

Information prescriptions

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Background

The White Paper 'Our health, our care, our say'¹ contained an explicit commitment to introduce 'information prescriptions'. The asymmetry of information between the health care professional and the client/patient has long been seen as an important characteristic of that relationship, and one which would need to be addressed as part of creating a more patient centred approach to delivery of health and social care, or supporting moves to self management of long term conditions.

A number of policy documents in recent years have emphasised the importance of access to information for users of services. For example, *Building on the best: choice, responsiveness and equity* set as a policy goal 'to ensure people have the right **information**, at the right time, with the support they need to use it.'² *Better information, better choices, better health* developed these ideas and introduced the concept of 'information prescription' as part of a process of routinely assessing individuals' information needs and signposting them to directly relevant information about their condition and the options open to them, within consultations.³

In the consultation exercise 'Your health, your care, your say', a majority (65%) of people with long term conditions said they wanted more information about their condition and about services, this rose to 84% - 89% when asked about information on specific services (to support independent living, and on benefits, for example)⁴. Finally, the Darzi Review explicitly linked information needs and provision to the promotion of choice and personal control for users of services,⁵ and the NHS Constitution makes the provision of appropriate

information to support choice a right⁶ and refers specifically to the introduction of information prescriptions.⁷

Referring directly to the success of other initiatives which have used the model of 'prescribing' ('exercise on prescription', for example)⁸ the White Paper made a commitment that all people with long-term health and social care needs and their carers would receive an 'information prescription' by 2008. However, the White Paper contained no further detail as to how information prescriptions would work, referring instead to the development work being undertaken to pilot the idea.

Aims

Information prescriptions are intended to enable users and carers to better manage their own care through the provision of information delivered in a timely, personalised and accessible fashion. In terms of the White Paper goals, they are intended to address the following: more support for people with long term needs; tackling inequalities and improving access to services; more local and convenient care; more choice and a stronger voice for individuals and communities; and better prevention and early intervention for improved health, independence and wellbeing.

The initiative

The term 'information prescription' covers a range of practices for giving individual service users access to better information about their condition, about the treatment options available to them and the pros and cons of different options, about the support networks they can access, and about ways in which they can manage their own health and wellbeing. The distinguishing feature of an information prescription should be the degree of individualisation involved – the term 'prescription' is intended to convey that

it is a personalised recommendation and not just a standard set of information. The corollary of 'prescribing' is 'dispensing'; the process by which the service user is given access to the information. It can take the form of written material, but can also be provided in other media; DVDs or podcasts, for example. Beyond this somewhat abstract description, the concept is open to a range of interpretations and forms.

In order to trial the introduction of information prescriptions, the DH recruited twenty pilot sites nationally (i.e. within England) and commissioned an evaluation to be carried out by a consortium comprising the Office for Public Management, (OPM), GfK-NOP and the University of York. The pilots were established in January 2007, with the aim of having introduced information prescription by January 2008. A feature of the initiative was the diversity represented by the pilots in terms of setting and conditions addressed. They covered health and social care settings including primary care, secondary care, acute healthcare and community mental healthcare, and addressed a range of long term conditions and age groups. This diversity was intentional as the initiative was intended to 'test and provide evidence on the effectiveness and impact of information prescription on users, carers, professionals, and organisations, including the voluntary sector'.⁸ Much of the work of the pilot sites was developmental; there was no single pattern for what information prescriptions were or how they should be delivered; each site created a locally agreed and owned model for delivery. Key elements of this were the type and quality of information to be included, the means by which it should be offered to the recipient and by whom ('prescribing'), and how the recipient would in practice access and receive the information ('dispensing'). One of the tasks of the evaluation was to map and categorise the emerging models of delivery.

There was always the intention that the development of information prescriptions at local level should be

supported by, and linked to, a range of ways to provide health information nationally, through the NHS Direct and NHS Choices websites, for example, and this was being developed at the same time as the pilot sites.

