DEVELOPING AN INFORMATION PRESCRIPTION SERVICE

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BACKGROUND By the end of 2008 everyone with a long-term health or social care need should be offered an ‘information prescription’ (IP) to guide them to reliable, personalised and timely information (DH, 2006).

The DH identified that a ‘one-size-fits-all’ approach would be inadequate, as IPs should meet individual needs. It recruited 20 pilot sites to develop, implement and evaluate IPs to inform a nationally available resource pack (NHS, 2008a).

The Northumbria Parkinson’s disease service is a multidisciplinary specialist service. It runs seven outpatient clinics and manages the long-term care of around 900 patients. Our service, working with the Parkinson’s Disease Society, successfully applied to be one of these 20 pilot sites.

For people with long-term conditions, key concerns are improving quality of life, and support to manage symptoms and live as independently as possible (DH, 2005).

AIM The overall aim was to inform the successful design and delivery of IPs nationally and support policy implementation (NHS, 2008b). All 20 pilot sites were expected to develop IPs within a strict time frame starting in February 2007, with the final report being submitted to the DH in January 2008. Our own aim was to develop a best-practice model to standardise information provision across our service.

METHOD Design

We used a quality-improvement cycle (Jennings et al, 2007) to design, assess, inform, modify and implement IPs.

Phase 1 – plan: gather information to define the problem, evaluate information provision and inform IP development;

Phase 2 – do: test the service;

Phase 3 – study: monitor and assess it;

Phase 4 – act: implement the new service.

Project management

A project steering group included staff in our service (Parkinson’s disease nurse consultant, consultant and health psychologist) and the national and local Parkinson’s Disease Society. A project manager led the initiative and reported to the steering group.

The steering group linked with the national consortium to learn from and share experiences with other pilots. It approved an outline project plan, developed following user consultation. This was registered with our clinical governance department for monitoring and review (Jennings et al, 2007).

Phase 1

Literature review: The initial review used the term ‘information prescriptions’ with an online search engine (Dialog Datastar).

Stakeholder involvement: An event was held to enlist the help of stakeholders and inform the service’s development. Delegates were asked to address four key tasks:

- Examine current information provision;
- Identify main topics and the most appropriate stages of Parkinson’s disease to provide information about them;
- Consider how the prescriptions should be issued and by whom;

CONCLUSION: IPs are essential to patient-centred care and can lead to additional benefits for patients, relatives/carers and clinical services.

IMPLICATIONS FOR PRACTICE

The DH makes a number of recommendations to enable other services to implement IPs (NHS, 2008b). In addition to this, we recommend the following:

- When developing an IP service, it is important to identify and then engage key stakeholders from the project’s outset, involving them in the design, implementation and continuous development of the service;

- IP services should not replace face-to-face consultation but should support information provision;

- To ensure information is personalised, IPs should be adapted to service users’ individual differences including stage of condition, age, learning style, health-seeking behaviour and preferred ways of receiving information;

- IP services should be adequately budgeted and resourced.
● Explore their format.

The topics from the second task were thematically analysed to inform directory development.

Baseline questionnaires: Two questionnaires (Joule and Swain, 2005) were adapted to evaluate information provision. One was distributed to health and social care staff, and another to patients and carers/relatives. The patient/carer questionnaires aimed to identify gaps in provision and explore how information was accessed. The professionals’ questionnaire covered information delivery, quality of provision and accessibility, and barriers.

Phase 2

Using information gathered in phase 1, the steering group designed and agreed an IP service. In June 2007 the IPs were trialled at an outpatient clinic before being rolled out to the trust’s other six clinics in November.

Phase 3

A process evaluation (WHO, 2000) explored IP coverage (who uses them) and process (how they were used). Numbers of IPs issued each month and by whom were recorded on a database.

All service users were asked two weeks after receiving an IP to participate in a telephone interview, using a topic guide.

Towards the end of the pilot, the project team and health professionals discussed their experiences of issuing the IPs, their impact on the Parkinson’s disease service and how the IP service could be improved.

RESULTS

Phase 1

Literature search

Thirteen articles including editorials were identified. They included: background information (Mettler and Kemper, 2005); issuing (Siegel et al, 2006); internet use, quality and accessibility (White and Hogg, 2005); and organisation of resources (Goldberg and Morales, 2004). Siegel et al (2006) used questionnaires to evaluate the impact of IPs on patients and health staff.

As IPs are relatively new, little information was available about implementing them in the NHS. None of the studies explored how IPs would affect the nursing role. As studies were limited to diabetes and paediatrics, we referred to a Parkinson’s Disease Society survey (2007) to find out the information needs of our service users and carers.

Despite the need for information on health and social care (DH, 2006), there was little guidance on how organisations could collaborate on this.

