Evaluation of Information Prescriptions

Final Report to the Department of Health

August 2008
Ewan King, Director, OPM
Kai Rudat, Director, OPM
Beth Anderson, Fellow, OPM
Anita Grabarz, Fellow, OPM
Richard Glendinning, Director, GfK NOP
Sarah McHugh, Associate Director, GfK NOP
Professor Roy Carr-Hill, University of York
Paul Dixon, University of York
# Contents

- Executive Summary .................................................................................................................. 1
- Recommendations .................................................................................................................... 6
- Section One: Introduction ......................................................................................................... 8
- Section Two: Methodology ....................................................................................................... 10
- Section Three: Preparation ...................................................................................................... 16
  - Determining the purpose and scope of the project ............................................................... 16
  - Preparing the ground ........................................................................................................... 17
  - Setting up management and support arrangements ........................................................... 24
  - Identifying content .............................................................................................................. 25
  - Developing directories ......................................................................................................... 28
  - Developing templates .......................................................................................................... 31
  - Conclusions on the preparation stage ................................................................................ 37
- Section Four: Development ..................................................................................................... 40
  - Engaging stakeholders ......................................................................................................... 40
  - Quality assurance and accreditation .................................................................................... 48
  - Information technology (IT) ................................................................................................. 52
  - Training and support ........................................................................................................... 66
  - Conclusions on developing Information Prescriptions ....................................................... 70
- Section Five: Delivery ............................................................................................................. 75
  - Personalisation of Information Prescriptions .................................................................... 75
  - Providing the right information at the right time ............................................................... 75
  - Providing information in the most appropriate way ........................................................... 79
  - Providing information in an appropriate format .............................................................. 80
  - Providing information at the right place ............................................................................. 82
  - Approaches to delivering Information Prescriptions ......................................................... 83
  - Activities and resources to develop and deliver information prescribing ......................... 91
  - The resource implications of the three models ................................................................. 96
  - Working in partnership to deliver Information Prescriptions ............................................ 126
  - Involving the workforce ...................................................................................................... 137
  - Conclusions on the delivery stage ..................................................................................... 143
- Section Six: Outcomes ........................................................................................................... 147
  - Conclusions on the outcomes stage ................................................................................... 159
- Section Seven: Conclusions and recommendations ............................................................. 161
  - Conclusions ...................................................................................................................... 161
  - Recommendations ............................................................................................................ 166
Executive Summary

The NHS white paper, *Our Health, Our Care, Our Say: a new direction for community services*, made a commitment to introducing Information Prescriptions for all long-term health conditions. The white paper proposed that health and social care services:

‘... give all people with long-term health and social care needs and their carers an ‘information prescription’. The information prescription will be given to people using services and their carers by health and social care professionals (for example GPs, social workers and district nurses) to signpost people to further information and advice to help them take care of their own condition.’

‘By 2008, we would expect everyone with a long-term condition and/or long-term need for support – and their carers – to routinely receive information about their condition and, where they can, to receive peer and other self care support through networks.’

To ensure the successful design and delivery of information prescriptions nationally, the Department of Health (DH) recruited 20 pilot sites to test and provide evidence on the effectiveness and impact of Information Prescriptions on users, carers, professionals and organisations, including the voluntary sector. The pilots are located in a range of health and social care settings, including primary, secondary, social care, acute and community mental health, and address a spectrum of conditions including cancer, cystic fibrosis, sight loss, Parkinson’s disease, diabetes, arthritis and asthma. Many of the pilots were delivered on the basis of partnership arrangements between national voluntary sector organisations and local statutory health and social care services. A brief summary of each pilot site can be found in Appendix One. The information and momentum built through this piloting phase will be used to develop the final strategy to inform local and national delivery.

An Information Prescription has five main components:

- **Information content** – the identification of reliable and relevant sources of information.
- **Directories** – repositories of information that link to individual Information Prescriptions.
- **Personalised process** – information is provided that is specific to the condition, place and point on the care pathway.
- **Issuing or prescribing** – creating and offering an Information Prescription to a user or carer.
- **Access** – Information Prescriptions are made available to users through a range of accessible channels, such as face-to-face engagement, the Internet, email, telephone and outreach.

