos are insulated by incentives which support the resources, power and income of providers rather than enhancing collaboration and exploitation economies of scale to advantage the patient and the taxpayer. The policy advocacy of the Labour government in the 1970s is remarkably similar to that of the current administration (see Alan Maynard, “Funding health care in times of austerity: what goes around comes around”, Journal of Health Service Research and Policy, January 2013).

**Four Inter-linked Questions**

1. Where is the evidence that community care is cost effective?

2. Where is the evidence that that community care can be delivered as a substitute for hospital care, rather than as a complement which improves patient care and inflates expenditure?

3. Where is the evidence that hospital costs and employment can be taken out and transferred to fund community care?

4. With existing perverse incentives which sustain existing providers, in particular PbR for hospitals and the GP contract, what reforms are necessary? Eg would nurse led primary care be more cost effective?

In seeking answers to these questions, one result is “we need more research”! le an evidence base is absent despite expensive and extensive “innovation” over decades... There is a continuous storm of expensive local “innovation” to save money and improve patient care, often with particular focus on “community care”. However this activity is not support by evaluation which enhances the evidence base. As a consequence we do not know whether community care is a complement to specialist care or a substitute for it. The problem is exemplified in Professor Sarah Purdy’s review “Avoiding Hospital Admissions”, Kings Fund, 2010 where most of the policies reported are shown to have no evidence base.

**Some Suggestions for Future Policy**

1. Require providers and CCGs to register their plans nationally for changes in service delivery with reference to evidence sustaining change where it exists, and where it does not exist lodging their plans for scientific evaluation. Existing institutions such as the NHS Centre for Reviews and Dissemination should be an integral part of NHS investment activity rather than largely ignored by busy managers focused on a “quick fix”.
2. All reforms are social experiments (DT. Campbell, “Reforms as experiments” American Psychologist, 1969) and as such they should be evaluated to inform future policy choices. CCGs and providers, public and private, who fail to register innovations and evaluate them should be fined.

3. Train clinical and non-clinical managers in analytical methods so that they can access this knowledge and add to it by leading their teams in policy analysis. This requires radical reform of “leadership” training with emphasis on economics, other social sciences and trial design.

4. Incentivise further researchers supported by public funds to disseminate their work better by demonstrating the policy implications of their work. Oblige them to distribute clear and simple one page summaries of their work to NHS and Whitehall users eg the Health Select Committee.

5. Require all CCG and Hospital business cases to include details if any of the evidence base, and how investment will be evaluated. Relate success in complying with this requirement to promotion and salary increments and decrements.

6. Create a national capacity to inform health policy reform similar to that provided for medicine by the National Institute for Clinical Excellence.

7. Sanction limited radical structural experiments with evaluation eg the merger of hospitals with a co-terminous local CCG. Has 22 years of the purchaser-provider divide been efficient? There is no evidence to sustain it so radical experimentation with careful design and learning from Scottish, Welsh and New Zealand abandonment of the purchaser-provider divide may be informative.

Finally

Inertia fuelled by faith based rhetoric characterises many public and private institutions. Everywhere there is lip service to “evidence based” decision making and decision makers neglecting to translate words into practice.

Two physicians invented the term “scepticaemia”. They defined it as “an uncommon generalised disorder of low infectivity. Medical school education is likely to confer lifelong immunity” P Skrabanek and J McCormick, Follies and Fallacies in Medicine, 1989).

In analysing the subject of long term conditions scepticaemia is essential. We must ask always where is the evidence, and where it is offered is it robust or optimistic advocacy?

9 May 2013

Written evidence from Arthritis Research UK (LTC 66)

1. Arthritis Research UK welcomes the opportunity to respond to the House of Commons Health Select Committee inquiry into the management of long term conditions.84 We would be pleased to expand on the points below, and to provide further information to the Committee as oral evidence.

2. Arthritis Research UK is the UK’s fourth largest medical research charity. Our vision is “a future free from arthritis”. Our remit includes arthritis and musculoskeletal conditions, which are disorders of the joints, bones and muscles—including back pain—along with rarer systemic autoimmune diseases such as lupus.85 Together, these conditions affect around 10 million people across the UK and, at £5 billion, account for the fourth largest NHS programme budget spend in England.86,87 Arthritis is the biggest cause of pain and disability in the UK, and each year around 20% of the general population consult a GP about a musculoskeletal problem such as arthritis.88 As a charity we fund research, provide information to patients and educational resources for healthcare professionals.

3. In response to the Committee’s call, this response focuses on the following areas:
   — Overview.
   — Obesity as a contributory factor to long term conditions and how it might be addressed.
   — The interaction between mental health conditions and long term physical conditions.
   — Personalised services for patients (Personalised health budgets; Care planning).
   — The effects of multimorbidity and ageing.
   — The implications of an ageing population.

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84 House of Commons Health Select Committee (2013), Inquiry on the management of long term conditions: Call for evidence.
88 Arthritis Research UK National Primary Care Centre, Keele University (2009), Musculoskeletal Matters.
Overview

4. Arthritis and other musculoskeletal conditions are primarily long term conditions. Common features of these conditions are pain, joint stiffness and limitation in movement. The symptoms fluctuate in severity over time and are often associated with psychological problems such as depression. Symptoms are often not visible to the eye and so people are sometimes not aware how severely musculoskeletal conditions can impact on people’s lives.

5. The impact and burden of such conditions is recognised by the World Health Organisation, which describes them as “leading causes of morbidity and disability, giving rise to enormous healthcare expenditures and loss of work”.89 Indeed, UK analysis of the Global Burden of Disease 2010 identifies musculoskeletal conditions as the largest contributor to the burden of disability in the UK—in 2010, such conditions accounted for 30.5% of all years lost due to disability in the UK. The study also showed the rising prevalence of musculoskeletal conditions over time.90 This upward trend demonstrates the urgent need for greater recognition of the growing burden and impact of musculoskeletal conditions, and highlights the need for an integrated and strategic response.

6. Around 20% of the general population consult their GP about a musculoskeletal problem like arthritis each year.91 That amounts to over 100,000 consultations a day, the majority of which will be for osteoarthritis and back pain, accounting for a substantial attendance and burden in primary care.92

7. Over a third of the population aged over 50 have arthritis pain that interferes with their normal activities.93 In terms of the most common form of arthritis—osteoarthritis—a recent survey found that 71% report some form of constant pain, while one in eight describe their pain as often “unbearable”.94 Back pain is a major cause of individual distress and working days lost, with one in six adults over 15 reporting back pain lasting over three months in the last year.95 Osteoarthritis of the knee causes pain and disability for one in five people in their fifties, rising to one in three by age 75. Over five million people from the UK live with osteoarthritis of the hand.96

8. At £5 billion, musculoskeletal conditions account for the fourth largest NHS programme budget spend in England.97 The high cost of such conditions reflects both the very large numbers of people affected and the substantial levels of joint replacement for severely damaged joints (the majority of which is caused by osteoarthritis), with over 80,000 hip and over 84,000 knee replacements performed in 2011 alone.98

9. The wider impact of arthritis and musculoskeletal conditions is significant with 7.5 million working days lost each year due to musculoskeletal conditions.99 This is second only to stress, depression and anxiety.100 The indirect costs of arthritis on society have been estimated at £14.8 billion, which includes the cost of lost work for those affected and their carers adding to the lost quality of life experienced by those living with musculoskeletal conditions.101

Obesity as a contributory factor to long term conditions and how it might be addressed

10. Obesity is now widely understood to be a major contributor to diabetes and cardiovascular disease, but the public and policymakers appear to be less aware of its relationship with arthritis. Obesity is a common cause of osteoarthritis in weight-bearing joints. The earlier someone becomes overweight or obese in their lives, the greater their risk of developing osteoarthritis.102 Studies show that, compared to someone of normal weight, an obese person is 14 times more likely to develop knee osteoarthritis.103 The danger that obesity poses to health and quality of life is profound. Excess body weight not only increases levels of pain and disability but also undermines the efficacy of treatment.104

11. Maintaining a healthy weight reduces the risk of developing osteoarthritis, relieves existing symptoms and helps to prevent further deterioration of the joint. It should be recognised that much can be done to reduce the pain and disability of osteoarthritis and to support those who live with it to lead active lives, particularly

91 Arthritis Research UK (2009), Musculoskeletal Matters.
94 Arthritis Care (2012), OA Nation.
96 For statistical information about osteoarthritis, see: http://www.arthritisresearchuk.org/arthritisis-information/data-and-statistics/osteoaarthritis
100 Oxford Economics (2010), The economic costs of arthritis for the UK economy.
101 Arthritis Research Campaign (2009), Osteoarthritis and Obesity.
102 Arthritis Research Campaign (2009), Osteoarthritis and Obesity.
103 Arthritis Research Campaign (2009), Osteoarthritis and Obesity.
through weight loss and appropriate exercise. 104 Indeed, current NICE clinical guidelines state that exercise should be a core treatment for osteoarthritis. 105

12. People with osteoarthritis should be aware that exercise is safe and the majority can benefit from some form of exercise. In addition to helping pain and reducing disability, the benefits of exercise can include feeling better and more self-confident. Feeling positive can affect the way a person copes with their condition, which is important for patient activation and empowerment. This can also be facilitated by care planning [see section 20 below], where people have a positive involvement in their own care.

13. Improving physical fitness is an important part of self-management and risk reduction for people with osteoarthritis. However, osteoarthritis itself can be a barrier to exercise due to pain and restriction of movement. Moreover, if a person is also obese then this too may make exercise more difficult. Healthcare professionals need to be aware of the barriers to exercise, which can include joint pain.

**The Interaction between Mental Health Conditions and Long Term Physical Conditions**

14. Pain is a common symptom across a range of long term conditions, including musculoskeletal conditions, and needs to be rigorously assessed. Among people with the most common long term conditions—including coronary heart disease, hypertension, diabetes and depression—around one in four will also have a chronic painful condition. 106

15. There is a lack of biometric markers for assessing pain (unlike, for example, blood pressure for hypertension or blood sugar for diabetes) which can lead to it not being addressed in a systematic way. The absence of a simple, standardised test may make routine assessment and monitoring more difficult. Pain should therefore be routinely assessed using standardised patient reported measures. 107

16. Persistent pain is an important symptom in its own right. If not adequately addressed, it may be a barrier to self-management of other comorbid conditions. We welcome the Government’s assertion that “everyone who suffers persistent pain should have a timely assessment in order to determine the cause of the pain—if a cause can be determined—and to advise on options for treatment, including self-help” and its recognition of chronic pain as a long term condition, “either in its own right, as a component of other long term conditions”. 107

17. Depression is four times more common in people with persistent pain than for those without. 108 Depression is common in musculoskeletal conditions. With 68% of people with arthritis reporting depression when their pain is at its worst. 109 Over 10% of people with rheumatoid arthritis report symptoms of depression. 110

18. The NICE clinical guidance for the treatment of people with osteoarthritis recommends that healthcare professionals conduct a holistic assessment of the person which includes giving consideration to their mood. 111 GPs should ask about depression as well as identifying other stresses in life. Once diagnosed, taking a collaborative approach to depression in this context can aid a reduction in disability and arthritis pain. 112,113

**Personalised Services for Patients (Personalised Health Budgets; Care Planning)**

19. Personalised health budgets

Following recent piloting, the Department of Health has announced the initial roll out of personal health budgets (PHBs) in England, which aim to give people with long term conditions greater choice, flexibility and control over their health services and the support they receive. From April 2014, all people receiving NHS Continuing Healthcare will have the right to ask for a personal health budget, whilst clinical commissioning groups and NHS England will be able to offer PHBs more widely. 114

However, as arthritis and other musculoskeletal conditions were not the dedicated focus of any of the pilot sites, Arthritis Research UK undertook work to ensure the perspectives of people with these conditions was heard.

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104 Arthritis Research Campaign (2009), Osteoarthritis and Obesity.
107 Hansard HC Deb 1 February 2012, vol 539, col 680W.
114 Department of Health (2013), Direct payments for healthcare: a consultation on updated policy for regulations.
Our August 2012 report Personal Health Budgets presents the findings of our survey, workshop and policy seminar, and includes five recommendations for action as PHBs become more widely available on the NHS:

1. Those involved in care planning for people with arthritis should take account of the nature and impact of arthritis, in particular allowing for contingencies during exacerbations and for regular reviews.

2. All health professionals involved in care planning and supporting people with common long term conditions should be alert to the presence of arthritis as a major comorbidity that must be taken into account in discussions about personal health budgets as part of the overall process to meet individual needs.

3. A range of options and/or case studies should be developed for potential personal health budget holders, with an explanation that these represent illustrative but not exclusive choices.

4. Training about personal health budgets should be routinely offered as part of continuing professional development for health professionals.

5. The supportive role of third sector organisations needs to be properly described so that it can be harnessed appropriately and effectively, and adequate additional funding will need to be identified and cannot be assumed.115

20. Care planning

For many musculoskeletal conditions, such as back pain and osteoarthritis, effective day-to-day self-management can make a substantial difference to the overall impact of the condition on a person’s health and wellbeing. We believe that a systematic approach to care planning can benefit people with arthritis and other musculoskeletal conditions, and that care planning offers important opportunities to deliver improvements in their care.