Stakeholder involvement

Thirty-nine people attended the stakeholder event, including patients, carers, voluntary organisations, health professionals in primary and acute care, social workers, information professionals and NHS Direct staff. The key themes were around information-giving and content.

Information giving: IPs should be quick and easy to issue in different settings (home visits, outpatient clinics and GP surgeries). They could be used to direct people to information, especially when they do not know what information is available or what questions to ask.

Prescriptions should not depend on online resources because of concerns about their accessibility and the quality of information. Information should be tailored according to age, learning style, health-seeking behaviour and how people prefer to receive it. Individual differences mean the stage of the condition does not clearly indicate what people need to know, so information should be given as problems arise.

Families and carers may want different information and should be treated as service users in their own right. Service users wanted ownership of their learning rather than having their needs defined by staff. They also wanted to be able to discuss the information and ask questions. To allow all staff to follow up and discuss information, records of IPs should be maintained.

IP content: Service users identified a wide range of topics they felt should be included in an IP – mainly about how to access services, diagnosis and drug treatment.

Information not specific to Parkinson’s disease was also needed, on topics such as continence services, palliative care, benefits and managing long-term conditions.

A directory should be compiled, containing prompts to help people identify information that they may not know is available. Information could be categorised by stage of condition or topic, or by staged access to each topic, for ease of use. Structuring from basic to more advanced information would help learning.

REFERENCES


Dialog Datastar (superseded by National Library for Health). www.library.nhs.uk


Service users wanted quality-assured national and local information in a variety of formats and languages.

Baseline questionnaires

Thirty-nine questionnaires were returned (35 from patients, three from carers and one completed by both).

There were high levels of satisfaction with information provision, except among a few respondents attending non-specialist or other services.

Important topics to be included in the IPs are: how Parkinson’s disease affects everyday activities; carer/relative information; how professionals and services can help; and benefits and financial advice.

The main sources of information were talking to someone (64%, n=25), leaflets (64%, n=25), booklets (67%, n=26) and copies of GP letters (39%, n=15). Few used the internet (10%, n=4). Most received
information from the Parkinson’s disease specialist service (62%, n=24), with fewer approaching the Parkinson’s Disease Society (51%, n=20) or searching for it themselves (51%, n=20).

Eighteen health and social care professionals returned questionnaires. They identified two barriers to information provision: staff only provide information if asked (67%, n=12); and limited time during consultations (50%, n=9). Open response data identified other barriers: lack of storage space; difficulties ensuring information is up to date; and lack of funding. Professional respondents considered information provision to be the responsibility of Parkinson’s disease nurse specialists. GPs and non-specialists did not know where to find reliable resources.

### Phase 2

Information was prescribed by health professionals using an IP template then followed up by an information specialist. A flow chart of the IP process was produced.

The IP template involved a three-tick process in which staff identified the stage of condition, type of information required and preferred delivery method. The stages of the condition were organised according to MacMahon and Thomas’ (1998) five stages of Parkinson’s disease with a ‘GP referral’ stage for those with suspected disease.

<table>
<thead>
<tr>
<th>Dispensing route</th>
<th>Advantages</th>
<th>Disadvantages</th>
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<tbody>
<tr>
<td>Parkinson’s Disease Society information and support workers</td>
<td>• Extensive knowledge and understanding of Parkinson’s disease&lt;br&gt;• Longer time discussing users’ health and social care needs and more information sent out&lt;br&gt;• Information needs of both patients and their carer/family assessed if required&lt;br&gt;• Trained to offer emotional support if needed&lt;br&gt;• Possibility of follow-up support and future contact point</td>
<td>• Currently these workers are not accessible to all Parkinson’s disease services&lt;br&gt;• Systems need to be agreed to transfer confidential service-user information to workers&lt;br&gt;• Potential cost implication&lt;br&gt;• Extensive health and social care databases would need to be developed&lt;br&gt;• Information worker’s time allocated to IPs may be limited</td>
</tr>
<tr>
<td>NHS Direct</td>
<td>• Nationally available&lt;br&gt;• Established and reputable service&lt;br&gt;• IP service was supported by IT software developed by NHS Direct&lt;br&gt;• Access to health and social care databases&lt;br&gt;• Trained information advisers</td>
<td>• Information advisers not specialist trained&lt;br&gt;• Potential cost implication&lt;br&gt;• Not locally based&lt;br&gt;• No close links with clinical team&lt;br&gt;• Less personalised</td>
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To reflect the IP template, the information was organised according to stage of condition and type of data. All newly diagnosed patients and carers were offered a diagnosis information pack.

Prescriptions were issued by nurse specialists, doctors and physiotherapists during outpatient appointments or home visits. The nurse consultant and project manager telephoned patients to clarify, access and send the information requested.

From November 2007, IP forms were sent to information advisers at NHS Direct and to Parkinson’s Disease Society information and support workers.