This report introduces a number of key terms, such as prescribing, dispensing and directories. We provide definitions for these in Appendix Eight.

The project has been supported and evaluated by a consortium of three organisations – the Office for Public Management (OPM®), the University of York and GfK NOP. A project board comprising stakeholders from the DH, national voluntary sector organisations and the pilot sites oversaw this work. This is an independent report produced by the Consortium for DH. The programme of evaluation and learning activities took place between February 2007 and March 2008, and was aligned with the duration of the pilot phase of Information Prescription rollout.
The evaluation itself was limited by several factors. Firstly, the pilot sites started prescribing later than expected and there were lower numbers who received Information Prescriptions than was first planned. This meant that the response to the surveys was also much lower than expected. Secondly, assessment of long-term impact on health outcomes and service utilisation was restricted by the short timescales for the overall evaluation. Finally, the evaluation did not involve a random control trial or experimental design, which limits our ability to attribute changes to patient and service outcomes to the pilot programme.

The Information Prescription pilot programme has led to a wide range of interesting and innovative practices being developed in providing information to users and carers. High numbers of users and carers have found the information useful and professionals involved in pilots were positive about Information Prescriptions. In qualitative interviews with pilots, there was strong support for the concept and potential of Information Prescriptions, with most of the pilots continuing to implement Information Prescriptions beyond the pilot funding allocation.

The pilot sites

The 20 pilot sites were established in January 2007 with the aim of developing and testing the introduction of Information Prescriptions within their local health and social care settings by January 2008. It is possible to identify four broad stages which the pilots experienced as they approached the task of developing and implementing Information Prescriptions and making these available to users and carers: preparation, development, delivery and outcomes.

Preparation stage

During the preparation stage, pilots set about: conceptualising and defining what Information Prescriptions meant to them; developing local plans to implement Information Prescriptions; consulting and engaging users, carers and professionals to gain their involvement and ownership over the plans; identifying information sources; and developing Information Prescription templates.

Pilots arrived at different views on how Information Prescriptions should be defined, with some describing concerns about the notion of information being prescribed, which they regard as overly ‘medicalised’. However, the majority of the sites arrived at a set of common ‘principles’ that they felt should underpin any future development of Information Prescriptions. All of the pilots felt it was crucial to involve users, carers and professionals in developing local proposals for implementing Information Prescriptions, with some pilots choosing to include users as members of local pilot steering groups.

Having developed implementation plans, pilot sites set about identifying relevant information sources. In doing this, some sites benefited from having pre-existing information held by partner organisations, such as national voluntary sector organisations, while others had to develop new sources of information. In the end, the majority of pilot sites felt it was important that a wide range of information sources were made available to users, not only representing their immediate care needs, but also helping them to improve their broader well-being and quality of life. In the majority of sites, pilots involved users and carers in identifying information sources, regarding their involvement as critical. The information was gathered...
and held on information directories, which came in a range of formats, including paper indexes, searchable databases and directories which could be accessed via a website.

**Development stage**

In the development stage, pilot sites set about: conducting a broader process of engagement with users, carers, professionals and the voluntary sector; ensuring that information was quality assured; developing information technology (IT) systems; and providing training and guidance to professionals involved in prescribing and dispensing.

Pilot sites understood early in developing their Information Prescription approaches that professional engagement was critical to building internal and external support for Information Prescriptions and tried to ensure people were happy to take up prescribing and dispensing roles. Pilots went about engaging professionals in a wide range of ways, including making presentations to existing health and social care partnerships locally, meeting senior professionals on a one-to-one basis, writing in staff newsletters and standard marketing, such as the use of posters, flyers and information sheets. It was felt to be most useful to use real case studies describing the benefits of Information Prescriptions to users and carers to inspire and encourage professionals to get involved.

Once gathered, pilots felt it was important that information was quality assured so that users and carers could be confident in the information they were receiving. Several different processes were used by sites to quality assure information, including existing quality assurance processes used by partner agencies in the voluntary sector or NHS Direct or other quality assurance tools such as the DISCERN tool.