The evaluation

Aims and objectives

The aim of the evaluation was to assess the overall effectiveness of the pilot programme, and to gather learning about what worked well in respect of the information prescription process, from the different approaches being adopted in each of the 20 pilots. More specifically, the evaluation was designed to help inform the four main goals of the pilot programme:

- To shape the practical design and delivery of information prescriptions nationally, including how this will be supported nationally at the locality level
- To provide evidence on the effectiveness and impact of information prescriptions on the public, professionals, and organisations alike
- To contribute to successful national implementation of information prescriptions by 2008 to people with a long term condition.
- To inform the policy direction, ensuring that the implementation of prescriptions is integrated with other major policy drivers.

Design

The evaluation was a mixed methods design, with the following main elements:

- Qualitative research: two waves of qualitative fieldwork comprising a focus group and set of in-depth semi-structured interviews with key stakeholders from each of the 20 pilot sites. Over 150 staff

took part in this element of the study.

- **Surveys:** two surveys of patients/users, carers and professionals involved in information prescriptions. The first of these covered 12 of the 20 sites, including 74 service users who had received information prescriptions and a further 94 who would have received them had their site started issuing them. It was originally intended to compare these two groups, but as they were not sufficiently comparable on a range of characteristics, the non recipient group was instead used as a comparison group for survey responders from the same sites in the second survey. The second survey was carried out in all 20 sites and included 299 service users (a 36% response rate), 164 carers (total number not clear, but an estimated response rate similar to that for users) and 243 professionals (49% response rate).
- **Activity data collection:** monthly pro forma returns to the evaluation team giving information about: the numbers of information prescriptions issued and by whom; the number of 'items' on a prescription and where and by whom the dispensing process was carried out; estimates of staff time involved and any other identifiable expenses. A 'stocktaking' exercise about previous information-giving activities was also carried out.
- **Review of Information Technology:** a review of the IT implications involved in the development of information prescription, examining the use of IT in pilot sites, stakeholder views on the current systems and the potential uses of IT to support information prescription in future.

As well as the data gathering described

above, the evaluation team carried out learning and support activities, running action learning events for participants from the pilots, and creating a website⁹. The website included a restricted area for discussion and provision of support tools among the pilots, as well as a public access point for the findings of the evaluation. The public website is still available as a resource.

Evaluation team's findings and conclusions

The headline findings were reported⁸ in terms of process issues and impact. The evaluation also provided estimates of the local and national resource implications of mainstream implementation of information prescriptions, based on the costs and activity levels of the pilots, combining these data with nationally available data on prevalence of long term conditions and associated service usage rates.

Process issues. The evaluation report divides the findings on the implementation process into stages: preparation, development, and delivery of information prescriptions.

Preparation involved for most pilots a process of definition and of agreeing 'principles' on which to provide information prescriptions, and the sourcing and collating of information.

Development involved a process of engaging local users, carers and professionals with the information prescriptions; quality assuring information; developing IT systems and training staff in delivery of information prescriptions. The *delivery* stage demonstrated the diversity of the pilots, with three broad models for delivery identified, reflecting different levels of 'depth' of prescribing, and mechanisms for dispensing.

- *Model One: Light touch prescribing and self dispensing*
In this model the prescribing process is quick and generally consists of a 'tick box' template or similar, pointing the user towards information they can access themselves via the internet, libraries or voluntary

sector organisations. The model was used mostly in primary care, for people with conditions that were relatively stable and did not require extensive input from secondary care.

- *Model Two: In-depth prescribing and linked dispensing*

In this model prescribing is usually done in a pre-arranged consultation session as part of a care pathway – at referral or review, for example. The prescription is a tailored list of resources, which is then taken to a designated dispenser. Dispensers include a range of providers – community information points and NHS Direct, for example.

