Nursing Practice

Discussion

Specialist nursing

The Multiple Sclerosis Trust developed a programme to help MS specialist nurses demonstrate their value. The model is transferable to other specialist groups.

Enabling specialist nurses to prove their value

In this article...

› Why specialist nurses find it difficult to prove effectiveness
› The programme’s approach and evaluation methods
› How the programme is benefitting nurses and patients

Authors

Amy Bowen is director of service development; Geraldine Mynors is Generating Evidence in Multiple Sclerosis Services programme manager; both at Multiple Sclerosis Trust, Letchworth. Jane Suppiah is director, Mynors Suppiah, London.

Abstract


As pressures on healthcare resources and staff continue to increase, all must prove their worth. Specialist nurses are no exception, but the nature of their work and their role within a wider multidisciplinary team can make it harder for them to gather data specific to their roles. This article describes a programme that was developed by Multiple Sclerosis Trust charity to demonstrate the value of multiple sclerosis specialist nurses. The model is transferable to other specialist groups and has been adopted by Dementia UK.

There are around 250 multiple sclerosis specialist nurses working in the UK who, like colleagues in other specialties, are under increasing pressure to demonstrate their effectiveness. Managers and commissioners of services are looking for information to show how specialist nurse roles translate into value for patients and the wider health service.

In 2011, the Multiple Sclerosis Trust, a national charity with a mission to ensure everyone diagnosed with MS has access to multidisciplinary specialist services, commissioned a report assessing the state of the evidence for the value of the MS Trust specialist nurses (MSSN). The resulting report by Mynors et al (2012) found a shortage of robust evidence to show that such services are cost effective. The reasons for this are many:

› Specialist nurses often don’t have the skills, experience or time to gather, analyse and communicate data about their service;
› There is often no expectation or motivation for them to do so until a service review is requested, at which point pulling together retrospective data becomes a challenge;
› NHS patient information systems are geared towards collecting episodic data on activity, rather than data tracking a patient caseload.

There is also the challenge of collecting data on outcomes. MSSNs work as part of wider teams so attributing particular outcomes to their interventions – which are distinct from neurologists, therapists or self-management – is challenging.

MS is progressive and deterioration is likely for most people, so having a comparator or control group that has no access to a nurse is an essential prerequisite for demonstrating the difference nurses make. This is, however, also fraught with practical and ethical challenges. Undaunted by these challenges, the MS Trust decided to invest in a project that would close the evidence gap, and address the lack of evaluation skills and tools among the nurses.

The need was clear: specialist nurse posts were under constant challenge, as demonstrated by calls to the organisation from teams being asked to justify their roles or grades, and fend off partial redeployment to ward shifts. There were many areas of the country where nursing
coverage was so stretched that many people with MS were without access to a nurse. As a result, the Generating Evidence in Multiple Sclerosis Services (GEMSS) programme was launched at the start of 2012.

The GEMSS programme
The GEMSS programme was established to provide hands-on support for teams to evaluate their own services using real-world data. As well as adding to the evidence base, it was designed with a:

- Professional development component to build the skills and capabilities of the nurses involved;
- Service development component to foster an improvement culture in the services evaluated.

In addition, it aimed to leave a lasting legacy for all MS nurse services by developing a set of common quality standards and measurement tools. The programme’s specific objectives are outlined in Box 1.

The approach
The GEMSS evaluation ran from 2012 until 2015. Two successive cohorts of MS nurses (five teams in GEMSS I and 11 teams in GEMSS II) were recruited onto the programme and each was supported to evaluate their own services over the course of a year.

The GEMSS approach was developed by the MS Trust in partnership with evaluation consultants Geraldine Mynors and Jane Suppiah, both of whom have expertise in evaluation and experience of working in the NHS. They acted as facilitators but collaborated with the MS Trust team on the programme design and development of the evaluation tools used. The shared vision and close working relationship between the MS Trust project director, Amy Bowen, and the facilitators were key to successful programme delivery.