Pilots found that IT could greatly assist with the development and delivery of a number of important processes, including the collection, storing and searching of information sources, prescribing processes – whereby information is tailored to meet the needs of users and carers – and dispensing, whereby information is given to the user. The quality of IT used by pilots varied greatly, as did the sophistication of the IT applications and infrastructure, with some pilots developing highly sophisticated websites which could be used for self dispensing, while others relied almost entirely on manual and paper based delivery methods.

Training and guidance was provided to a number of professionals involved in the pilot sites, ranging from the provision of very basic introductions to Information Prescription processes through to more substantial training to help professionals provide information to users and carers with disadvantages or requiring significant additional support. More training is desired by some professionals to support them with Information Prescription processes, particularly hospital-based non-specialist nursing staff and mental health staff.

**Delivery stage**

In this stage, pilot sites had arrived at the point of making Information Prescriptions available to users and carers. The approaches to delivering Information Prescriptions varied greatly across the pilots and were determined by a number of factors, including: the nature of the local user and carer population (e.g. ethnicity, age, stage in condition, socio-economic status, disabilities); the amount of time different professionals can spend with users; local geography (e.g. urban, suburban or rural); the structure and configuration of local services; and the extent of local professional involvement.
The result of this diversity of approaches is that Information Prescriptions are provided by a vast range of professionals, across many different health and social care settings. It is possible to identify three main broad models of delivery, although there are marked differences even within these broad models.

In developing local delivery models, pilots were influenced by two high level considerations: firstly, how to personalise Information Prescriptions so that the right information is provided at the right time and location for users and carers; and secondly, how to ensure that the most disadvantaged users can access and benefit from Information Prescriptions. Both these considerations were regarded as important, but the method for achieving them varied across sites, with some developing much more personalised approaches than others. As survey findings demonstrate, the degree to which disadvantaged users were enabled to benefit from Information Prescriptions varied between sites.

Pilots sought to personalise Information Prescriptions by:

- **Mapping care pathways with users and carers** to establish critical stages in care and their information needs at each stage.
- **Using these pathways to develop tailored templates** which are used during prescribing to identify what information a user needs and when.
- **Developing structured scripts or prompts** to be used by professionals to guide them through the prescribing and dispensing processes so that they ask the right questions about user’s information needs.
- **Consulting users on their preferred method for receiving information** – information formats, where they like to receive information, and how, i.e. by mail, through the Internet, by email or through face-to-face engagement.
- **Ensuring that Information Prescriptions are made accessible** to those with certain disadvantages. Pilots developed a number of strategies that they felt could improve how pilots respond to the needs of those facing disadvantages.
- **Providing additional support** to users facing disadvantages during both the prescribing and dispensing, such as ensuring that information is explained to the user, comes in the right format and language, and can be easily understood by different audiences.
- **Providing information at locations** where disadvantaged users congregate or feel comfortable. Some pilot professionals spoke of the benefit of making Information Prescriptions available in ‘naturalistic settings’, such as community centres, youth centres or older people’s centres and day care facilities, where users who may not regularly access mainstream services, such as GP services, can more easily access Information Prescriptions.
- **Providing Information Prescriptions through different channels** – pilots felt that they could increase access to disadvantaged users by providing Information Prescriptions through a range of communication channels, such as telephone help lines, a range of face-to-face channels such as hospital consultations, through the Internet and home visits.
- **Providing information in a range of formats** – Many of the pilots tested out different formats with different groups of users, such as younger vulnerable people or older Black and Minority Ethnic (BME) users, which resulted in the pilots developing Information Prescriptions templates into a range of formats. For example, several sites found that
their users from a younger age group preferred information via video clips and snappy visual diagrams.

Pilots benefited from adopting a whole systems approach to delivering Information Prescriptions, which involved leading, managing and coordinating Information Prescription systems across the local health and social care system. Such an approach helped pilots to: maximise the involvement of different professional groups; build most effectively on existing systems, information resources, and knowledge of professionals; link Information Prescription processes to integrated care pathways; and ensure, from the users’ perspective, that Information Prescriptions appear seamless and are easy to access wherever you are in the local care system.

Outcomes for users, carers, the voluntary sector and professionals

Information Prescriptions aim to achieve positive outcomes for users, carers and professionals by developing an integrated and seamless system for providing information to users and carers that helps them better manage their own care and keep healthy.