- *Model Three: In-depth prescribing with information centre*

This model involves prescribing by a specialist professional – a consultant, a care manager or a specialist nurse, for example – in a structured and tailored way as part of a care pathway. It may involve a two stage prescribing process, with initial and more detailed assessments. Dispensing is then done within a specialist health information centre. This model was predominantly used in secondary care, for high risk or highly complex conditions.

The information technology review identified the multiple stages of information prescription and commented on appropriate technology and issues to be resolved at each stage. The review identified issues reflected elsewhere in the evaluation: the time consuming nature of using electronically generated information prescriptions; issues of quality assurance of information; accessing and storing appropriate information (in particular how to reconcile the need for standard, national, accredited banks of information and quite detailed local information); the complexities of recording prescriptions, to be kept with

individual records; inequities of access to information technology.

Impact on users. Comparison between the group of users in the first survey who had not received information prescriptions, and those who had received them in the second survey suggested a positive impact; there was a drop in the proportion of users who said that professionals did not discuss information with them (40% in the first survey: 12% in the second), and that any information given was not easy to understand (31%:11%). Among those who did receive an information prescription, high numbers of users (73%) reported having more confidence in asking questions about their condition, half (52%) said it had improved their care, while two thirds (66%) said they now felt more in control of what was happening with their condition. However, detailed analysis of these figures suggested consistent differences between groups of users, with those who were in poorer general health, those living in disadvantaged areas, people under 65 and those where the information prescription was delivered through a 'light touch' model less likely to report these favourable outcomes.

Impact on carers. Very high numbers (89%) of those carers who had received or seen an information prescription found it useful. However, a third (35%) overall and nearly half (44%) of those in 'light touch' sites did not know about the information prescription.

Impact on professionals. Two thirds of professionals (66%) were satisfied with how information prescriptions were implemented in their site, with only a few (7%) actively dissatisfied. Just over half (57%) of professionals said that information prescriptions compared favourably with the ways in which information had been given in their site previously. However, a third (36%) felt it was about the same and a small number (5%) felt it was worse. Professionals reported making an assessment before offering information prescription as to whether they thought the user and carer would be able to

make good use of the information.

Resource implications of mainstream implementation. The report provided estimates of demand, and resource implications of national implementation of each of the three models, and identified key steps to be taken at local and national level to implement each. If Model One ('Light Touch') was rolled out in primary care, it was estimated that 65% of consultations for long term conditions would result in the take up of an information prescription. For a general practice with a list of 10,000 patients, this would mean 5575 such prescriptions a year for patients with the long term conditions covered by the Quality Outcomes Framework (QOF) registers (and over 8,000 if a wider range of long term conditions is used). This would also generate 1115 (1673) contacts with local and national voluntary organisations, 613 (920) contacts with Benefits Offices and 279 (419) contacts with local libraries. It was estimated that for a small to medium sized PCT, the implementation of this model of information prescription would require a full time senior coordinator, plus a junior support post.

The resource implications of the other two models are much harder to gauge as it proved very difficult to identify the time spent by professionals on the prescribing element: estimates ranged from 10 – 15 minutes for relatively straightforward conditions to over an hour for more complex ones though this could include 'dispensing' where this was done within the same consultation. The resource implications in terms of staff time, in particular for Model Three, where senior clinicians would be heavily involved, were high but no actual figures were given in the report. Where dispensing was done by designated other agencies, this would need to be resourced either through commissioning or some form of payment by results.

Conclusions/recommendations

The report makes 11 key recommendations on how information

prescriptions should be implemented. These are to do with stakeholder involvement in planning, the content and accreditation of information directories, the importance of templates and 'structured scripts' in delivery, the need for personalisation through a diversity of delivery mechanisms and formats, and issues for local partnerships in planning and delivering information prescription. The recommendations also include the need to ensure information prescriptions are accessible and useful to disadvantaged users and carers.