Although the term “care planning” is not used directly, NICE clinical guidelines recommend the development of a management plan for people with osteoarthritis and the offer of an annual review to people with rheumatoid arthritis.116,117 However, recent survey estimates show that only 18% of people with osteoarthritis and 20% of people with rheumatoid arthritis have an agreed care plan.118.119

A welcome recent development is the introduction of rheumatoid arthritis into the Quality and Outcomes Framework (QOF) for 2013–14. In addition to maintaining a register of people with rheumatoid arthritis, GPs will be incentivised to ensure patients have an annual face-to-face review, which may provide an important opportunity to systematically integrate care planning conversations for people with rheumatoid arthritis. This is the first time that measures for people with rheumatoid arthritis have been included—other measures included are fracture and cardiovascular risk assessments.120 While this new addition to the QOF represents a valuable opportunity to improve the management of rheumatoid arthritis, it is also important to ensure there is effective communication between primary and secondary care.

Musculoskeletal conditions are generally long term conditions which often fluctuate over time. For example, rheumatoid arthritis is often categorised by periods of flare-up interspersed with periods in which symptoms lessen. This is something that the care planning process should take into account. Much can be learnt from extending the model of high quality proactive care that has driven improvement in diabetes—particularly the Year of Care programme which focused on the practicalities of the delivery of care planning in primary care settings.121

Care planning should not be an isolated exercise and records and plans should be described in language which is accessible and familiar to the person involved, along with clear communication about how the process works. We welcome the development that has already been made in this area, with the recently revised NHS Constitution now including the pledge “to involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one”.122

Over time, we wish to see care planning embedded across the NHS for people with long term conditions. In particular, we ask that NHS England meets the commitment set out in its mandate that “everyone with a long term condition … will be offered a personalised care plan that reflects their preferences and agreed decisions”.123

115 Arthritis Research UK (2012), Personal Health Budgets: perspectives from people with arthritis and other musculoskeletal conditions.
118 Arthritis Care (2012), OA Nation.
119 Arthritis Care (2012), Three wasted years: Evaluating progress in delivering improved rheumatoid arthritis services.
121 Year of Care (2008), Getting to Grips with the Year of Care: a practical guide.
122 Department of Health (2013), The NHS Constitution.
THE EFFECTS OF MULTIMORBIDITY AND AGEING

21. Long term conditions policy must take into account the effects of multimorbidity and ageing. Multimorbidity itself becomes more common with age and a significant proportion of those with a long term condition are multimorbid.\textsuperscript{124} For example, 82% of people with osteoarthritis have at least one other long term condition such as hypertension, cardiovascular disease or depression, which can exacerbate the impact of osteoarthritis itself.\textsuperscript{125}

22. A model of care is needed which recognises that the pain and disability caused by one condition may well have an equal or greater impact on quality of life than the disorder for which someone might be being seen. There is the need to move away from a single-disease approach towards person-centred care. Interventions for any long term condition must take into account the high likelihood of multimorbidity by taking an holistic approach, addressing the needs of the whole person rather than any one specific condition in isolation.

THE IMPLICATIONS OF AN AGEING POPULATION

23. Musculoskeletal conditions are life-long conditions causing pain and disability. The risk of developing a musculoskeletal condition increases with age so the ageing population represents a growing challenge. A recent report from the House of Lords Select Committee on Public Service and Demographic Change suggests that the number of people in England aged 65 and over in 2030 will be 51% higher than in 2010.\textsuperscript{126} Indeed, projections suggest that the number of people with arthritis is set to increase by over 50% in 2030.\textsuperscript{127} These increases will have a major impact on the availability and delivery of services, with large increases in demand for health and social care.

24. UK data from the Global Burden of Disease study shows that life expectancy in the UK has increased over the last two decades. This means that more people are living longer where the prevalence of chronic disabling conditions is higher. The study shows that the burden of musculoskeletal conditions is rising, largely because more individuals are living into the age groups at highest risk. Present trends suggest that musculoskeletal conditions in the population will only increase further, with the authors of the UK report suggesting the area requires “urgent policy attention”.\textsuperscript{128}

9 May 2013

Written evidence from Diabetes UK (LTC 67)

Key recommendations:

— The five key elements for improving diabetes care are:
  — prevention;
  — risk assessment and early diagnosis;
  — implementation of NICE quality standards;
  — education for self management; and
  — individual care planning underpinned by access to well co-ordinated care based on multidisciplinary local networks;

— People with diabetes need timely access to specialist services and interventions to help manage their condition;

— Integrated pathways of care for diabetes must be commissioned across primary, intermediate and secondary care providers across the whole local system of care.

1. ABOUT DIABETES

1.1 Type 1 diabetes develops if the body cannot produce any insulin. About 10% of people with diabetes have Type 1. It cannot be prevented and is treated by daily insulin doses by injections or via an insulin pump.

1.2 Type 2 diabetes develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly (known as insulin resistance). It usually appears in people over 40 and accounts for around 90% of people\textsuperscript{129} with diabetes. It is treated with a healthy diet and increased physical activity. Tablets and/or insulin can be required.


\textsuperscript{125} P C Breedveld (2004), Osteoarthritis: the impact of a serious disease, Rheumatology 43:1, i4-i8.


\textsuperscript{127} HL Select Committee (2013), Ready for Ageing?


\textsuperscript{129} Diabetes UK (2012). Diabetes in the UK
1.3 Diabetes is one of the biggest health challenges of our time:

- 3.9 million people live with diabetes in the UK.\(^{130}\)
- Numbers are rising rapidly with 140,000 new diagnoses each year.
- It is estimated that over five million people in the UK will have diabetes by 2025.\(^{131}\)
- Seven million people in the UK are at high risk of diabetes, this number is rising every year.\(^{132}\)
  It is estimated 80%\(^{133}\) of these cases are preventable with good risk assessment and effective lifestyle interventions.
- 24,000 people with diabetes die early from diabetes in the UK every year.\(^{134}\)
- Diabetes is a progressive condition, affecting all parts of the body. It is now the major cause of lower limb amputation, blindness, kidney failure and stroke.\(^{135}\)
- 41% of people with diabetes have depression and 30–50% of cases are undetected.\(^{136}\)

**Cost of diabetes:**

- The NHS spends £10 billion on diabetes every year.\(^ {137}\)
- 80% of NHS spending on diabetes is for managing avoidable complications.\(^ {138}\)
- Societal costs associated with diabetes (from increased death and illness, work loss and the need for informal care) are estimated at £13.9 billion.\(^ {139}\)

This submission is divided into three priority sections for improving diabetes care and reducing costs: provision of care; integrated and personalised care and managing contributory factors.

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\(^{130}\) Based on the number of diagnosed people (three million) plus those who are unaware they have diabetes or have no confirmed diagnosis (approx 850,000).

\(^{131}\) Figures based on AHPO diabetes prevalence model

\(^{132}\) Diabetes UK (2011). *Impaired glucose regulation (IGR) / Non-diabetic hyperglycaemia (NDH) / Pre-diabetes.*

\(^{133}\) WHO. (2005). *Presenting Chronic Diseases: A vital investment*

\(^{134}\) HSCIC, (2010–11). *National Diabetes Audit*

\(^{135}\) Diabetes UK (2012). as above

\(^{136}\) NHS Diabetes and Diabetes UK (2010). *Emotional and psychological support and care in diabetes*

\(^{137}\) Hex, N Barlett, C Wright, D Taylor, M Varley, D (2012). *Estimating the current and future costs of Type 1 and Type 2 diabetes in the United Kingdom, including direct health costs and indirect societal and productivity costs*

\(^{138}\) Kerr, M (2011). *Inpatient Care for People with Diabetes—The Economic Case for Change.*

2. ** Provision of Care**

The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service redesign for costs and effectiveness and

The readiness of local NHS and social care services to treat patients with long term conditions (including multiple conditions) within the community

2.1 Integrated pathways of care must be commissioned across primary, intermediate and secondary care to ensure people with diabetes get the care and specialist treatment they need to manage their condition. Diabetes care cannot be provided solely in primary and community care. Access to specialist care when required is vital. In particular, Type 1 diabetes support should be co-ordinated primarily from secondary care.

Stronger community and primary care services with appropriate upskilling in diabetes expertise should ensure the focus of care is: coordination, prevention, structured chronic disease management, patient education and care planning to support greater self management. This will help cut wastage and inappropriate hospital admissions. Where hospital admissions are needed, ensuring patients have access to specialist inpatient treatment can reduce length of stay by three days and save £400 per admission.

2.2 Good quality care provision in the areas outlined below would help to reduce the need for hospital inpatient care, by improving the management of diabetes within primary and community services.

**Prevention and early diagnosis**

2.3 Up to 850,000 people are unaware they have Type 2 diabetes. Early diagnosis, half show signs of complications. Early diagnosis is therefore crucial to ensure good management of diabetes can start before expensive and life-threatening complications develop and also prevents existing complications getting worse. It is estimated that by 2025, five million people will have diabetes, most of which will be Type 2. Investment in effective public awareness campaigns (explaining the seriousness of Type 2 diabetes and its complications) and full implementation of the NHS Health Checks programme will help prevention and early diagnosis.

2.4 25% of children and young people are diagnosed with Type 1 due to being admitted to hospital with Diabetic Ketoacidosis (DKA). Increasing awareness of the signs and symptoms of Type 1 diabetes, through public health initiatives aimed at schools, the general public and general practice, can help earlier diagnosis of Type 1 and cut the number of people who suffer DKA.

**Provision of appropriate care checks**

2.5 Everyone with diabetes should get a planned programme of NICE recommended checks each year. They are designed to identify the early signs of avoidable diabetic complications. However, only a third of adults with Type 1 diabetes and half of people with Type 2 diabetes are getting all the recommended annual tests. This is compounded by a “postcode lottery” of care, which means the percentage of people receiving all checks ranges from 16–71% depending on their location.

2.6 These nine checks must be made accessible to all people with diabetes through annual care planning reviews. The results of these checks must be used to ensure effective treatment and support for self-management and so cut complications. Where the checks are delivered within an integrated care pathway, they can make a significant difference in supporting effective self management and reducing complications.

**Education for self management**

2.7 It is estimated that around 95% of diabetes care is self management. NICE guidelines, backed by strong international evidence, recommend that structured education is made available to all people with diabetes to help them understand and manage their diabetes.

2.8 But too few people are offered it and not enough attend courses:

- A 2012 Diabetes UK survey showed nearly a third (31%) had never been offered structured education, not even at initial diagnosis.
- The National Diabetes Audit found that people with diabetes recorded as having attended structured education ranged from 0%–46.1% between PCTs.

140 NHS Diabetes (2013). Best practice for commissioning diabetes services: an integrated care framework
141 M Kerr (as above).
142 Figures based on AHPO diabetes prevalence model
143 HSCIC (2010–11) (as above)
144 AHPO (as above)
145 an acute complication of type 1 diabetes which can lead to coma or death if diagnosis and/or treatment is delayed or improper.
146 RCPCH (2010–11). National Paediatrics Diabetes Audit
147 HSCIC (2010–11) (as above)
149 HSCIC (2010–11) (as above)
The interaction between mental health conditions and long-term physical health conditions

2.9 There is a greater prevalence of psychological conditions such as depression, anxiety and eating disorders among people with diabetes than the general population. Poor emotional wellbeing is associated with sub optimal blood glucose control, which in turn can lead to the development of complications. For example, depression is twice as common in people with diabetes and can have an affect on an individual’s ability to control their diet or manage their medication.

2.10 Despite this, and the fact that treatment of psychological conditions has been shown to improve psychological wellbeing and other health related outcomes, 85% of people with diabetes have no access to psychological care and support. Access to emotional and psychological care should become a routine part of diabetes management, reducing the “costs” of untreated psychological conditions.

3. Supporting the Implementation of Integrated and Personalised Care

The practical assistance offered to commissioners to support the design of services which promote community-based care and provide the integration of health and social care in the management of long-term conditions

3.1 To achieve maximum efficiency, effectiveness and to avoid duplication and gaps in service, evidence shows the need to commission fully integrated and well co-ordinated pathways of diabetes care across primary, secondary and community providers. This is key to providing positive health and management outcomes.

3.2 There is a wealth of information to support this:
- Commissioning Diabetes Without Walls (2009) describes how to commission a whole system, integrated approach, covering the entire diabetes patient journey to ensure that opportunities for improving care and making most efficient use of resources is realised;
- Best practice for commissioning diabetes services: an integrated care framework (2013), explains how CCGs should be commissioning services to achieve effective and fully integrated diabetes services.

The extent to which patients are being offered personalised care

3.3 People with diabetes can live for as little as a few years or as long as 80 years with their condition. Personalised care should be coordinated around the person with diabetes, who is enabled to take a proactive lifelong role in shaping their care.