Impact on users

Three quarters agreed that they felt more confident in asking questions about their condition (73 per cent). A cancer patient in the qualitative interviews said that ‘Anything else I want, I can get it when I go to my follow up appointment.’ Agreement was lower among those with self-ascribed poorer health (62 per cent) and people living in disadvantaged areas (60 per cent).

Half (52 per cent) of patients and service users who said that they had received information agreed that it had helped to improve their care. This average figure was lower for the under-65s (44 per cent), those in poorer general health (41 per cent) and people who got an Information Prescription through primary care (42 per cent). The figure was also lower for those in areas where information was offered using “light touch” methods (in pilot sites that largely enabled users to access their own information through self-dispensing, with limited information tailoring or the provision of additional support) (45 per cent) and for people living in less affluent areas (46 per cent). Higher figures were recorded for people living in more affluent areas (58 per cent) and for those who received an Information Prescription through Acute settings (62 per cent).

Two-thirds (66 per cent) agreed that they now felt more in control of what was happening with their condition. There were again some marked variations across the sample with less evidence of impact for the under-65s (55 per cent), mental health patients (57 per cent), those in poorer general health (52 per cent), people who had light touch Information Prescriptions (52 per cent) and people living in relatively deprived areas (also 52 per cent).

Impact on carers

While carers agreed that, when they had seen it, they found information useful (89 per cent), many of those taking part in the survey (35 per cent) were actually unaware of the Information Prescription (especially those cases from sites with light touch Information Prescriptions, 44 per cent). This raises issues about the extent to which pilots were
systematically giving carers information, or ensuring that, where appropriate, the patient or service user shared the Information Prescription with carers.

**Impact on professionals**

The majority of professionals surveyed who issued Information Prescriptions in the pilots (66 per cent) were very or fairly satisfied with how the Information Prescription process was being implemented at their site, while only 7 per cent were actually dissatisfied, although this was notably lower (52 per cent) amongst professionals working in primary care (notably GPs and practice nurses).

Over half of the 155 issuing professionals (57 per cent) said that the Information Prescription process compared favourably with the ways in which information had previously been given at their site, while 5 per cent thought it was worse than the old process and 36 per cent felt it was about the same.

**Recommendations**

To support national and local delivery of Information Prescriptions the following is recommended:

1. Ensure that local users, carers, professionals and the voluntary sector are fully involved in the development of local Information Prescription systems, engaging them in order to determine local needs and information preferences, to inform the design of Information Prescription delivery systems, Information Prescription templates and materials, and to ensure that they can hold the local Information Prescription delivery systems to account.

2. Information Prescription directories cover a wide range of information sources that enable users to access information that can help them to self manage their condition, improve their quality of life, and enhance their well being. Most critical is for directories to cover information about the management of conditions, information on social care services, links to a range of statutory and non-statutory care services, guidance regarding benefits and finance, and information for carers.

3. Develop a national directory of information that stores accredited information on long-term conditions linked to established care pathways. Ensure that this directory can be accessed by both professionals involved in prescribing and dispensing, and by users and carers who wish to self-dispense.

4. Provide a range of ready-to-use Information Prescription templates in a range of formats that can be downloaded and used locally.

5. Information Prescription processes should be personalised to ensure that users receive the right information to support the management of their care at the right time. Tailored templates and structured scripts can ensure this happens. Personalisation can also be widened by enabling users to receive information in a range of formats, through a range of delivery mechanisms (such as through email or post or by telephone) and locations (such as through consultations or drop-in sessions, or at home).
6. There are a range of delivery models which can be used to provide Information Prescriptions and it is likely that local areas will need more than one, or a mix of models, to ensure that all local users and carers can benefit from Information Prescriptions. Local models need to be designed to respond to a range of factors including local population needs, information preferences, the quality and coverage of existing information systems, the local configuration of services, and the structure of the local workforce.

7. Ideally information on any national directory should be accredited using The National Information Accreditation Scheme – an accreditation scheme for health & social care information – thus avoiding the need for local areas to undertake their own quality assurance processes. However, local areas need to develop directories covering links to local services and find appropriate ways to quality assure this information.