Comments on the evaluation

This was a complex evaluation, combining developmental and learning activities with more traditional evaluative methods. As indicated by its stated aims and objectives, the intention of the evaluation was not to provide evidence for a decision about whether or not information prescriptions should be implemented; this had already been determined by a prior policy decision announced in the White Paper.

The formative aspect of the evaluation was strong; the information prescriptions website, and the online resources available from it, provide a wealth of information and tools for other sites wanting to develop information prescription. The report identified very clearly the steps that would need to be taken both locally and nationally to implement information prescription. Where the evaluation was weakest was in terms of looking at the effectiveness and impact of information prescriptions.

One reason for this is that the development stage took longer than anticipated and many pilots issued far fewer information prescriptions in the evaluation period than had been expected. This reduced the number of respondents to the surveys of users and carers. Another reason is the difficulty of interpreting evidence from so many disparate sites and contexts in a way that makes it useful, in particular for service delivery, past an initial stage of development.

All the findings on activity, and inferred resource implications, are estimates. It was difficult for the evaluators to get good data on time and resources expended on the process. It was also very hard to identify what sites had been doing before, and therefore to quantify what difference the information prescription pilot actually made. The report assumes that take up would decrease over time as people became better informed, however, it is also possible that people would come to expect a higher level of information giving in consultations. In particular the aim of personalising information suggests that an individual's information needs would be reviewed on a regular basis – information prescription in this case would not be a one off process.

Our interpretation of the findings

This evaluation appears to comprise a number of disparate elements of data collection, with some elements being much stronger than others. The evaluation had a strong formative function in helping those implementing information prescriptions to learn from each other. The qualitative work also provided a useful typology of the different approaches to implementing information prescriptions that developed. However, the collection of data on outcomes was hampered by the smaller numbers of respondents than intended and the extent to which aggregating results across the pilots makes it difficult to interpret in the light of different models for delivery. Some analysis by broad category of model ('Light touch' etc) and by different groups of recipient was carried out. But this analysis raises rather than answers questions that would be important in terms of the White Paper goal of tackling inequalities.

Other relevant evaluation work

We also looked at the development of information prescriptions in a site not included in the national initiative. This site had, at the time of our fieldwork, not reached a stage of issuing any information prescriptions, and so was

unable to provide any evidence on delivery or outcomes. However, in terms of development, experience here echoed that in the pilots – that the process of developing a model and quality assuring information was extremely time consuming. Since the national evaluation reported, a further piece of work has been published, evaluating different models of providing information prescriptions through online websites,¹⁰ This small scale study compared three locally provided UK sites (two of which had been in the national pilot evaluation) and the national NHS Choices site. It also included one international (US-based) site. While this study could not look at impact or outcomes for users, it did assess the quality and accessibility of the sites against published checklists for evaluating information sources. Overall, this study found that the national and international sites were better sources of up to date and detailed condition-specific information, while the local sites were strong on providing links and information about local services.

Conclusions about the evidence that the initiative achieved its objectives and delivered policy goals

The initiative was intended to enable people with long term conditions to better manage their own care through the provision of timely, personalised and accessible information. The evidence is that setting up systems to make that information available is complex and potentially resource intensive. Within the evaluation, and also in the later study comparing online sites for information prescription, there is emerging evidence of the need to ensure that an appropriate balance is struck between local and national systems of information gathering, quality assurance and provision. Local systems for information prescription, especially for the 'light touch' model should make use of the resources available nationally. In terms of the White Paper goals, information prescriptions are clearly a means of providing more support for people with long term needs, and were well

received by many users. What is not clear, because of the lack of data on outcomes, is whether they are a cost effective means of doing so and whether they do in fact lead to better prevention and early intervention for improved health, independence and wellbeing, and more choice and a stronger voice for individuals and communities. There are also issues raised by the evaluation about whether they are a means of tackling inequalities and improving access to services, or whether they may in fact reproduce some existing inequalities.

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