The evaluation report of GEMSS (Suppiah et al, 2015) highlights a number of distinctive features that drove it forward:

- Competitive selection process: Teams were chosen through a national, competitive selection process to represent a cross-section of MS services. Thirty-one teams applied to take part in the programme across the two cohorts. The primary criteria for selecting teams were a demonstrable willingness and enthusiasm to engage with the process as well as local management support – but an additional factor was ensuring a balance of small and large, acute and community, and urban and rural teams. Successful teams were asked to nominate “GEMSS leads” to drive their team’s engagement in the project. In total, 14 teams in England and two in Scotland were selected.

- Facilitator support: GEMSS offered teams practical support from the start to the completion of their project. Each participating team received around nine days of tailored facilitator input delivered through a combination of conference calls and two further training workshops. Thirty MS specialists (27 MSSNs, two physiotherapists and one research coordinator) took part in GEMSS training.

- Co-production: The GEMSS model involved GEMSS teams not only in collecting data, but as partners in the design of the evaluation logic and tools. The evaluation framework, key process indicators (KPIs) and user surveys were all jointly developed with teams from the GEMSS I cohort.

- Expert advisory group guidance: The broad membership of the advisory group, including representatives of other professions and specialties, as well as national policy makers and service users, enabled it to deliver critical feedback and analysis on the scope, development and findings of the project throughout.

- Relationships with senior managers in trusts and hospitals: Buy-in and support from managers in the GEMSS teams’ organisations was an important component of the programme. It facilitated the practical support required for activities, such as the patient survey, and ensured findings presented by teams in their local reports were disseminated and acted on. In the second cohort, GEMSS II, each nurse team held a local ‘launch’ of GEMSS in their trust or health board to present the project to other team members, neurologists, managers, service users, commissioners and wider stakeholders.

- Central support for survey activities and report writing: In recognition of the limited time GEMSS leads would have, the MS Trust removed much of the administrative burden of surveys and technical analysis by handling this centrally at the charity’s headquarters. GEMSS leads were required to provide case studies and a service description, but the MS Trust facilitators populated individual GEMSS teams’ reports with data. This allowed the leads to focus on working collaboratively with facilitators to develop conclusions, recommendations and a narrative for the body of the reports.

- Data collection tools: Monitoring and evaluation tools were developed to provide a practical means teams could use to collect data about their activities and outcomes. While existing NHS information systems were used to gather data wherever possible to avoid

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**BOX 1. GENERATING EVIDENCE IN MULTIPLE SCLEROSIS SERVICES: PROGRAMME OBJECTIVES**

The Generating Evidence in Multiple Sclerosis Services (GEMSS) programme aimed to:

- Provide support for the evaluation of a total of 16 multiple sclerosis specialist nurse services
- Identify the organisational and individual skills and resources required to undertake service evaluation and to seek to build these in the nurse teams involved
- Produce reports on MSSN services for key commissioning and management audiences in each location
- Explore the feasibility of identifying general quality indicators and key process indicators for MSSN services
- Explore the feasibility of developing general tools for data collection for MSSN service evaluation, including a patient experience survey and a simple framework for capturing activity and outcome data
- Aggregate the results from all GEMSS teams into an overall report on the value of MS specialist nursing in response to the evidence gap outlined in Mynors et al (2012)
- Identify and develop the support mechanisms needed for teams to continue to evaluate and improve their services beyond the year of intensive GEMSS support

The GEMSS I programme was launched at the start of 2012. Two successive cohorts of MS nurses (five teams in GEMSS I and 11 teams in GEMSS II) were recruited onto the programme. The GEMSS model involved GEMSS teams not only in collecting data, but as partners in the design of the evaluation logic and tools. The evaluation framework, key process indicators (KPIs) and user surveys were all jointly developed with teams from the GEMSS I cohort.

- Competitive selection process: Teams were chosen through a national, competitive selection process to represent a cross-section of MS services. Thirty-one teams applied to take part in the programme across the two cohorts. The primary criteria for selecting teams were a demonstrable willingness and enthusiasm to engage with the process as well as local management support – but an additional factor was ensuring a balance of small and large, acute and community, and urban and rural teams. Successful teams were asked to nominate “GEMSS leads” to drive their team’s engagement in the project. In total, 14 teams in England and two in Scotland were selected.