8. Local models of delivery need to make provision to ensure that disadvantaged users benefit fully from Information Prescriptions by providing Information Prescriptions through multiple channels of delivery, ensuring that information is easy to read and comes in a range of accessible formats, and putting in place additional support in terms of providing users with explanations and advice.

9. Information Prescription processes need to ensure that carers benefit more fully from Information Prescription systems by involving carers in the design of processes, providing tailored information to carers, and providing additional support to carers, especially those from disadvantaged backgrounds.

10. Local Information Prescription systems need to be developed through a whole systems approach, and across the local health and social care system, which should preferably be defined as falling within local authority (LA) and Primary Care Trust (PCT) boundaries. Local partnership arrangements and joint commissioning arrangements should be utilised to provide strategic direction, planning and commissioning for local Information Prescription delivery.

11. Identify ways to embed and support the development of skills and competencies required by professionals involved in Information Prescriptions through occupational standards and competencies, professional education programmes, and continued professional development.

An expanded set of recommendations can be found in Appendix 10.
Section One: Introduction

The NHS white paper, Our Health, Our Care, Our Say: a new direction for community services, made a commitment to introducing Information Prescriptions for all long-term health conditions. The white paper proposed that health and social care services:

‘... give all people with long-term health and social care needs and their carers an ‘information prescription.’ The information prescription will be given to people using services and their carers by health and social care professionals (for example GPs, social workers and district nurses) to signpost people to further information and advice to help them take care of their own condition.’

‘By 2008, we would expect everyone with a long-term condition and/or long-term need for support – and their carers – to routinely receive information about their condition and, where they can, to receive peer and other self care support through networks.’

To ensure the successful design and delivery of information prescriptions nationally, the Department of Health (DH) recruited 20 pilot sites to test and provide evidence on the effectiveness and impact of Information Prescriptions on users, carers, professionals and organisations, including the voluntary sector. The pilots are located in a range of health and social care settings, including primary, secondary, social care, acute and community mental health, and address a spectrum of conditions including cancer, cystic fibrosis, sight loss, Parkinson’s disease, diabetes, arthritis and asthma. Many of the pilots were delivered on the basis of partnership arrangements between national voluntary sector organisations and local statutory health and social care services. A brief summary of each pilot site can be found in Appendix Six. The information and momentum built through this piloting phase can be used to develop the final strategy to inform local and national delivery.

An Information Prescription has five main components:

- **Information content** – the identification of reliable and relevant sources of information;
- **Directories** – repositories of information that link to individual Information Prescriptions;
- **Personalised process** – information is provided that is specific to the condition, place and point on the care pathway;
- **Issuing or prescribing** – creating and offering an Information Prescription to a user or carer;
- **Access** – Information Prescriptions are made available to users through a range of accessible channels, such as face-to-face engagement, the Internet, email, telephone and outreach.

The aim of the evaluation was to assess the overall effectiveness of the pilot programme, and to gather learning about what works 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, which sought to:

- Shape the practical design and delivery of Information Prescriptions nationally, including how this will be supported nationally at the locality level;
• Provide evidence on the effectiveness and impact of Information Prescriptions on the public, professionals, and organisations alike;
• Contribute to successful national implementation of Information Prescriptions by 2008 for people with a long term condition; and
• Inform the policy direction, ensuring that the implementation of prescriptions is integrated with other major policy drivers.

How to read this document

The sections that follow present the findings from the evaluation of the pilot programme and our recommendations for the national and local implementation of Information Prescriptions. This report replaces the interim report that was produced in November 2007.

Section Two provides a short description of the overall evaluation methodology.

Sections Three to Six provide evidence from the evaluation in relation to the four main phases in the implementation of Information Prescription processes by pilot sites as outlined in the impact model; preparation, development, delivery and outcomes for users and services.

In each of these sections we describe how the pilots addressed each of these phases, highlighting examples of good practice and learning from the pilots on successful approaches to implementation in several places. These sections conclude with identification of:

• Success factors associated with successful implementation
• Barriers and challenges facing the pilots

Section Seven provides an overview of the main conclusions and recommendations.