The advantages of better partnership working are shown in the 2011 Year of Care Programme. Care planning delivered personalised care in routine practice for people with long term conditions, using diabetes as an example.
- It worked in disadvantaged communities: patient reported involvement in care rose from 56% to 82% in the Tower Hamlets pilot site.
- Service redesign also encouraged a systematic approach to routine care. Tower Hamlets achieved the highest rate of people with Type 2 diabetes receiving all nine key care processes in England (72.4%) and individuals with good control of HbA1c, blood pressure and cholesterol increased from 24% to 35%.

3.4 Despite this, only 50% of English patients reported that clinicians share decisions about treatment with them, and a Diabetes UK survey in 2012 found that only 36% had developed a care plan by discussing their individual needs to set targets with their healthcare professional.

Examples of effective integrated care

3.5 North West London Integrated Care Pilot: Introduced integrated care pathways for people with diabetes. The pilot standardised and improved co-ordination of existing good practice and held regular multi-disciplinary case conferences (involving specialist consultants). Over one year, the rate of hospital admissions for foot ulcerations fell from 84% to 47% and the median length of stay reduced from 16 to 11 days.
3.6 Integrated Care for Patients with Diabetes, The Derby Model: Introduced a new organisation commissioned to provide the routine and specialist aspects of diabetes care. Between 2009 and 2011 significant improvements included:

- 51% increase in the percentage of patients achieving a cholesterol target of <5mmol/L.
- Reduced admissions of patients with a primary diagnosis of diabetes.

3.7 Integrated foot care pathway. Where effective services are in place for people with diabetes who have foot problems they are at much lower risk of amputation. As part of the integrated footcare pathway, people with a foot problem should have speedy access to a multidisciplinary specialist foot team. This has been shown to significantly reduce the risk of amputation meeting national standards, saving costs, feet and lives.

3.8 While these examples are encouraging, they are the exceptions and not nationally representative.

4. MANAGING CONTRIBUTORY FACTORS

Obesity as a contributory factor to Type 2 diabetes

4.1 Obesity accounts for 80–85% of the overall risk of developing Type 2 diabetes. As almost two in every three people in the UK are overweight or obese, the main strategy for reducing the rising prevalence of Type 2 diabetes should be to tackle the rise in obesity. Full implementation of the NHS Health Check programme would lead to better early diagnosis and prevention of diabetes. Other priorities are:

- Incentivising GPs to know who is at risk of developing diabetes and helping those people cut their risk.
- Marketing restrictions on unhealthy foods, and positive marketing of healthier food.
- Schools should educate and normalise healthy eating.

The implications of an ageing population for the prevalence of diabetes and the extent to which services have the capacity to meet future demands

4.2 Older people are more likely to have diabetes. In England the prevalence of diabetes across all ages is currently 5.5%. This increases with age to 14% prevalence in over 65s. It is likely therefore, that the ageing population will contribute significantly to the increasing prevalence of diabetes and co-morbidities.

4.3 Current services do not have the capacity to meet predicted future demand. This is largely because diabetes in older people requires careful management due to the complex interaction between the process of ageing, the increased prevalence of co-morbidities, widespread vascular disease and functional loss.

4.4 It is therefore essential that prevention, education, better care and the implementation of integrated pathways of care are prioritised to address this.

5. CONCLUSION

5.1 People with diabetes must have access to high quality services to enable them to effectively manage their condition. Commissioning and care delivery needs to focus on improving organisational processes, engaging people with long term conditions in their own care and changing healthcare professionals attitudes across each local care system. To achieve this, strong national leadership, collaboration between multiple commissioners and providers, effective systems of accountability and a joined up system of incentivisation are needed to ensure integrated, personalised care is the norm.

9 May 2013

Written evidence from the Patients Association (LTC 69)

- There is a need to address the often poor communication between different care providers. Patients frequently contact us to complain that their care is disjointed. They tell us that there are failures of communication between different departments and varied quality of treatment for those that require a multiple disciplinary approach to tackling their medical needs. This causes stress for the patient and can have detrimental health implications.

- Effort should be aimed at easing the patient transition between care settings. This is particularly acute for patients moving between hospital and a care home setting. Relatives of patients who have been transferred to care homes from hospitals tell us that often they arrive at the care home without a care package in place or without required modifications being carried out.

159 Marion Kerr (2012). Foot care for people with diabetes in the NHS in England: the economic case for change
160 Marion Kerr (2012) as above
162 WHO (2005). What is the scale of the obesity problem in your country?
163 Diabetes UK (2012) as above
— As GPs take on more responsibility for commissioning patient care, we’re concerned about their level of experience and understanding of commissioning specialised services where the needs of patients with multiple long-term conditions may be more complex.

— GPs as commissioners may also find it challenging to commission services for rare conditions or conditions that they have no experience of treating or rarely encounter. There is a danger that these services may be commissioned in a fragmented manner.

— NHS IT programmes have been plagued by severe problems and in order for integrated services to be effective there needs to be compatible IT support systems between providers. With increased competition, and suppliers/providers of services, this could become increasingly difficult.

— Patients with long-term conditions and those with complex conditions (ie the elderly and those with learning disabilities) are often the heaviest users of the NHS. It is essential that the voices of these patient groups—who are often the hardest to reach groups—are heard by decision makers and service providers.

OVERVIEW

I. The majority of patients want to be treated as quickly as possible in hospital and then be back in their own homes, amongst family and loved ones. With a move to local control of health and the rise in the elderly population, we need to make sure the NHS adapts to fulfil this need. Inpatient care and local services must serve the needs of patients so that they receive the best treatment possible and appropriate follow up community care. It may be beneficial to integrate and consolidate services into fewer sites and centres of excellence, as long as this does not restrict services available to patients. We must never forget that by merging services to be provided from one site, there will be patients who may struggle to get to them because they are too far away. It is vital that services reflect the needs of the community and are available in a variety of formats including respite care and community hospitals. The Department of Health must not be afraid of making difficult decisions that will ultimately mean better and more efficient services for patients.

II. However, inequalities continue to plague and divide healthcare across the UK. The link between early diagnosis and life expectancy in relation to the relative level of an area’s deprivation is truly alarming. On several occasions public health experts have warned that the current reforms could make health inequalities worse. The Government must make sure that the pursuit of its reforms does not get in the way ensuring that ALL patients have access to the treatment and care they need.

III. As we move towards a system built around the patient’s needs, with adequate local support and provision to help them diagnose, manage and live actively with their conditions, we must ensure that we address the increasing prevalence of treatment rationing that leads in many cases to the creation of avoidable long-term health issues. Every day our helpline hears from patients that can’t hear because they have to wait weeks for an audiometry appointment, can’t see properly because they have been denied a cataract operation, can’t work because they are in pain and can’t walk because they have been denied hip, knee or podiatric treatment. This is the human cost of a long-term condition, where treatment is not integrated, financial motives are put above patient care and ongoing support is lacking. How can we expect people to live a full and active life if they are burdened with crippling pain or unable to move about without suffering?

IV. Patients should never be denied treatment for non-clinical reasons. There may be some instances where lifestyle choices may need to be taken into consideration when deciding if surgery is clinically appropriate, but the breadth of these restrictions is worrying. We must ensure that these restrictions are not being put in place as an excuse to save money by denying patients the ability to access treatment.

V. There are four main areas of concern relating to the management of long-term conditions that we feel should be a focus of the inquiry:

— Integration and continuity of care.
— Access to General Practitioners.
— Supporting and informing patient’s decisions.
— Recognition of pain as a long—term condition.

I. INTEGRATION AND CONTINUITY OF CARE

1.1 The Government’s commitment to improving the care of patients with long-term conditions is to be welcomed. One key issue is that many patients find the pathways for chronic conditions confusing and muddled. This is particularly true for chronic pain. The Patients Association published a report, Public Attitudes to Pain, in 2010 which found that for the majority of chronic pain sufferers, there is no clear care pathway for chronic pain. This is despite evidence from the Chief Medical Officer’s report in 2008 that 7.8 million people in the UK suffer from chronic pain.

1.2 We need clearer care pathway for all conditions which is discussed and agreed with patients at the outset of their treatment so that they understand what is happening to them and what to expect from their treatment. Any changes that might need to happen to the care pathway must also be discussed and agreed with patients.
1.3 The lack of integrated provision and continuity of care between providers is a major obstacle in the provision of quality care for sufferers of long-term conditions. When patients are being moved between care settings, we have heard that oftentimes their medical records and information about their ongoing care are not properly passed on. There must be effective systems in place to ensure that when patients are moving between care settings, the information about their care follows them and that all professionals involved in their care are fully prepared to treat their condition holistically.

2. ACCESS TO GENERAL PRACTITIONERS

2.1 We already hear from patients who have difficulty accessing GP services, in particular there are issues with getting appointments. GP’s first and foremost duty and role must be to provide high quality medical care for their patients. With all these different roles pulling them in all directions, we are concerned that many GPs will not have the time to fulfil them all.

Case Studies:

A patient who contacted us was told that he could only discuss one item within a five minute appointment. He felt that this was restrictive and that the practice constantly puts pressure on patients to see the practice nurses. He feels it is a bit intrusive and feels it also puts receptionists under increased stress, because they are forced to tell the patients.

One patient told us that he had been trying to get a GP appointment for three and a half weeks and has been unable to manage it due to their obscure booking system and caller caller problem with the GP appointment system as he commutes to work and cannot phone after 8.30, even when trying to reason with them they will not move and this is the only method which they use for appointments.

Another patient who suffers from a chronic condition told us that they operate a 10 minute limit on the time available for consultation. When/if they do see his GP then it takes the entire 10 minutes to update her on her condition and if she sees a locum it takes the ten minutes to update them on the medication she is on. She is very unhappy, especially considering she may wait weeks to see even see the GP and then does not get to talk about any ailments apart from the chronic condition she suffers from.

2.2 Patients calling the Patients Association Helpline frequently tell us that they want more time with their GP and that this is a particular problem for sufferers of long-term conditions.

2.3 While GP consultations are relatively short, they have been increasing in duration in recent years. Between 1992 and 2007, the average time patients had with their GP rose from 8.4 minutes to 11.7 minutes. However, many patients report that they would like to have more time with their GP and that this would help them become more involved with their care. Evidence suggests that patient empowerment and outcomes for patients are affected by consultation time with longer consultation times resulting in better outcomes for patients. Indeed, patients are more likely to adhere to chosen treatments and have confidence in clinical decisions if they are able to spend more time with their healthcare professional. With the proposed move to GP Commissioning, there are concerns amongst doctors, patients and patient groups alike, that GPs may find they have to spend more time managing finances and have less time to care for patients. This may have a real detrimental effect to patients’ physical and mental wellbeing as well as poorer health outcomes.

2.4 In addition to the beneficial impact that the length of time a consultation continues for can have on patient confidence and outcomes, it also important how that time is spent. GPs must use the time to ensure they have the opportunity to give the patient all the information they need to make effective decisions about their care and that the patient also has the time to discuss any questions they may have. By making greater efforts to address the concerns of patients by going through information with them to make sure they understand it and are not confused by it, evidence suggests that patients would be more likely to adhere to medical advice.

2.5 The Patients Association fully supports plans to allow patients to choose their GP practice, but remains concerned that the Department’s resolve and commitment to implementing this policy has began to wane. Allowing patients the freedom to choose their GP regardless of location offers real benefits to some patients who may wish to register with a practice closer to their work, near their child’s school or with a practice that will not have the time to fulfil them all.

163 Ogden, J; Bavalia, K; Bull, M; Frankum, S; Goldie, C; Gossian, M; Jones, A; Kumar, S; Vasant, K. “I want more time with my doctor”: a quantitative study of time and the consultation, Family Practice, Volume 21, Number 5, pp. 479–483(5), October 2004

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structure is arcane and does not reflect modern needs. Instead it continues to ignore the fact that it is increasingly commonplace for patients to live or work outside the area of their preferred GP practice.168

3. SUPPORTING PATIENT DECISIONS

3.1 Healthcare professionals must be supported to have full and frank discussions about a patient’s care and be in a position to make clear the clinical reasons for their recommendation, including the potential effectiveness and drawbacks of a recommended treatment—or any other treatment discussed or licensed for use by NICE. If the healthcare professional does not know enough about a specific treatment, patients should be signposted to a third sector organisation which specialises in that particular condition for further advice and information. We have also already commented on our belief that there needs to be a “cooling off” period before patients are required to make certain decisions.

Case Study:

One patient told us that they had been receiving the same drug from her GP for the past eight years and has not been put on a different drug. She felt that this was because of money saving and would like to discuss it with her doctor who was not being communicative.

3.2 Giving patients a greater say in their care and giving them more opportunities to choose for themselves what they want is certainly commendable and to be welcomed. However, for many, choice is illusory at best due to personal circumstances. If patients are particularly frail or from a less well of background, it is unreasonable to suggest that they will be willing/able to travel for tests or treatment—particularly for those living in rural areas.

3.3 Even for those who are able to travel, travelling significant distance for diagnostic tests is unlikely to appeal to many patients. Patients want to be able to access good services locally. For most the choice is actually between two local hospitals rather than a local hospital and a centre of excellence miles away.