- Facilitator support: GEMSS offered teams practical support from the start to the completion of their project. Each participating team received around nine days of tailored facilitator input delivered through a combination of site visits, phone calls and emails. This helped them establish their data collection systems, offered analysis and reflection on monitoring and survey data as it became available, and supported them to produce their individual final reports.

- Central support for survey activities and report writing: In recognition of the limited time GEMSS leads would have, the MS Trust removed much of the administrative burden of surveys and technical analysis by handling this centrally at the charity’s headquarters. GEMSS leads were required to provide case studies and a service description, but the MS Trust facilitators populated individual GEMSS teams’ reports with data. This allowed the leads to focus on working collaboratively with facilitators to develop conclusions, recommendations and a narrative for the body of the reports.

- Data collection tools: Monitoring and evaluation tools were developed to provide a practical means teams could use to collect data about their activities and outcomes. While existing NHS information systems were used to gather data wherever possible to avoid
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BOX 2. FINDINGS REVEALED BY THE GEMSS PROGRAMME

Multiple sclerosis nurse caseloads
- The average caseload of the Generating Evidence of Multiple Sclerosis Services (GEMSS) teams is 511 people with multiple sclerosis per whole-time MSSN, far in excess of the “sustainable” caseload of 358 recommended by MS Trust.
- 38% of people with MS on the combined caseload rely on a stick, frame or wheelchair; a further 16% have more severe disability and are immobile.
- Around half of working-age people with MS who were diagnosed >10 years previously report that they have stopped work early on the grounds of ill health.
- MS specialist nurses are the professionals the greatest number of people with MS (78%) have seen about their condition in the previous year.
- People with progressive forms of MS had less contact with MSSNs and neurologists in the past year than those with relapsing remitting MS, but were more likely to have seen a therapist, social worker or community nurse.

Activity, productivity and responsiveness
- People with MS, on average, had 1.4 face-to-face consultations and 1.5 telephone contacts with an MSSN during the year, with substantial variation between individuals.
- People with multiple sclerosis who are on disease-modifying drugs get more contact from MSSNs than those who are not, suggesting that those with progressive forms of MS may be missing out on the care they need.
- There is significant unmet demand from people with multiple sclerosis for more self-management programmes. In total, 68% of people with multiple sclerosis responding to the GEMSS survey said they had not been invited to a course about managing MS symptoms but would like to be.
- Responsive telephone work constitutes a large proportion of MSSN activity, with 78% of people with multiple sclerosis reporting being able to speak to an MSSN the same or next working day last time they telephoned. Conversely, however, 11% said it was generally not easy enough to get hold of their MSSN.
- Activity per whole-time equivalent nurse varies between teams and can be improved by using key productivity levers and having sufficient, effective administrative support.

Outcomes
- MSSNs perform well against national measures of patient experience: 95% of people with multiple sclerosis said they were definitely treated with dignity and respect by their MSSN, 90% said they definitely had trust and confidence in their MSSN, 71% said they would be “extremely likely” to recommend the service to friends or family in a similar situation.
- People with MS cited, on average, 4.5 benefits of having an MSSN in the previous year and provided a wealth of qualitative examples of how their nurse had helped them.
- Features of MSSN services particularly valued by people with multiple sclerosis were consistent in terms of availability and accessibility, a positive and empathetic attitude, specialist expertise, and knowledge and accessibility of consultation location.

Economic effectiveness
- Using conservative assumptions, GEMSS data suggests each whole-time equivalent MSSN participating in GEMSS saved £77,400 in ambulatory care costs during the year.
- MSSNs also reduce hospital admissions and the savings generated are likely to far exceed the costs of employing an MSSN.
- Six percent of working-age people with multiple sclerosis said their MSSN had helped them remain in paid employment in the previous year, resulting in personal and wider societal economic benefits.

duplication, nearly all teams used the GEMSS data collection tool to some extent. This comprised an Excel database for recording caseload, activity and KPIs on a monthly basis, which provided an analysis ‘dashboard’ and ready-made charts showing trends over time. Data was recorded on:

Caseload and case mix
Basic demographics, characteristics and use of disease-modifying drugs were recorded to provide a dashboard of quick reference charts and tables summarising caseload data.