The following appendices support this report:

Appendix One: Survey Annex
Appendix Two: Resourcing the implementation of Information Prescribing
Appendix Three: Literature search
Appendix Four: Exploring the contribution information technology can make to Information Prescribing
Appendix Five: Detailed information on the evaluation impact model
Appendix Six: Pilot Site descriptions
Appendix Seven: Examples of Information Prescription templates
Appendix Eight: Glossary of terms
Appendix Nine: DH Pilot Criteria Document
Appendix Ten: Detailed Recommendations
Section Two: Methodology

Figure 1 illustrates the stages and activities of the evaluation programme, the elements of which are described in more detail underneath.

**Figure 1**

Developing an impact model

The theory of change (ToC) methodology is the pre-eminent, theory-based framework for evaluating organisations, initiatives and interventions operating in complex environments.¹ This method entails developing a coherent conceptual understanding of how an initiative operates and intends to bring about changes to outcomes for services, users and carers. The initial scoping phase of the evaluation involved building a coherent theory of change for the Information Prescription programme. We have called this an **impact model**. The model attempts to set out the main activities, products and outcomes associated with the Information Prescription approach. It also seeks to articulate assumptions about why and how Information Prescriptions make a difference to services and service users/carers. We have called these assumptions ‘**change mechanisms**’.

The purpose of the impact model is to:

---

• Help inform the design of our research instruments, including the qualitative interview guides, surveys and activity data templates.

• Provide us with a clear theory and hypotheses that can then be tested to discover the extent to which the theory holds or practice deviates from it. Specifically, the model can help us examine:

  • What elements of the Information Prescription process – as these were understood at the start – worked or did not work;
  • What changes did not occur as expected and why;
  • What outcomes were achieved or not achieved, and why;
  • How the context in which the pilots operated affected the success or lack of success of the Information Prescription process.
The scoping work led to the development of both site-specific impact models and an overarching impact model. The specific models looked at how Information Prescriptions were being developed in relation to specific conditions or within specific health and social care settings. For example, in the Royal Marsden NHS Trust, the model looked at how the pilot was establishing Information Prescription processes in relation to prostate cancer care (see Figure 2). The model describes the stage in care where the Information Prescriptions are issued, which professionals issue the Information Prescriptions, and where the issuing takes place.

Figure 2
The overarching impact model (see Figure 3) describes the process of establishing the systems to deliver Information Prescriptions, the delivery process itself and its impact on user and service outcomes. The numbers on this diagram refer to ‘change mechanisms’ which are in Appendix 5.

Figure 3
The overarching model describes the products and activities within the four components – preparation, development, delivery and outcomes – of the Information Prescription process. Linking these products and activities together are 17 change mechanisms, each of which describes how one component or part of the model links to the other. The impact model is described in more detail in Appendix Five.

Qualitative research

The Consortium conducted two waves of qualitative fieldwork: the first in April/May of 2007, the second in October/November 2007. Each wave was comprised of a focus group and a 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, including GPs, hospital consultants, nurses, social workers, and volunteers.

In addition, we talked with staff in the sites on a number of other occasions.

Action learning

The Consortium organised five action-learning events during the course of the evaluation. Each event was designed to enable people from the pilots to work together to identify common challenges and develop joint solutions. Following each event, OPM produced a report summarising the learning from the day. The emerging themes from these sessions fed back into the ongoing evaluation work.

Website

A project website was created to provide a forum for information exchange and learning. All those involved in the project – pilot site representatives, the consortium organisations and DH teams – were given access to a secure section of the site, inaccessible by the public. This restricted area included a discussion forum and information and tools to support pilots.

The website can be found at http://www.informationprescription.info/

Survey of patients/users, carers and professionals involved in Information Prescriptions

In August and September 2007, the Consortium conducted two surveys of patients/users, carers and professionals involved in Information Prescriptions. These surveys were carried out at most of the pilot sites, including some that had already begun to issue Information Prescriptions and others who were still in the development phase.

Activity and baseline data collection

From the work of the pilots, the evaluation team identified activities and mechanisms that will help the widespread introduction of Information Prescriptions. Many of these have been described elsewhere in the report. The pilots also provided data on how information was being provided before the pilot programme started and on the scale of resources required to introduce Information Prescriptions locally – albeit on a limited scale. This part of the report brings these two strands of work together to provide a summary of the main types of resources required to introduce different ways of delivering information prescriptions.