3.4 Being involved in decisions about their care is becoming increasingly more important to patients. In 2003, a Department of Health survey found that being involved in decisions was a high priority for patients.169 The Patients Association also published a report in 2011 which found that 84.6% of patients wanted to be more involved with decisions about their care.170 Another survey by the Department of Health in 2007 further supported these findings.171 This is important not only from a patient experience point of view, but also with a view towards clinical outcomes. There is evidence that patients who are more involved in decisions about their care are more likely to adhere to medical advice.172 This can result in better clinical outcomes.173

3.5 In a recent straw poll of our members, the majority of patients did feel at least reasonably involved in decisions about their care (54.7%). However, 18.6% said they only felt a little involved and 8.6% said they were not involved at all. While many said they were reasonably involved in decisions about their care, the vast majority wanted to be more involved with 91.3% of respondents stating that.

3.6 It is also noteworthy that when asked whether they more value being able to choose who will treat them or being involved in putting together their treatment plan, the majority of patients (69.8%) said they more valued being involved in decisions about their treatment plan. The Patients Association welcomes plans to give patients with long-term conditions greater opportunities to control their own care. Patient care is about two sets of expertise: the medical expertise of the doctor to propose treatments, diagnose and identify problems, and the patient’s own expertise in how they feel, what they need to make them feel better and the support they need to remain healthy. Combining these two viewpoints to come to a solution which is not only clinically appropriate, but also right for the patient are the core principles of shared decision making. It is also not unheard of for patients with long-term conditions to have more significant knowledge about their condition than their doctor. It is also not uncommon for specialised third sector groups to be able to better support and offer advice for sufferers, although professionals remain apprehensive to refer or advise patients to seek help from these groups. Giving patients the chance to be equal partners in the design, and implementation of their own care will, we believe, be beneficial for many patients.

4. PAIN

4.1 We receive numerous calls to our Helpline regarding the issue of pain and we are amazed that at the beginning of the twenty first century we are still not meeting the pain management needs of many people in the UK.

4.2 The medical and alternative therapies to relieving chronic pain are widely known and constantly developing. There is no reason for anyone to live needlessly with exhausting and debilitating pain. Chronic

168 Subsection 14B(6) and section 14D
169 Department of Health, Choice, Responsiveness and Equity National Consultation, 2003
170 Ibid 2
171 Department of Health, What Matters to our Patients, Public and Staff, 2007
pain is one of the most common reasons people seek medical help and depending on the severity of their pain, sufferers are thought to use health services up to five times more often than the rest of the population. Chronic Pain is a particularly serious problem in later life and can cause tremendous suffering for patients. The effects of chronic pain can leave its sufferers depressed, withdrawn from social activities and isolated. These effects significantly impact quality of life and nowhere are they more apparent than amongst older people.

9 May 2013

Written evidence from the Royal College of Nursing (LTC 81)

1.0 Introduction

1.1 With a membership of over 410,000 registered nurses, midwives, health visitors, nursing students and health care assistants, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector. The RCN promotes patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

1.2 Nursing staff play a key role in coordinating care between services. The RCN has played a significant role in the debate on the management of long term conditions as well as the integration of health and social care services in this context. The RCN welcomes the opportunity to submit evidence to Health Committee on this important topic.

2.0 Executive Summary

2.1 The RCN supports efforts to achieve integrated care and has previously participated in the Government’s work in this area, most recently through the NHS Future Forum’s consultation. We welcome the Secretary of State’s prioritisation of long term conditions as a priority area within the NHS Mandate.

2.2 Many RCN members, particularly those working in the community, work at the interface of health and social care and implement integration at a local level. Nursing staff are, therefore, well-placed to offer advice and information on best practice in this area.

2.3 In view of this inquiry, the RCN supports the following measures to achieve better integrated care for people living with long term conditions.

— Allocation of community resources: With a larger proportion of health and care now taking place in the home or in community settings, a more urgent approach is needed to reallocate resources and skills to the community, including increasing staff numbers.

— Specialist nurses and a single point of care: People living with long term conditions, as well as other health and care professionals, often benefit from the specific knowledge and skills of specialist nurses. They are skilled at navigating the often complicated path of health and care services as well as being able to provide a single point of contact for patients throughout their care.

— Health and Wellbeing Boards (HWBs): The creation of HWBs is promising and something which should be invested in. HWBs could be critical in providing locally tailored integrated care, providing that they have adequate funding and autonomy, and are compromised of personnel with the appropriate skill mix.

— Personal health budgets (PHBs): For some people living with long term conditions, PHBs and personalised care can dramatically improve their outcomes and experience. Where this works it should be continued and properly managed. However, this is not necessarily the most beneficial approach for all people living with long term conditions. Provisions must be available from already existing services to assist those for whom PHBs are not the right fit.

3.0 The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness

3.1 Nurses working in the community can play a key role as community champions and ambassadors with people about their health. To ensure improved integrated care and to help stop the “revolving door” of hospital readmissions following discharge, community nursing services must be invested in. There is an increasing need for community nursing expertise if health services are to effectively meet the emerging challenges of long term conditions. These challenges include; a growing number of older people and other vulnerable groups requiring nursing at home; the associated drive to prevent hospital admissions for those with long term conditions; and to ensure end of life care can be delivered in the home. Unfortunately, rather than

having supported to rise to these challenges, the RCN *Frontline First* campaign has highlighted that the 
community nursing workforce has actually contracted.¹⁷⁵

3.2 Increased self care brings many benefits, not only for the individual, but for clinicians, commissioners, 
the NHS, Government and society as a whole. Self care empowers individuals to take ownership of their 
condition and some aspects of their treatment, such as managing their medication and making changes to their 
lifestyle. Nurses play an essential role in this process, encouraging and teaching patients how to manage their 
condition themselves. It is often specialist nurses, whose knowledge and expertise is specific to a particular 
condition, who are best able to carry out this role. However, specialist nurses’ jobs are under threat, they are 
often senior nurses meaning they can appear as an expensive outlay to an employer, the full benefit they bring 
to the care system and to the patient is also often underestimated. In times of financial constraint specialist 
nurses are often the first to be cut or redeployed to inappropriate settings.

3.3 When considering long term conditions it is also important to include health prevention as part of the 
conversation. Many long term conditions, such as diabetes, can be managed better by initial prevention and 
prevention of deterioration. The RCN is concerned that the budget available for prevention work, in terms of 
public health services commissioned by local authorities, is relatively small. The need for local authorities to 
show immediate progress against public health outcomes framework measures will divert resources from long 
term prevention measures.

3.4 Even with the budget for public health ring fenced, the RCN has real concerns over the future funding of 
preventative services as local authorities position themselves to provide these services during a period of 
great financial constraint. Much of their budget will be spent on demand led services, such as sexual health 
services and substance misuse services, leaving little left for prevention work on issues such as obesity and smoking.

3.5 Health prevention must be considered equally alongside intervention by commissioners.

4.0 The readiness of local NHS and social care services to meet patients with long term conditions (including 
multiple conditions) within the community

4.1 Health and care services in the community have a duty to provide those with long term conditions with 
continuous care across all services including acute, community and welfare.

4.2 Nurses are ideally placed to provide this continuity and often act as the single point for all care needs. 
As care coordinators, nursing staff play a key role in working to ensure that patients do not notice where one 
service starts and another ends. Their broad clinical expertise gives them a unique insight into a patient’s needs, 
enabling them to anticipate gaps in the system and to ensure that services are in place throughout the patient’s 
journey. Nursing care is a fundamental tool in ensuring a seamless, joined up patient experience.

4.3 It is worth noting that people with learning or physical disabilities also frequently live with long term 
conditions. These patient pathways are often less well managed because of the complexity of multiple services 
required and the lack of integration between them. The RCN would like to see the skills of disability nurses 
used effectively to work collaboratively with GPs and other professionals, to inform and advise, on the best 
care pathways for those people.

4.4 The RCN is concerned that professionals in the community have the necessary skills to manage the needs of 
those with long term conditions. However, in order to achieve the readiness desired to achieve integration 
and seamless care, a genuine commitment to move services from acute settings to the community, must be 
made. Resources must be reallocated so that there is sufficient capacity to deal with the number of people who 
live with long term conditions as well as the increasing amount of care taking place in the home.

4.5 In order to deal with the changing needs of the population, we must see a real shift of resources and 
expertises from acute settings to the community. The latest official statistics show that in the last ten years the 
nursing workforce has not shifted from the acute to the community sector to help meet this significant 
challenge.¹⁷⁶ In terms of resources and expertise in treating those with long term conditions, what is proven to 
be beneficial to community nursing staff is the support of specialist nurses. They can support community staff 
to better improve care for their patients.

4.6 The RCN report *Specialist nurses: Changing lives, saving money*,¹⁷⁷ identifies the crucial role that 
nurse specialist nurses play in managing long term conditions. They provide direct patient care and educate patients 
on how best to manage their symptoms, as well as offering important support following diagnosis. In many 
cases the involvement of a specialist nurse can prevent patients being re-hospitalised or presenting at primary 
and emergency care settings. In a joint document with Parkinson’s Disease Society, Multiple Sclerosis Society 
and the RCN, *Developing integrated health and social care services for long term conditions*,¹⁷⁸ the role of 
nurse specialist and community matrons was highlighted as being central to good management of long 
term conditions.

Congress_2012_Update.pdf
5.0 The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long term conditions

5.1 Clinical Commissioning Groups (CCGs) are still in their infancy, it is, therefore, somewhat too early to tell the effectiveness of the practical assistance available to commissioners in the new commissioning system. However, given the role that nurses’ play in managing the care of those with long term conditions and the expertise that they hold, it is vital that CCGs draw upon this expertise at board level to ensure the best possible commissioning decisions are made.

5.2 There is some confusion around which services will be commissioned through CCGs and which will be commissioned on a broader, national basis through specialist commissioning. This is particularly concerning in the context of long term conditions. For example, it appears that neurological services will be provided through specialist commissioning, meaning that there will be an overlap of commissioning systems for the services required by the patient. The RCN would like to see clarity on the remit of CCGs and specialist commissioning and a commitment to a joined-up approach to ensure seamless provision of services.

5.3 The RCN has raised concerns throughout the passage of the NHS (Procurement, Patient Choice and Competition) Regulations, relating to section 75 of the Health and Social Care Act 2012. The RCN is concerned at the delay of the Government and Monitor in issuing robust guidance which sets out clearly when and how commissioners will need to use competition when allocating contracts to providers. The RCN has made it clear that commissioners must not be forced in to using competition based solely on financial reasoning or where they believe it is not beneficial for the patient. Financial incentives for the provision of integrated care should not be the only incentives. Integration of services must be patient-led and have commitment from all health and care professionals.

6.0 The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions

6.1 A measuring tool for integrated care is often the successful implementation of a single point of care, where all services are provided through one assessment which is controlled, funded and provided through one source. Whilst this is not unheard of, it is certainly uncommon. The RCN supports the notion of a single point of care and although we know nurses unofficially fulfil this role, we would like to see steps taken to formally imbed this in patient care.

6.2 A single point of care can provide the continuity and flexibility required to manage the care of people living with long term conditions. Long term conditions are constantly fluctuating, therefore, the provision of services must be flexible and responsive to altering conditions which can deteriorate or improve rapidly. A single point of care can be beneficial in effectively monitoring and assessing a person’s condition and what services are required at any given time.

7.0 Obesity as a contributory factor to conditions including diabetes, heart failure and coronary heart disease and how it might be addressed

7.1 Causes and contributing factors of long term conditions, such as obesity, can be addressed through effective public health interventions, education, public health training for community nurses and support for local services. The integration and communication between local public services such as local government, schools, and health and care services is vital in educating young people about the risks of developing long term conditions.

7.2 Health and Wellbeing Boards (HWBs) have the potential to play a very significant role in promoting integration of services, providing multidisciplinary oversight for long term condition services and promoting public health across services. We welcome the duty on HWBs to encourage integrated working between all health and care providers and commissioners, for example, encouraging the use of pooled budgets and integrated provision of services. However, the RCN is concerned that if HWBs are not granted adequate financial autonomy from local authorities, who will fund HWBs to varying levels, the impartiality of HWBs will be called in to question. Without this autonomy they will struggle to act independently of the local authority, or to work in meaningful partnership with representatives from other organisations. In addition to this, there needs to be a correct skill and knowledge mix on the HWB boards to effectively target local population needs.

8.0 Current examples of effective integration of services across health, social care and other services which treat and manage long term conditions

8.1 The RCN has identified a number of different nurse-led and innovative working practices and processes which facilitate the delivery of integrated care for individuals accessing the health and care systems. These include examples of utilising single entry points and single assessments, multidisciplinary teams, early intervention and regular needs reassessments and discharge planning. Two recent examples are detailed overleaf.
8.2 Stroke assessment services at Mid Yorkshire Hospitals NHS Trust

Mid Yorkshire Hospitals NHS Trust has implemented a round-the-clock stroke assessment nurse service. The service provides stroke assessment nurses 24 hours a day, seven days a week for staff to refer patients to. Through its access to stroke assessment nurses, the service facilitates rapid assessment, delivery of thrombolysis and ensures stroke patients are admitted directly to the Hyperacute Stroke Unit, where appropriate. Early commencement of rehabilitation, drawing on a number of services, provides multi-faceted and integrated treatment for patients from diagnosis through to recovery.