Copies of covering letters to service users were retained in their notes and the issue of an IP included in the clinic’s letters to GPs.

Phase 3

**IP coverage:** The total number of prescriptions issued between June 2007 and January 2008 was lower than originally predicted (400). None were issued until planning had been completed in June 2007, and a limited trial was undertaken before full implementation in November. Some queries were better discussed at the point of care (for example those about sexual problems), and not everyone offered an IP wanted one.

**IP process:** The advantages and disadvantages of dispensing IPs using NHS Direct and Parkinson’s Disease Society workers were compared (Table 1). Each IP took approximately 45 minutes to do and cost £15–£19 per service user.

**Service user evaluation**

Follow-up telephone interviews were carried out with 14 carers (nine women) and 41 patients (22 women). Generally, service users were satisfied with the IP service and how they received information, appreciated the opportunity to discuss information needs on the phone, and liked being sent this rather than searching for it themselves.

Most found that the information was easy to understand, comprehensive, concise, well written and that it addressed their initial queries. Those receiving information by email were particularly satisfied.

The prescribed information was relevant and timely. There were individual differences regarding the best time to provide certain information and it was important to assess how much people wanted at any point.

**Benefits of IPs:** Written information was useful because recipients could refer to it in their own time and share it with carers or relatives. It also helped to clarify what had been discussed during consultations. Service users became more aware of the information available and how to obtain it.

Service users found the information helped...
them to adjust to their diagnosis, reassured them that they were doing the right thing, and helped them make decisions about drug treatments and complementary therapies.

Some followed recommendations in the IP, such as adopting a new exercise regime, or seeking more information, advice or support from health professionals or the Parkinson’s Disease Society helpline. Some carers felt the information enabled them to take better care of patients.

Problems: We experienced problems with telephoning patients. Five were difficult to contact and did not get their IP dispensed. Some had problems with speech (Parkinson’s Disease Society, 2008a) and found telephone communication difficult.

Other problems were that people could not remember receiving the information or had poor recall of it due to memory problems (Parkinson’s Disease Society, 2008b). About one-third had not read or only ‘skimmed through’ the IP but most believed it would be useful. Some information (such as that about drugs) was difficult to understand.

One person had been upset to learn about their condition but wanted to know about it. Health professionals were informed about complex queries or potentially distressing information so additional support could be offered. Service users were also directed to the Parkinson’s Disease Society helpline.

Health professional evaluation

Some team members (including Parkinson’s disease nurse specialists) struggled to see the benefits of IPs, given the amount of information already offered. There were concerns that the IP service would replace current provision rather than enhance it, that the telephone would replace face-to-face discussions, and that information dispensed by others would not be reliable.

The nurse specialists in particular had a strong sense of ownership over information provision and a few felt uncomfortable about delegating this role, as they were concerned this would adversely affect the nurse-patient relationship and continuity of care.

Initially, IPs created extra workloads as staff found discussing information needs time consuming, and nurses felt they often had to ‘pick up the pieces’.

As the role of the information specialist in identifying specific needs was clarified and systems were put in place to link IPs into the service, these problems diminished. Health professionals gained confidence in the prescription service and identified benefits for both themselves and service users.

DISCUSSION

In common with the DH evaluation of the pilots, our service users were satisfied with the information and supportive approach to IPs, understood most information, and felt IPs enabled them to better understand, manage and be more in control of their condition (NHS, 2008b).

Information is a critical component of patient-centred care that patients value and, in future, is likely to influence their choice of care provider. IPs are now embedded in our service.

This was an ambitious pilot project. Timescales for the pilot sites were short, which limited the opportunities to trial the IP template, directory and IT solutions, develop a more user-led model and engage and include professionals in decision-making.

In less than a year, the pilot was able to establish IPs in our service, trial different methods of delivery and evaluate the impact on service users and health professionals.

Involvement of all stakeholders is crucial to quality improvement (DH, 2002) and some people resisted the IP service as they saw it as a threat to their role. It was important to recognise and address these concerns.

There is now a need to continue the quality-improvement cycle to establish a standardised and sustainable approach to IPs that can be used in our trust for all long-term conditions and across disciplines, linking primary and acute care.

Limiting the IP service to Parkinson’s disease meant the cost of IPs per service user was relatively high. However, economies of scale can be achieved by extending it to other long-term conditions and Parkinson’s disease services.

It will be essential to engage the support of voluntary organisations where they have quality-assured resources and, ideally, user-led information support systems.

CONCLUSION

IPs are an essential component of patient-centred care and can provide additional benefits for people with Parkinson’s disease, relatives/carers and the clinical service. National implementation of IPs will reduce regional variability in access to personalised and timely information.

REFERENCES


Parkinson’s Disease Society (2007) Results of the Parkinson’s Disease Society’s members’ survey: Life with Parkinson’s Today – Room for Improvement. London: PDS.


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