Service activity
Teams collected monthly data on clinic consultations, “DNAs” (non-attendees), home visits, education sessions delivered and phone calls received and made.

Key process indicators
A small set of measurable key process indicators was developed as measurable markers of a high-performing service.

Service user experience
The GEMSS patient survey was piloted with a small group of five to six people with MS. In each participating organisation, the MSSN team sent the survey out to a representative sample of their caseload. The number sent out varied with the size of the team, but the aim was to achieve at least 50 respondents per nurse, allowing for a 50% response rate. Results were received and analysed by MS Trust, with the findings providing some of the key outcomes data presented in the local and national reports.

Achievements
At the outset, teams notably had limited information about:
- The number and characteristics of patients on their caseload;
- Their service capacity;
- How well they were using it;
- What people using the service thought of that service.

Few had much experience of collecting service experience data or using data analysis to make an argument. By the end of the year of participation, this situation had been transformed. Every team stayed the course throughout the year and produced their local evaluation report; four of the five GEMSS I teams were still collecting data two years later, enabling them to be part of the meta-analysis of data that took place at the end of GEMSS II.

Fig 1 illustrates the difference taking part in GEMSS made to team leads’ understanding of their services, based on a five-point scale – one indicated they had no information and had not given the issue much thought, while five meant they had comprehensive information they knew how to use.

As a result of taking part, 81% of GEMSS team leads said GEMSS had enhanced the
Comprehensive, more than 15,000 people with MS, and represents a combined caseload of aggregated for meta-analysis. This dataset anonymised data from the teams to be trusts and health boards that allowed for standing with the participating NHS

What has been demonstrated?
The MS Trust had memoranda of understanding with the participating NHS trusts and health boards that allowed for anonymised data from the teams to be aggregated for meta-analysis. This dataset represents a combined caseload of more than 15,000 people with MS, and constitutes a unique compendium of information.

Besides a final report of the project (Mynors et al, 2015) the early findings enabled the MS Trust to develop a "sustainable caseload model" for MS specialist nursing (Mynors and Bowen, 2014). This, in turn, has been used to map nursing capacity across the country against what is required by local populations. The GEMSS data has highlighted a variety of points about:

- MSSN nurse caseloads;
- Activity, productivity and responsiveness;
- Outcomes;
- Economic effectiveness.

These are detailed in Box 2.

The GEMSS experience has been a rewarding one for the MS Trust and has resulted in three areas of benefit for:

- Participating teams

Being involved in GEMSS has been beneficial for both their own skills and confidence in evaluation, and in improving the services they are able to provide for people with MS. Many of the GEMSS teams have reported that they have reorganised aspects of their service since participating, or made business cases within their organisations for additional nursing staff or administrative support;

- The wider MS community

The data and knowledge generated through GEMSS has enabled the MS Trust to produce a whole range of outputs from the project, including a capacity planning tool and a national user survey service, which are now offered to any MS service in the UK;

MS Trust as an organisation

GEMSS has deepened its understanding of how MS specialist services are working in today’s NHS and has laid the foundation for the MS Forward View project that is underway. GEMSS continues to inform the training and development the MS Trust provides to MS specialists.

Future developments

The process of seeking to improve MS specialist services has not ended with the completion of GEMSS. Based on the findings, the MS Trust is now working on MS Forward View, which aims to create a sector-wide plan for using the workforce more effectively in MS services. The project is looking at parts of the disease pathway, such as the increasingly complex and time-consuming task of monitoring disease-modifying drugs and using a workforce-mapping approach to identify how roles could be used in new and more efficient ways (see www.mstrust.org.uk/ ms-forward-view for more information).

Conclusion

GEMSS has demonstrated the value of joint working between the NHS and a third-sector organisation that has the appropriate level of expertise. Dementia UK has now adopted the GEMSS approach to develop Getting Evidence into Admiral Nursing Services, a similar programme working with Admiral nurses.

GEMSS has demonstrated that nurses can, and should, evaluate their services – but only with the right level of support. None of this would have been possible without the commitment and hard work of the participants who saw the value of collecting meaningful data alongside their work supporting people with MS. NT

References


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