8.3 Breathing Space Clinic, St Joseph’s Hospice, Hackney

Nursing Standard’s “Nurse of the Year 2013”, Matthew Hodson, a Clinical Nurse Specialist at Homerton University Hospital in East London, set up a clinic with colleagues for people with advanced chronic obstructive pulmonary disease (COPD). Recognising that there was little support for patients with COPD, Matt launched the Breathing Space clinic in 2011. The clinic is a multi-disciplinary, inter-organisational hospice based pilot to support the holistic needs of COPD patients. The clinic helps patients better manage their illness, control symptoms, improve their outlook and plan for their future. A multi-professional and integrated approach is used for all patients with care from a palliative care consultant, a COPD nurse consultant and a palliative care physiotherapist to manage the symptoms of COPD and improve quality of life.

9.0 The implications of an ageing population for the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand

9.1 An ageing population, an increasing rate of lifestyle related illnesses, and patients suffering complex long term conditions are all contributing to a significant rising demand on the NHS and wider care services. Alongside this, the current financial situation that the UK finds itself in has led to huge pressure upon public spending and services.

9.2 Although the Department of Health and NHS has escaped budget cuts like those seen in other Government departments, it is still required to make significant savings of at least £20 billion by 2015 and it is widely expected that this figure is likely to rise. Cuts to other public services, such as local government, are having a knock on effect on the NHS. For example, local authority funding restrictions have affected local social care provision and other supportive services. These cuts increase demand for health services creating a bottle neck of activity and pressure on the NHS.

9.3 The RCN has frequently highlighted concerns about the need to properly address the way in which we care for the increasing numbers of older people, who have complex and demanding needs. In the RCN document, Safe staffing for older peoples wards, we stress the importance of ensuring the correct staffing levels and skill mix to properly care for the increasing numbers of older people in hospitals.

9.4 In addition to the increasing elderly population, it is important to note the significant number of younger people who have multi-morbidities and have additional needs in terms of accessing work, education and housing services. Integration, in this sense, requires cross-departmental working from the Department of Health, Department of Work and Pensions, Department for Communities and Local Government and Department for Education to effectively provide for those with long term conditions so that they can lead fulfilling and healthier lives, both mentally and physically.

10.0 The interaction between mental health conditions and long term physical health conditions

10.1 The RCN supports efforts to achieve integrated care between mental and physical health. Much of what has already been said above is relevant to this particular point. A single point of contact for those with mental health conditions and long term conditions can be beneficial in providing seamless care between services. Additionally, patient held records and clear care pathways managed by an integrated team can also be used to improve the integration of services.

10.2 For those with long term and mental health conditions, access to primary care services is vitally important in diagnosing and continually assessing often fluctuating conditions. The flexibility and sensitivity of primary care services is crucial to being able to manage mental health conditions. For example, the length of appointments at GP surgeries with doctors or nurses must be long enough to properly assess the physical and mental condition of a patient.

10.3 Patients must feel able to disclose information about their mental health and seek care and support for all physical and mental conditions. For this to happen, health and care professionals must be appropriately trained and educated to deal with both mental and health conditions, this is not often the case and patients experience different levels of care from different people. The RCN encourages approaches to train and educate nursing staff to manage both the mental and physical health of patients so that a more integrated approach could be achieved.

10.4 Often the simple reason for disjointed services is the geographical location of professionals and resources. To achieve a more integrated approach, the RCN would like to see mental health professionals and resources located in primary care settings, resulting in a co-location of mental and physical services.

10.5 Social isolation is often a factor for those living with long term conditions. Variables such as employment and education are known to have an impact on mental health and effective integration of local public services can be beneficial to the overall whole-person health outcomes.

11.0 The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes)

11.1 The RCN strongly supports the delivery of personalised care, with 88% of respondents to an RCN member survey on social care stating that individuals should be able to tailor their care to their own preferences and needs. Members also stated that personalised services and care are crucial to preventing health and care needs from developing or deteriorating, and hence represent an invest to save approach. Members identified personalised care plans, support to help make choices and regular reviews of care needs from appropriately trained staff, as critical to an individual’s experience and outcomes.

11.2 Personal health budgets (PHBs) are one tool which can help deliver personalised care for some patients. In the same RCN survey, 58% of respondents agreed that PHBs improve choice and control. Almost the same percentages were reflected in members’ responses to whether everyone should be entitled to a personal health budget with 57% concurring that PHBs improve choice and control.

11.3 However, even with appropriate resourcing and safeguarding in place, the RCN does not believe that PHBs will be an appropriate way to deliver personalised care for all patient groups and individuals. Different methods to personalise care will be required. Therefore, the RCN believes that PHBs must be optional. To maximise choice and personalisation, the Government will have to look how it will resource and deliver existing “traditional” services alongside additional services that personal budget-holders commission.

9 May 2013

Written evidence from The Royal College of Psychiatrists (LTC 82)

This submission is from the Faculty of Liaison Psychiatry at the Royal College of Psychiatrists.

1. Introduction and Summary

1.1 The Royal College of Psychiatrists (RCPsych) is the leading medical authority on mental health in the United Kingdom and is the professional and educational organisation for doctors specialising in psychiatry.

1.2 Liaison psychiatry is the sub-specialty which provides psychiatric treatment to patients attending general hospitals, whether they attend out-patient clinics, accident and emergency departments or are admitted to in-patient wards. Therefore it deals with the interface between physical and psychological health.

There is now abundant evidence that medical and surgical patients have a high prevalence of psychiatric disorder which can be effectively treated with psychological or pharmacological methods.

1.3 Our evidence focuses on the interaction between mental health problems, such as depression and anxiety, and long-term physical health conditions, and the implications of this interaction for individuals, clinicians, healthcare providers and commissioners. This evidence will also be relevant to other issues under consideration by this Select Committee, including the location of care for people with long-term conditions (LTCs) and the integration of care across traditional healthcare boundaries.

1.4 The issues we consider include:

1. (1) What constitutes a long-term condition.
2. The problem of multimorbidity.
3. Where is the majority of healthcare for LTCs provided?
4. What do patients with multimorbidity and complex healthcare needs want?
5. Problems in the current system.
6. What is needed to address the problems in the current system.
7. Specific recommendations.

1.5 Our evidence will show that, among people with long-term conditions:

1. Depression and/or anxiety are also commonly present.
2. Depression and/or anxiety are associated with much worse physical and psychological outcomes.
3. Such depression and anxiety is unlikely to be adequately treated.

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180 RCN survey on social care reform, 2011
2. WHAT CONSTITUTES A “LONG-TERM CONDITION”?

2.1 Long-term conditions are those conditions that are long-lasting and not curable, but are manageable with drugs and treatment. Such conditions include long-term physical health conditions (some of which are medically unexplained) and long-term psychiatric conditions. Depression and anxiety are treatable but chronic and recurrent disorders, resulting in considerable distress and disability. In the recent government report Long-term conditions compendium of information,181 depression constitutes the second most common LTC, affecting nearly five million individuals, according to Quality and Outcomes Framework disease registers. The WHO identifies depression as the leading cause of disability in high-income countries.182 Depression and anxiety must be considered when planning services for people with LTCS.

3. THE PROBLEM OF MULTIMORBIDITY

3.1 The prevalence of long-term conditions is predicted to remain fairly stable over coming years, but the prevalence of multimorbidity, where people suffer from more than one LTC is likely to increase with the aging of the population.183 A significant proportion of this multimorbidity arises due to the co-occurrence (ie comorbidity) of depression and/or anxiety with a long-term physical health condition. Around 10–20% of people with a long-term physical health condition also suffer from depression, which is about two to four times the prevalence seen in the general population. A similar percentage of people suffer from a range of other common mental disorders and symptoms, including anxiety, adjustment disorder and worry.

3.2 The importance of depression and anxiety when present in someone who also has a long-term physical health condition is that they are associated with much worse outcomes for the physical condition, including doubling of mortality and morbidity, worse health-related quality of life, greater healthcare utilisation and increased healthcare costs. Depression and anxiety probably exert such effects by complicating self-care,183 reducing adherence to medication, healthy diet, and exercise, and increasing maladaptive health behaviours, such as smoking, drinking and taking illegal drugs. It has been estimated that up to 18% of the NHS costs of managing LTCS is attributable to the presence of comorbid depression and anxiety.184

4. WHERE IS THE MAJORITY OF HEALTHCARE FOR LONG-TERM CONDITIONS PROVIDED?

4.1 Specialist secondary care services mostly focus on single diseases or disorders affecting single bodily systems and (with few exceptions) are not equipped to manage the growing numbers of people with multimorbidity. Consequently the majority of care for people with long-term conditions, particularly those with multimorbidity, is managed within primary care, with support for the management of specific disease provided by secondary care.

5. PROBLEMS IN THE CURRENT SYSTEM

5.1 Current health services are not well organised to support an integrated response to patients with complex healthcare needs due to multimorbidity, because care is organised around single conditions.185 This has always been a problem in secondary care specialist services, though introduction of health policies and service targets that mostly focus on single disorders (National Service Frameworks, NICE guidance, Quality and Outcomes Framework targets) mean that primary care in now similarly affected. There is limited service organisation around multimorbidity and when multiple conditions co-exist, they are dealt with “in series” rather than “in parallel”,186 with the result than treatment of some conditions is prioritised over that of others, and some conditions never receive adequate attention. Professionals recognise the tensions between focusing on disease-orientated targets and providing care that focuses on the individual needs of the patients, and that they are exacerbated in people with co-morbidity.

5.2 The institutional and professional separation of mental and physical healthcare means that care becomes particularly fragmented when physical and psychological health problems co-exist.187 Depression and anxiety...
among people with long-term physical health conditions are often not detected, and even when they are detected often remain under-treated, due to:

(i) the prioritisation of the associated long-term physical health condition,
(ii) a reluctance to diagnose stigmatising conditions such as depression and anxiety, and
(iii) a lack of time to assess, diagnose and negotiate treatments for depression and anxiety.188,189

5.3 Support/supervision available from secondary care to manage such patients is very limited. For patients this failure to treat depression and anxiety leads to persistence of unpleasant psychological symptoms and the continued adverse impact on physical health. Inefficient and poorly co-ordinated care further adds to the illness burden on patients, with repeated visits to multiple professionals. For primary healthcare professionals, depression and anxiety complicate both assessments and management decision-making; they also place a strain on limited resources, such as short appointment times. Such care is often split between professionals, for example between practice nurses and psychological therapists, so inter-professional communication becomes more important but also more complicated and therefore likely to fail.190 Under such circumstances, the quality of patient care is poor and patients’ confidence in and satisfaction with their healthcare can suffer as a consequence.

6. What do Patients with Multimorbidity and Complex Healthcare needs want?

6.1 In a survey of public opinion, patients with LTCs said that they want to be supported to engage in their care and to contribute to the decisions made about it. They also want a proactive and seamless service, in which the NHS acts as a team and they are treated as a whole person.191 This is very consistent with the preferences stated by individuals with multiple long-term conditions,192 who stressed convenience of access, continuity of care, clear communication, care that is individualised around their own unique requirements and to have their opinions heard. Considerable value is placed on care being integrated around the needs of individual patients, rather than fragmented due to a focus on single diseases.

7. What is needed to Address the Problems in the Current System?

7.1 Some of the problems around the detection and management of depression and anxiety in people with long-term physical health complaints relate to the inadequate training of professionals in primary and secondary care. In medical and nursing schools the emphasis on psychiatric training is placed on diagnosing and managing hospital patients with psychosis, despite the fact that very few trained doctors/nurses are ever required to treat such severe disorders. Training around detection and management of depression and anxiety in people with long-term physical health problems is virtually non-existent, despite the fact that all doctors will encounter these problems. Training in mental healthcare among qualified professionals usually does not extend to the complexities of diagnosis and management of people with long-term physical health conditions (even among psychiatrists).

7.2 In additional to training, there are broader and more deeply ingrained problems around the management of patients with multiple problems. When faced with a patient with complex needs, commonly a professional will formulate a problem list, with objectives ranked and addressed from those perceived to be the most important downwards. In current circumstances, in which resources, not least time, are limited, this frequently means that not all problems are given adequate priority. Mental health problems are usually seen as having minor importance, and consequently are not dealt with at all.

7.3 Systems of care, such as collaborative care, which integrate psychological and physical care, have been shown to be cost-effective in primary and secondary care settings. In such care, depression and anxiety are treated at the same time as the long-term physical health condition, by the same healthcare professionals, using synergistic treatments that are coordinated. Such care is most effective when supported by supervision from experts in physical and psychological health, for example by a liaison psychiatrist. However, integrated care such as that delivered by collaborative care is seldom available. Most of the evidence supporting its use comes from the US; it remains unclear whether it is effective in NHS primary care setting and how it is best implemented, indicating that further research is required.