**Literature search**

The University of York Centre for Reviews and Dissemination conducted a literature search on research evidence pertaining to Information Prescriptions and the impact of information on patients.

**Review of Information Technology (IT)**

The Consortium conducted a review of the IT implications involved in the development of Information Prescription systems that ran in parallel with the main Information Prescription evaluation. This study examined the use of IT in pilot sites, exploring stakeholder views on the current systems and the potential uses of IT to support Information Prescriptions in future.
Section Three: Preparation

This section describes how pilots carried out the preparation phase. For most pilots, the preparation phase took place between January 2007 and April 2007, although the progress made by individual sites varied greatly with some pilots starting and completing this phase later than others. This phase involved pilots defining the scope and scale of the project, building internal ownership amongst professionals, identifying user and carer information needs, identifying information content, establishing directories, and developing information prescription templates.

Determining the purpose and scope of the project

What is an ‘information prescription’?

Before looking at their experiences in detail, it may be worth drawing out some essential core components of information prescribing. These are the components, set out prior to piloting, which reflect the original DH vision and appear to be essential to any future national roll out. It is also possible to identify some components that may not be workable in practice or require further consideration.

Whilst it was not possible to arrive at a shared view of the definition for Information Prescriptions, there was broad consensus that Information Prescriptions needed to reflect a number of broad principles. Information Prescriptions need to be:

- **Holistic** – information should be available to support users in improving or managing their own condition, wider health, well being and quality of life;

- **Personalised** – information should be designed around the needs of individuals, responding to their needs regardless of their backgrounds;

- **Flexible** - the Information Prescription process should provide a flexible approach so that a professional can offer a mixture of specific detailed information and signposting to further sources of information, based on the needs of their patient at that time;

- **Trustworthy and reliable** – the information should be reliable, credible and quality assured;

- **Supported** – users and carers have access to additional support to enable them to benefit from Information Prescriptions; and

- **An integrated part of care** – Information Prescriptions are made available as part of the standard delivery of care by professionals so that, regardless of where users and carers come into contact with service providers, whether in health, social care or voluntary sector services, they can access the information they need.
Preparing the ground

Where did the pilots start?

The sites started from very different points and therefore some had more preparatory work to do in order to commence Information Prescriptions than others. The nature of the planning phase varied greatly between pilots. In some sites, including most of the cancer pilots, some form of structured, individualised information giving was already taking place before the Information Prescription pilot programme was introduced. These were typically supported by well-established local and national networks that were in broad agreement about the information pathway that supports the condition-specific care pathway.

Extract from Mid Trent Cancer Network’s initial staff briefing on Information Prescriptions

The pilot is focusing on how Information Prescriptions will be delivered along three clinical cancer pathways, lung, head and neck and gynaecology. The network already has information pathways in place and the Information Prescription project explored how these can be enhanced and developed further to ensure patients and carers get information that is appropriate, personalised and given at the right time throughout their cancer journey. The Information Prescription has been designed to provide information to the patient or carer and signpost to other information that will help them through the journey. The prescription will not be a ‘one-off’ but instead will travel with the patient and carer, helping them navigate, direct and manage their own care.

In other sites, due to a less evolved culture of information giving, the introduction of the Information Prescription pilot necessitated significant effort in the planning stage, in order to explore the implications of the approach and the work needed to ensure its success. This generally involved consulting health and social care professionals, users and carers locally, as well as national and local support groups. The detail of this engagement work varied from site to site with some, for example, holding large consultative events while others established small working groups to develop possible options for the pilot. Many pilots used survey data gathered in relation to existing information provision to inform this development process.

Each site needed to determine the focus of the project

Many factors determined the shape of these early stages in each of the pilots, including:

- The site’s prior history of information giving;
- The existence of suitable models for information templates;
- Previous work on information needs;
- The settings in which the prescriptions were to be issued;
- The nature of the condition and the needs of the service users; and
- The nature of the service and the local health or social services community.

In particular, sites worked to determine: users’ information requirements, the role of different professionals in the Information Prescription process, and the information currently available.
In some cases, there were limiting factors in relation to one or more of these key areas that had the potential to hinder progress.