8. Conclusions

8.1 The natural home for management of people with multimorbidity, particularly with combined physical and psychological problems, is primary care, with specialist support easily available from secondary care.

8.2 Depression and anxiety are common in people with long-term physical health conditions, predict worse medical outcomes and increased costs.

8.3 Depression and anxiety are usually under-detected and under-treated in people with long-term physical health conditions due to:

(i) a lack of knowledge and skills to detect depression and anxiety, then to negotiate, initiate and monitor evidence-based treatment.

(ii) limited resources to manage people with complex healthcare needs arising from combined physical and psychological problems.

(iii) systemic barriers that prevent easy access to supervision and support from specialists with expertise in managing people with complex physical and psychological healthcare needs.

8.4 Systems of healthcare that integrate physical and psychological care are available, but their effectiveness in the UK is unclear, as is the best means to implement them.

9. Specific Recommendations

9.1 Informed and supported self-care should remain the basis of care for many people with LTCs.

9.2 Appropriately resourced general practice should remain the main location for managing the majority of care for people with LTCs, including patients with depression, anxiety and long-term physical health conditions. Primary healthcare professionals skilled in the detection and management of depression and anxiety would provide integrated healthcare for long-term physical and psychological problems. For patients with the most complex needs, specific professionals could work across practices, to coordinate care, maintain continuity, promote inter-professional communication and to ensure healthcare needs are met. This professional role might look something like that of Community Matrons, though with enhanced training in the management of depression and anxiety, which was not previously considered a significant part of the professional role. Access to high-quality liaison psychiatry support in primary care, either via outreach from secondary care or the development of primary care liaison psychiatry services, would assist with the supervision of care of the complex patients. Other specialist secondary care services should be available as required and available within the primary care setting wherever possible.

9.3 Training of generalist healthcare practitioners in primary care should include an increased focus on the causes, effects and treatments of depression and anxiety in people with long-term physical health conditions. This training should start in medical and nursing schools and should extend to qualified healthcare practitioners, with appropriate expertise being a required outcome of professional training.

9.4 Systems of healthcare are required which direct delivery of treatment, maintain continuity of care, and which integrate care across the boundaries of professional expertise, healthcare settings and service providers. Such models of care are available, are even known to be cost-effective and are part of current healthcare policy, such as collaborative care (in which a particular healthcare professional takes responsibility for coordinating and integrating care), stepped care (where care is escalated to meet patient needs), and shared care (in which care for patients with specific combinations of health problems is shared between professionals).

9.5 Lack of information on the effectiveness of these approaches within the UK National Health Service and guidance on how to implement these complex systems of care, for example when to change care in stepped care, and which professionals deliver collaborative care, mean that delivery of such care is patchy and incomplete. Much of the evidence supporting the use of these complex healthcare systems has been developed in the US and does not necessarily transfer to the UK NHS. More research is required to identify the models of care most appropriate for use in the NHS, and to produce evidence to support the successful implementation of such models of care.

9.6 IT systems should be developed that facilitate both information sharing and communication across boundaries, between providers of health and social care.

9 May 2013

Contributors:

Chris Dickens
Professor of Psychological Medicine
University of Exeter

Michael Sharpe
Professor of Psychological Medicine
University of Oxford

Peter Aitken
Chair-elect of the Liaison Faculty of the Royal College of Psychiatrists
Written evidence from National Voices (LTC 91)

SUMMARY
— National Voices’ members—health and social care charities in England—are impatient for a new deal for people with long term conditions.
— The models and approaches that can provide this are known and evidenced: the challenge is to “move from rhetoric to reality”.
— Impetus for this has not been possible during the last two years of structural reform, but there are now significant opportunities to gather momentum behind the “House of Care” concept for service delivery, the common definition of what service integration is about, the new statutory provisions for social care entitlements, and the duties for healthcare commissioners to promote patient involvement.
— However, healthcare commissioners will need support both from inside and outside NHS England, and social care entitlements must be funded.
— There needs to be clarity as to whether NICE will now publish common (integrated) Quality Standards across health and social care for the same conditions).

ABOUT NATIONAL VOICES
1. National Voices is the national coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have more than 150 members with 130 charity members and 20 professional and associate members. Our broad membership, rooted in people’s experience, represents millions of individuals, and covers a diverse range of health conditions and communities.
2. National Voices grew out of the former Long Term Conditions Alliance. We have an active group of charity members, large and small, promoting our call for “a new deal for people with long term conditions” and for the health and social care systems to “move from rhetoric to reality” by delivering it.

SUBMISSION
3. This submission is an overarching view from patient and service user charities which will give our view, based on previous consultations with members, of the adequacy of current provision for people with long term conditions, and of the potential for service redesign to create better services.
4. National Voices members told the NHS Future Forum in 2011, during the “pause” in the Health and Social Care Bill, that we wanted a “new deal for people with long term conditions” based on getting the right care in the right place at the right time.193
5. We stated that patients and service users should be supported to:
— understand our conditions and medications;
— learn how to use health information;
— take achievable steps to improve our health;
— prevent emergencies developing;
— navigate the available services and support;
— manage our own care and treatment; and
— take part in deciding our care plans and our treatment options.
6. We said that for this to happen, services must be both more personalised and more integrated—“integration, integration, integration” was top of our list of demands.
7. These demands were securely based on the lived experience of the people with and for whom our charity members are working. With regard to health services, people managing long term conditions are using multiple services which are not joined up, which do not transfer information effectively so that it travels with the patients, which do not coordinate care around the patient, and where genuine care planning is still, despite the policy intentions of successive governments, only available to a minority.
8. NHS services are, by and large, dominated by GP and hospital-based services which primarily work on a medical model (“diagnose and treat”) rather than a bio-psycho-social model that considers the whole person and their needs and capabilities, and works to support them to achieve health goals in the context of their broader life and circumstances.
9. With regard to social care services, the culture of care and support is very different, and more informed by the ethic of supporting people to identify and achieve their own goals for an independent life. However, funded social care services are increasingly limited to a small minority of people with substantial needs, leaving people with moderate needs to fund their own provision or remain without support. As is well documented, social care and health services often do not join up around the person.

10. In its White Paper of 2010, “Liberating the NHS”, the government rightly identified many of the challenges posed by the growing incidence of long term conditions, and also touched on some of the things people need, especially in relation to greater involvement in decisions about their health and healthcare.

11. However, the last two years have been occupied with the structural reorganisations triggered by that White Paper, with the new organisations being barely established at 1 April 2013. Thus there has yet to be any impact at service level on the way people with long term conditions are identified, managed and supported.

12. In the view of National Voices members, many of the approaches that would both improve the quality of life of people with long term conditions, and lead to more rational and appropriate use of scarce system resources, are already known, and there is a substantial evidence base for them. For example, the NHS model for management of chronic conditions was published in 2004. National Voices manages a website which provides commissioners and providers with the results of 280 systematic and high level reviews of research evidence relating to the greater involvement of patients in healthcare.104

13. The problem, in the view of our members, is not with the “what”, it is with the delivery. The NHS has shown very little capacity to understand the changes both to culture and to service design which are required to deliver a new deal. Hence we do not wish to be involved in any further developments at the level of mere policy, but to assist the system to “move from rhetoric to reality”.

14. National Voices members do believe that there are now opportunities within the reformed system to begin delivering better services, and we reference some of these in the remainder of this submission.

15. The key, in our view, is to understand clearly that the approaches that will be more effective in support people to manage their conditions successfully—such as building health literacy, educating people for self-management, giving people access to their records, training professionals in health coaching and motivational interviewing, involving people in treatment decisions, and enabling genuine care planning—are not one-off, stand-alone interventions. Rather, they require a delivery system that changes the design of services and pathways, and the broader culture of services and consultations, repositioning the patient as equal and active partner, rather than passive recipient.

16. As noted below, we believe this should be based on the “Year of Care” or “House of Care” approach piloted for the Diabetes Year of Care and recommended by the RCGP as a generic approach to long term conditions management.

Social care reform

17. The Care Bill will introduce a clear single statutory framework for social care based on common entitlements that include holistic needs assessment and care and support planning both for adults with needs and their carers. National Voices has worked with the Bill team, the joint scrutiny committee on the draft Bill, and the Care and Support Alliance to help strengthen and clarify draft provisions in relation to care planning and direct payments specifically, and areas which can drive a more coordinated approach to the delivery of care.

18. It is essential that the health system, nationally and locally, takes note of these new provisions, and works to ensure that, where a person has needs that span social care and health, there are common systems for these entitlements, shared by cross-boundary and multidisciplinary teams, rather than placing the person with needs in jeopardy of double assessments and competing care plans.

19. In order to aid this, National Voices is currently working with members and partners on a set of Principles for Care Planning. In due course, we hope that these will be adopted by health and social care professionals and used by patients and service users who could benefit from these processes.

20. However, joint working and common systems for health and social care will only have meaning if social care is adequately funded for larger numbers of people with continuing conditions and disabilities. As part of the Care and Support Alliance, National Voices is calling for the funding of social care entitlements for people with moderate needs.

“Integration” and the Narrative for person centred coordinated care

21. As noted above, integrated services are much more likely to be able to provide people with a holistic approach to treating and managing their conditions. We welcome the fact that duties to promote and provide integrated care were inserted in the Health and Social Care Act 2012; and we particularly welcome the announcement by all key national system leaders of a common approach to supporting integration.105

22. This common approach is based around a new common definition of “integration” as “person centred coordinated care”, contained in a “narrative” that shows what such care would look like from the point of view of patients and service users. National Voices co-produced this for the national partners and it represents

104 www.investinengagement.info
many of our original demands from 2011 in a form approved both by members and service users, and by system leaders.196

23. The aim is to provide commissioners with a statement of goals and aims that they can use to benchmark progress towards integration, in a way which keeps them focused on the benefits to service users rather than the needs of organisations.

The domain 2 vision and ambition framework

24. NHS national responsibility for achieving better outcomes for people with long term conditions lies with NHS England and in particular its “domain 2” team. We are impressed by the commitment of this team and welcome the fact that they are seeking to place the “House of Care” delivery concept, and the Narrative, securely at the heart of their approach.

25. However, this team will need full support from the NHSE Board, from national clinical directors, from the patient experience domain, and from the commissioning development directorate, to turn these ambitions into delivery through the commissioning system.

26. National Voices will play its part in developing and supporting these ambitions as a “strategic partner” to NHSE. However, we believe there is a need to establish a strong external coalition of third sector organisations, think tanks and experts to gather momentum around the House of Care approach and to challenge commissioners to develop and implement it.

The patient involvement duties for commissioners

27. As a result of a campaign by National Voices, the Health Foundation and others, the Health and Social Care Act 2012 was amended not once, but twice, to create the clearest possible common duties for NHSE and CCGs to “promote the involvement of each patient in decisions relating to prevention, diagnosis, care and treatment.

28. This gives a statutory push to efforts to introduce patient involvement interventions. National Voices has been and will continue to be involved in helping NHSE to publish statutory guidance on how the CCG duty should be fulfilled (currently in draft for consultation).

Support for commissioners

29. Guidance, tools and incentives to help commissioners achieve better outcomes with and for people with long term conditions must now be produced by NHS England. In our view these should be securely based on the House of Care delivery concept; the Narrative for person centred coordinated care; and the best evidence for interventions to support greater patient involvement.

30. They should also draw on knowledge of the benefits of “co-production”, whereby service users are involved as equals in redesigning services, as evidenced recently by Nesta.197 They should include models for commissioning the financially small but crucial contributions to holistic care and support—such as patient information and literacy, education for self-management, peer support, and motivational activities—from voluntary and community organisations. VCS organisations have various concerns about their future role: they may be excluded from service delivery if there is too much focus on “procurement” models of commissioning based on competitive tender, or conversely if there is a return to “closed shop” models favouring NHS providers.

31. Recent research by the Nuffield Trust demonstrated what many of our members have described anecdotally—namely that much commissioning for long term conditions has struggled to move beyond “bite size commissioning” at the level of small, manageable service change, to tackle larger scale and generic service redesign.198

32. It is essential that commissioners are supported and trained to rise to this challenge. NHS England’s new improvement body, NHS Improving Quality, has a programme of training and support called “Transformational capability building within Clinical Commissioning Groups” that addresses this need. In National Voices’ view, all CCGs would benefit from this programme, and NHS England should put priority resources into enabling them to do so. The draft authorisation framework should be further revised to ensure CCGs know they will be assessed on their capacity to initiate large scale redesign and to work collaboratively with local partners to achieve it.

197 The People Powered Health Programme, Nesta: http://www.nesta.org.uk/areas_of_work/public_services_lab/health_and_aging/people_powered_health/assets/features/people_powered_health
Other issues

33. In the government’s reforms it was envisaged that Quality Standards issued by NICE would have a key role in promoting common standards and approaches across the health system. Subsequently NICE has taken over responsibility for setting standards for social care also. National Voices would support the production of common (integrated) standards across health and social care for the same condition or conditions. Clarity is required from the government and NICE as to whether this will be the goal.

34. The deal for people with long term conditions will be further enhanced by broader efforts to invest in and improve the quality of primary and community health services, which continue to be squeezed of funds in comparison with the acute hospital sector.

35. Finally, there is often a tendency in policy circles to underestimate the diversity of people with long term conditions. The needs of frail, older people are a big part of the picture but not the only part. It is also necessary to address the needs of children and young people, people with physical and learning disabilities, people with less common conditions (especially those not part of the national specialised commissioning arrangements), people with complex and fluctuating conditions, people from marginalised or excluded communities and family carers.

15 May 2013

Written evidence from the Royal College of General Practitioners (LTC 93)

The Royal College of General Practitioners (RCGP) is the largest membership organisation in the United Kingdom solely for GPs. Founded in 1952, it has over 46,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline. We are an independent professional body with enormous expertise in patient-centred generalist clinical care.

EXECUTIVE SUMMARY

We welcome the opportunity to contribute to the Inquiry. Caring for patients with long term conditions is at the core of day-to-day practice for GPs, with such patients representing over 50% of GP appointments. GPs have a vital role to play in supporting those living with long term conditions because:

— Whilst many health professionals may be involved in providing support to patients with long term conditions, general practice can serve as a natural “home” ensuring that continuity of care is maintained over time.

— GPs’ holistic approach means they are best placed to provide “whole person” care that takes into account patients’ social, mental, and physical wellbeing in the round. As expert generalists, GPs’ breadth of knowledge also means they are able to support the increasing number of patients living with multiple long term conditions.

The increasing prevalence of long term conditions is one of the biggest challenges currently facing our health and social care systems. We need a shared vision for how we adapt to meet this challenge at a time when the UK’s population is ageing and funding is predicted to remain flat. The following will be vital to delivering a successful strategy on long term conditions:

— Moving to a “whole system” approach: We must explore new ways of providing joined up care and support to those with long term conditions, redesigning the way care is provided in the community. Integrated models of care—with GPs working in multi-disciplinary teams alongside secondary care, social care and others—have the potential to deliver better patients outcomes.

— Making care planning the norm: We must move away from reactively treating individual episodes of illness—often in secondary care settings—to better anticipating patients’ needs by planning and managing long term care in the community. Care planning should become the norm for all patients with long term conditions, and general practice is already taking the lead in terms of implementing this in practice. Key to this approach is patient empowerment through the promotion of shared decision making and self care, putting patients in control.

— Focusing in on multiple morbidities: Health and social care services must shift their focus away from treating individual long term conditions towards a “whole person” approach to better meet the needs of the growing number of people with multiple long term conditions. Multiple morbidity is rapidly becoming the norm amongst those with long term disease. Whilst the total number of people with one long term condition is expected to remain relatively stable over the next 10 years at around 15.4 million, the number of two or more long term conditions is projected to increase from 5 million today to 6.5 million.

— **Shifting resources into primary care**: The primary care team will be vital to any successful future model of support for patients with long term conditions. However, the system of funding for NHS services remains skewed towards hospitals care. Over 2010–11 and 2011–12 spending on general practice fell in real terms (compared to real terms increases for hospital care, mental health and community health services). If we are serious about anticipating the care needs of those with long term conditions and putting them in control of their care, we must look at how we can provide primary care—where 90% of patient contact with the NHS takes place—with better resources.

**Response to Specific Issues Highlighted by the Select Committee**

1. **Defining “long-term conditions”**

   Given the Committee’s stated aim to review the definition of long-term conditions, RCGP offers the following proposed wording:

   *A long term condition is any medical condition that cannot currently be cured but can be managed with the use of medication and/or other therapies. This is in contrast to acute conditions which typically have a finite duration such as a respiratory infection, an inguinal hernia or a mild episode of depression.*

   As with many concepts in healthcare, there are likely to be many different interpretations of what constitutes a long term condition. Ultimately, the best means of defining what is and isn’t a long term condition, and making decisions about care requirements, is as part of a conversation between an individual and their doctor (usually a GP).

2. **Moving care out of hospitals and into the community—are we ready?**

   It is vital that in the coming years we see a major shift towards managing and planning “whole person” patient care in the community, moving away from the focus on treating individual episodes of illness in secondary care. The increasing prevalence of long term conditions and multiple morbidity mean that the “status quo” is not an option.

   However, we absolutely must avoid moving care out of hospitals without first establishing a clear plan for how services in the community should be re-designed and resourced to accommodate this change. In RCGP’s view we need to effect change in three key areas:

   (i) **Service redesign, care planning and “communities of practice”**

   We need to establish new models of generalist-led care in the community in order to meet the changing needs of patients with long term conditions. Currently it is still the norm that different professionals work within their own organisational silos, funding systems and cultures. We need to redesign services in a way that encourages shared ownership and accountability for ensuring that those with long term conditions are supported to manage and plan their own care.

   One potential model is to create multi-disciplinary teams based within primary care. This consists of different health care professionals, drawn from the wider primary care team, working together to deliver routine care, health advice and case management to high-risk patients. The model ensures such patients have access to longer appointment times, and health professionals are trained in skills such as chronic disease management, shared decision making and prevention.

   Another powerful tool is care planning, an approach pioneered by the diabetes “Year of Care” initiative (see section 5 below). This involves agreeing a plan to improve an individual’s health and well-being, and co-ordinating across a range of health, social care and other professionals to ensure the provision of support and services to address the patient’s needs. There is strong evidence that care planning can improve outcomes for patients, reduced unnecessary hospital admissions and save money. We now need to embed care planning into the “core business” of general practice and other parts of the system. RCGP is hosting a consortium of charities and primary care organisations to develop a set of “communities of practice” in a number of pilot locations in the UK. These will work together to break down barriers to change, agreeing the redesign of services, developing shared risk stratification metrics, determining how to share resources and agreeing use of IT to support the process.

   Finally, Under the right circumstances, pooled budgets can help to drive integration between health and social care, potentially leading to better outcomes for patients and reduced hospital admissions. However, safeguards are needed to prevent cost shifting between service areas, by using means such as tying the use of

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**203** The concept of “communities of practice” builds on the development of GP federations—through which practices can pool resources and expertise to redesign services in a way that better meets the needs of patients with complex care needs, an approach that has been successful in Redbridge and Cumbria.
funds to the delivery of jointly agreed outcomes based on shared needs analysis, and the application of open book accounting procedures. Personal health budgets potentially offer the opportunity to meet individuals’ health and social care needs in a more integrated way, but pose various practical challenges and risks.204

(ii) Investment in primary care

Delivering on the aspiration of moving more care out of hospitals, and at the same time integrating care more effectively around patients with long term conditions, will require a change in the balance of resources within the NHS. At the moment, the systems through which NHS care is funded continue to encourage activity in hospitals. In contrast there has been marked underinvestment in general practice, as indicated in the following chart from the Nuffield Trust.205

Balancing resources towards primary care would enable general practice to:

— Focus time and funding on redesigning services in the community to better meet the needs of patients with long term conditions.

— Offer patients with complex need—particularly those with multiple morbidities—more time with their GP. The standard 10 minute consultation is no longer enough to deliver a shift towards more anticipatory care. In the future greater flexibility will be needed, but with GP workload currently under severe strain most practices are unable to offer this.

— Focus time and funding on risk profiling GP practice populations, and engage more with patients in GPs’ local community to assess need.

In addition, an urgent review of Payment by Results is needed. It acts as a barrier to integrated care, because:

— Payment is structured around single episodes of care, discouraging the development of integrated services around long term conditions and care pathways.

— Reimbursement is based on activity (and to a certain extent quality), rather than health outcomes.

— By making the income of secondary care providers dependent on the volume of patients they treat, it pits their interests against those of commissioners and undermines efforts to provide more services in the community.

(iii) Workforce planning and training

Continuing to move care out of hospitals and into the community has significant implications for the primary care workforce. The Centre for Workforce Intelligence has highlighted that the GP workforce is not growing quickly enough to meet predicted increases in demand.206 The CfWI has recommended a 17% increase in recruitment into GP speciality training, which will necessitate a reduction in recruitment into training in hospital-based specialties. We need a robust long term approach to workforce planning, led by Health Education England, to ensure that patients with long term conditions are supported by an adequate GP workforce.

As the needs of patients change—and as the rise of multiple morbidities continues to lead to increases in the complexity of care—we also need to ensure that GP training reflects this. The RCGP’s proposals for extending the length of GP training from three (currently the shortest of any medical specialty) to four years207 are in the process of being considered by the Government, with a decision by health Ministers across all four

204 The College has published a position statement on Personal Health Budgets: http://www.rcgp.org.uk/policy/rcgp-policy-areas/~ media Files/Policy/A-Z%20policy/RCGP-Personal-Health-Budgets-position-statement-June12.ashx


nations of the UK expected in late 2013. Extending and enhancing GP training will mean that GPs of the future are better equipped to provide care and support to those with long term conditions.

3. Can we deliver “whole person” care for people with long term conditions?

Personalisation is strongly associated with better patient outcomes and experience and is rooted in the same values of holism and patient centredness as general practice. The NHS and social care still focus too much on individual disease areas, and a shift in focus is needed towards supporting patients with two or more multiple morbidities. Potential solutions include:

- Embedding a stronger core element of medical generalism in all medical training, including providing all junior doctors with greater opportunities to spend time working in the community.
- Reviewing the incentives and standards embedded throughout the NHS and considering how they need to change to tackle multiple morbidities. For example, NICE could develop clinical guidance focusing on multiple conditions rather than single disease areas.
- We need to redefine the primary care consultation, supporting GPs to spend more time face to face with patients who have complex needs.
- Joining up community mental health services with general practice to ensure that the needs of people with long term physical and mental health needs are addressed. This could involve co-locating mental health professionals into practice based multi-disciplinary teams.

5. Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions

We would point to two examples that the Committee could consider in this context:

The diabetes “Year of care” and care planning

The “Year of Care” programme demonstrated the potential for care planning to deliver improved health outcomes for people living with long term conditions, using diabetes as an exemplar. Pilots were undertaken in three diverse pilot sites (Calderdale & Kirklees, North of Tyne and Tower Hamlets). Key outcomes include:

- People with diabetes reported improved experience of care and real changes in self care behaviour.
- Professionals reported improved knowledge and skills, and greater job satisfaction.
- Care planning was found to be cost neutral at practice level, with some making savings.
- The programme found that care planning takes time to embed and requires whole system change.

Joint working between GPs and care homes in Sheffield

Patients living with long term conditions who live in care homes may suffer from poorer access to support tools such as care planning. In some areas, GPs are working collaboratively with local care homes to better meet the needs of their residents. In Sheffield, local GPs have been leading on the delivery of proactive, coordinated healthcare to care home residents through a Locally Enhanced Service (LES) first set up by NHS Sheffield in 2008. The initiative focuses on developing clear lines of communication between care homes and GPs and establishing effective access to community health services. The scheme has contributed to a reduction in hospital admissions in the area and has been popular with both residents and GPs, with 94% of surveyed residents saying the service provides for their needs.

6. How can the new commissioning system deliver more integrated care for people with long term conditions?

The introduction of clinically-led commissioning is an opportunity to deliver new ways of working that benefit people with long term conditions, but there are both risks and opportunities associated with the new NHS structure as it comes into force. Key factors include:

- Whether GPs feel “ownership” of the process. GPs need to be able to lead the redevelopment of services along lines that they judge will benefit their patients, and CCGs will need to engage effectively with all GPs in their areas, as well as with patients and other professional groups.


CCGs must be given the freedom and responsibility to explore the development of new models of care, and shouldn’t be held back by concerns about having their decisions overruled (eg in the courts) due to competition law. The Government has given assurances that the “Section 75” procurement, patient choice and competition regulations recently passed by Parliament won’t restrict CCG freedom and will encourage integrated commissioning; however, some uncertainty remains around the legal implications of the regulations.

7. As a contributory factor to conditions including diabetes, heart failure and coronary heart disease, how can we address obesity?

Obesity is well known to be a fundamental risk factor for a series of conditions, such as diabetes, heart failure and coronary heart disease. Its impact on psychological problems, low self esteem and even suicide risk should also not be forgotten. The impact on health budgets, workload and service development is immense. Potential solutions include:

- A multi-disciplinary approach is needed involving the whole health and social care system with coordinated services at all levels.
- GPs can and do have a role to play in supporting patients to live healthily. However, evidence suggests that GP practices should not be running first line weight management clinics themselves, but rather should signpost patients to an appropriate source of support, such as a weight management group.
- To achieve real traction on obesity, however, major public health interventions are needed to such as tackling the food industry, legislation around sale of high calorie sweets and drinks and improving access to exercise.

17 May 2013

Written evidence from Nuffield Trust (LTC 96)

SUMMARY

1.1 Many health systems face the challenge of rising prevalence of chronic health problems coupled with increasing longevity, resulting in more people surviving into old age with multiple chronic conditions. The UK has been no exception and over the past decade there has been a plethora of policy initiatives designed to increase longevity, resulting in more people surviving into old age with multiple chronic conditions. The UK

1.2 A benefit of having a single payer of healthcare with universal coverage is that several years of inpatient data for the whole population are available and can be used, through time series analyses, to explore whether in combination national and local preventive care initiatives are having an impact on the rates of emergency admissions. This can be a useful approach given that new initiatives in the NHS are often grafted onto a range of older ones which are still developing, and evaluations of individual programmes might not be undertaken over long enough periods, nor take account of the interplay of different policies and initiatives.

1.3 Having a single payer also makes it possible to discern the aggregate balance of spending across different sectors of the NHS in England (ie hospital, primary and community services) from the annual accounts of strategic health authorities, primary care trusts, NHS and foundation trusts, which are consolidated into annual accounts produced by the Department of Health and Monitor. The following submission draws on findings from these data sources, as well as recent modelling work quantifying the funding pressures facing the NHS in England over the decade to 2021–22, and a two-year in-depth study of commissioning practice in three high-performing primary care trust (PCT) areas (Calderdale, Somerset and the Wirral).

The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness

2.1 Both the Health Committee214 and the National Audit Office215 have previously pointed out that the more appropriate use of acute hospital services is critical for the future achievement of efficiency savings. To achieve this, effective community health services are important, as is the quality of primary care. One important gauge of these services’ effect on the health system are rates of admissions for “ambulatory care sensitive
2.2 A 2013 Nuffield Trust observational study of hospital admission data spanning the period between March 2001 to April 2011 revealed that the number of emergency admissions per year for ACS conditions had increased over the decade by 40%, rising from 701,995 admissions per year to 982,482 annually.216 Emergency admissions for ACS conditions were more common among the oldest and youngest age groups. When the age-standardised rates of emergency admissions for ACS conditions were compared, the overall increase was 25% indicating that not all of the decade long rise in admission rates was due to the changing demographic structure of the population. The overall trend also masked differences between the three broad categories of ACS conditions (acute, chronic and vaccine preventable). For acute ACS conditions the age standardised rate of increase was 44%, while vaccine preventable rates (such as for influenza) went up by 136%, albeit from a much smaller base.

2.3 The rate of admissions for chronic ACS conditions held roughly steady. Among this group, the conditions with the highest rises in the absolute numbers of admissions were chronic obstructive pulmonary disease (COPD) and convulsions and epilepsy. The number of admissions for diabetes grew by 95% and contributed an extra 16,996 admissions. Meanwhile age-standardised rates of admissions for congestive heart failure and angina showed marked and significant reductions (-27% and -41% respectively).

2.4 There are a number of possible explanations for the observed increases in the chronic group of ACS admissions. For some ACS conditions changes could be due to the differences in the underlying prevalence of disease; changes in health-related behaviours such as smoking or improvements in the effectiveness of treatments for some diseases for example, statins for angina. Other possible explanations include changes in the way health systems operate, for example changes in the thresholds for admission to hospital. It may be the case that patients admitted now are less sick than they were 10 years ago, or that the rise in short stay admissions and lower rates of mortality shown in an earlier Nuffield Trust study.217 Or that admission decisions are in part influenced by the perceived lack of alternatives to inpatient care (for example an absence of social care or community based alternatives to hospital).

2.5 Some caution is required as the evidence connecting the rising trend in ACS admissions to specific policies is weak. For example the introduction of the four hour A&E target and changes to the GP out of hours contract (both in 2004) are commonly cited as increasing the overall level of emergency admissions, yet our study suggests that emergency admissions continued on an underlying upward trend at this point, with no obvious acceleration in the rates of ACS or non-ACS emergency admissions. Indeed some of the more common ACS conditions show trends that closely mirror the rise in rates of emergency admission for non-ACS conditions. This suggests that the organisation and financing of the health system itself are perhaps more important determinants than the changing health needs of the population over the decade—specifically the expansion of acute sector capacity from 2002. We know from the consolidated NHS accounts that community health services have experienced particularly rapid growth in spending since 2006–07. Acute spending also continues to increase but spending on primary care, and in particular GP services, has been falling in recent years in real terms.218

2.6 Thought needs to be given to how national and local policies are impacting on the pattern of admission for patients, either because of suboptimal preventive ambulatory care, or changes in thresholds for admission to hospital. It is clear that there is a role for much more comprehensive, independent and transparent analysis of policies and local initiatives that might make an impact on quality and costs. This work is beginning and could be modelled in line with emerging evidence from research findings, for example the impact of: the increased funding of community services since 2006/07; service reconfiguration; integrated care;219 workforce skill mix; changes to social care funding; and greater use of telehealth and telecare.220

The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community

3.1 In its June 2011 summary report the NHS Future Forum called for the commissioning of integrated care for patients with long-term conditions, complex needs and at the end of life. It was an important acknowledgement that the ageing population and increased prevalence of chronic diseases requires a decisive shift away from the current concentration of resources in acute hospital settings towards greater preventive care, self-care, more consistent standards of primary care and community based health and social care services that are also well coordinated.221 The Department of Health subsequently approached The King’s Fund and
the Nuffield Trust for help in supporting the development of its national strategy on integrated care. In our resulting report we identified a set of organisational and policy barriers that need to be addressed.222

3.2 They included:

- The institutional divisions between primary and secondary care in the NHS and between health and social care that often make it difficult for multidisciplinary teamwork to happen.
- The absence of a shared electronic patient record enabling care that can cross organisational boundaries.
- NHS regulation that focuses too much on the performance of organisations and not enough on performance across organisations and systems.

3.3 Some local areas have attempted to overcome these and other obstacles. For example the North West London Integrated Care Pilot (ICP) is a large scale innovative programme designed to improve the coordination of care for people over 75 years of age and adults living with diabetes.223 Multidisciplinary groups of local care providers segment patients according to risk; share care plans across care settings; identify patients needing intensive case management, and monitor care plan implementation. Sophisticated governance structures have been put in place, with all staff involved in the pilot, together with representatives of local patient organisations and providers coming together under an Integrated Management Board (IMB). Financial incentives have also been designed to support the aims of the pilot in relation to care planning, collaborative care management, and the development of innovative alternatives to hospital admission.

3.4 Likewise NHS organisations in Trafford, a borough of 215,000 people in Greater Manchester have been trying to develop closer collaboration between community based primary, general acute medicine, specialist outpatient and diagnostic care to enable more care to be delivered outside hospital. Initial implementation of the programme involved nine “vanguard” general practices working with community, acute and social care to redesign selected care pathways, share data, identify patients at risk of unplanned hospitalisation, and generally to act as a test bed for implementing and evaluating integrated care.224

3.5 Neither area is unique in attempting new ways to deliver care closer to the patient. However in terms of scope and ambition they are certainly not the norm. It is perhaps instructive that in both cases there were substantial initial prompts; in the case of Trafford, it was an ambitious PCT and groups of clinicians that funded and drove the need for change, while in North West London the set up phase was helped by financial and other support from NHS London; enabling the system in IT, pilot leadership, coordination of multidisciplinary groups and project management. While recent Government announcements pledging to align policy initiatives in favour of more integrated care for set of “pioneers” are welcome, it is also likely that other local examples of innovation will emerge as a result of the current spending squeeze and it is important that these are also supported and evaluated.

3.6 A key determinant will involve the extent to which commissioners are supported to balance the possible tensions that can arise when policies in support of competition and choice (and the associated procurement laws) interact with the planned shift to greater coordination of community based services. These ought not to be mutually exclusive policies but in practice there is a risk that the scope for regulatory action is perceived by commissioners as potentially being so wide and far reaching that it inhibits service redesign and innovation. Second, those commissioners wanting to redesign services appear to be faced with a high burden of proof. Emerging Competition and Cooperation panel guidance suggests that commissioners and providers will have to show that their actions produce benefits that are “significant, quantifiable and evidence based” to set against the theoretical costs of any reductions in competition and patient choice.225 This is a high threshold of evidence to meet, particularly when the effects of large scale integrated care projects can take several years to emerge fully.

The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

4.1 Earlier this year the Nuffield Trust published a major National Institute of Health Research-funded study exploring what commissioners actually do when commissioning care for people with long-term conditions, and how this might be improved.226 The research was based on 15 months of detailed observation from November 2010 to January 2012 in three commissioning communities: Calderdale, Somerset and the Wirral. These sites were selected because on various indicators they appeared to be at the forefront of commissioning practice. The research focused on the commissioning of care for people with long-term conditions: diabetes in

all three sites (to allow comparison), and a second condition chosen by each primary care trust: dementia in Calderdale and the Wirral, and stroke in Somerset.

4.2 A huge amount of effort was observed going into commissioning across all six service developments, in terms of strategic planning, service review, and hands-on work (typically by middle managers within primary care trusts) to implement and support change. The research further revealed that the commissioning was not seen as a two-sided transaction across the “purchaser-provider split”, at least where long-term conditions are concerned. Local commissioners were instead developing an alternative approach based on collaborative working between providers and commissioners. While there are clear benefits to this, in terms of clinicians driving change, there are also risks; including potential conflicts of interest, for example providers using senior clinicians to help ward off challenges from commissioners, or providers being actually involved in design of services for which they subsequently tender.

4.3 The study concluded that commissioning is a labor-intensive activity, often concentrated on relatively marginal rather than mainstream service developments. It was also noted to be much more relational than transactional in nature, with commissioners appearing reluctant to engage in challenge of providers and decommissioning, preferring to focus on service planning and design, involvement and consultation with local stakeholders, and implementation of new developments. In the new commissioning system, given recent management cost reductions of some 40%, clinical commissioning groups will have to be very selective about how they allocate their time and effort. Commissioners’ traditional role of as convenors of the local health system may also have to adapt, or at the very least be scaled back—they will need to be brave enough to “cut and run” and make difficult decisions when they feel they have undertaken enough consultation and engagement, even if this flies in the face of NHS (provider and commissioner) culture that favours extensive involvement and consultation as a way of reviewing and making changes to services.

4.4 The implication of this is that done well, commissioning can be a leading role, especially when it involves the “tough work” of changing services—work that is likely to threaten professional and provider interests, or prove unpalatable with some in the wider community. Commissioners will need intelligence from commissioning support units to challenge providers on quality and value for money, and where necessary, use procurement to let contracts for services for their populations. This should include high-quality public health and needs assessment advice, sophisticated and realistic contract designs, services, accurate comparisons with national benchmarks, efficient payment and invoicing systems, and support for modelling and planning future care. In addition, commissioners will need support in undertaking public consultation, accessing and analysing patient and public experience data, providing local system leadership, and handling procurement within a cultural context of collaboration.

The implications of an ageing population on the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand

5.1 Population growth and demographic change are fundamental drivers of future health care activity. Clearly, as a population grows, demands for health care will rise. Additionally, a population with a higher proportion of older people will have a greater need for health care. While health service utilisation tends to increase with age, there is also an increase of health services as people approach the end of their life, regardless of age. This increase is less pronounced for people aged over 85 years, but is still evident. Use of health services is thus dependent not just on ageing, but also on the number of people who are expected to die at any particular time.

5.2 Our December 2012 report mapping the medium term NHS productivity challenge used the principal ONS projections from 2008 for population, mortality and fertility to create a projection to 2021–22. The population is projected to grow for all age groups of 50 years and above, for both males and females. The probability of having an inpatient admission related to a chronic condition is higher for older age groups than younger age groups. Admissions linked to chronic conditions are therefore likely to rise as the population ages. However, recent trends suggest that this probability is also rising within age bands. If this trend continues, the impact on the NHS due to chronic conditions will amplify the effect of population growth alone.

5.3 For primary care, we examined trends in the number of times a year individuals visit their GP. The number of consultations at a GP practice per person per year rose from 3.9 in 1995–96 to 5.5 in 2008–09. Over the same period, the proportion of these consultations occurring with a GP, rather than a practice nurse, fell from 75% in 1995–96 to 62% in 2008–09. We have assumed that both of these trends will continue over the period 2010–11 to 2021–22, so that by 2021–22 there will be 7.8 consultations per person per year, 55% of which will be with a GP. We applied a similar technique to the mental health model to predict how many people would require mental health services each year, based on the number of people using services between 2008–09 and 2010–11. This projection would see the proportion of people aged over 65 years using mental health services growing by just over 50% by 2021–22.

5.4 Further protection of the NHS budget is not guaranteed due to the uncertainty of the economic outlook for the country. Our analysis concluded that without unprecedented, sustained increases in health service productivity, including more effective management of chronic conditions, funding for the NHS in England will

need to increase in real terms between 2015–16 and 2021–22 to avoid cuts to the service or a fall in quality. Yet with no clear signs of economic recovery, it is conceivable that NHS funding may be frozen for further years. If this is the case, a major rethink of how health services in England are funded and organised will be needed. It is crucial, therefore, that the NHS becomes much better at preventing and managing long-term conditions.

24 May 2013