Figure 4 illustrates the three questions that were found to be central to the development of Information Prescriptions across sites.

**Figure 4**

Choosing a name for information prescriptions

The term ‘information prescription’ was debated at length in many pilot sites. Among many staff, this term was considered inappropriate for describing this concept and its impact on service users. The following reasons were posited:

- Prescription is a ‘medicalised’ term that does not reflect the wider purpose of Information Prescriptions to provide a range of different information sources, some non-medical, or include social care settings;
- The term ‘prescription’ suggests to users that it may ‘cost money’;
- The term also suggests something which is compulsory – ‘you have to take your medicine’; and
- Prescriptions are usually perceived as being only paper-based and are not available through the Internet or by other means.
South Staffordshire and Shropshire Healthcare NHS Foundation Trust

‘That Place’ is a young person’s drop-in centre, involving multi-agency services and professionals to empower young people. The project team, working with users, felt the title ‘Information Prescription’ was potentially misleading and confusing as most people view a prescription as something that is exchanged for medication at a pharmacy. For the purpose of this project the information prescription was referred to as an ‘Information Option’, to reflect that a person may receive information in a variety of ways, which is their first option, but can then choose whether to act upon it, which is their second option. They also used the pneumatic ROUTE to make sure information was – Reliable, achieve Outcomes, Understandable, Timely and Evidence Based.

Nonetheless, some sites in healthcare settings found that users liked the term. These users spoke of feeling ‘reassured’ because the term suggests something professional, reliable and important. Some sites also found that professionals liked the term for similar reasons.

Some sites created different names for Information Prescriptions that they felt will work better with their user groups. The South Staffordshire pilot, for example, has decided to refer to Information Prescriptions as Information Options, with the template being described as a ‘to do’ list. Examples from other sites include the creation of the ‘PIP-OX’ brand in Oxfordshire and the ‘Healthclick’ website in Darlington.

In general most sites kept the reference to information prescription, regarding it as having a good national policy currency in view of the use of this term in the white Paper and ministerial speeches. However, it was recommended that for purposes of national branding, the more holistic focus of Information Prescriptions needed to be clearly captured in a supporting ‘strap-line.’ One suggestion was that it could be called ‘Information Prescriptions – information for your health, care and well-being’.

Identifying information needs

In many cases, the first task for a pilot site was to determine the specific information needs of their target group. Having identified these needs, typically through consultation with staff, users and carers, sites could begin to develop their ideas about how the Information Prescription process could help to meet these needs.

In some cases, however, it was necessary to undertake another piece of work in the first instance, which sought to identify the target audience. This activity involved researching the information needs of a number of potential target groups, analysing the potential implications of using Information Prescriptions to support the different groups, and selecting an area of focus. Typically, the focus tended to be on piloting Information Prescriptions with individuals with a specific condition. For example, cancer sites typically chose a small number of cancer types, such as lung or head and neck.

Many sites would have liked a stronger sense of the clients they were aiming to involve. There was a concern that there was a lack of good data about local users that made it difficult to design appropriate processes. Where sites were able to move more quickly in defining their focus and processes, there was often better data and a shared understanding.
of the local target population. There was agreement that it would help greatly if local agencies collected data on the local population prior to more detailed planning and design of approaches. It would help if guidance were available to help localities quickly pool data and segment this in relation to different perceived user needs. For instance, sites could use and build on the local area profile data sets that are produced by the Audit Commission to help local partnerships respond to their communities.

Sites deployed a number of strategies for accessing and engaging users, carers and staff. In some cases, this involved ‘piggy-backing’ on existing user groups and/or consultation events. Other approaches included using a range of formal research methods, e.g. interviews, surveys and focus groups, and less formal approaches, such as ad hoc conversations, group discussions and email exchanges, to engage staff. Two examples of how early engagement activity was used to inform project development can be found below.

**Royal National Institute for the Blind (RNIB) Leeds: Identifying potential gains for users**

RNIB convened a number of focus groups to discuss information needs and preferred provision options. One group was with the Association for Blind Asians, another was a general service user group, and the third was a group of clinical and social care professionals. These groups looked at specific issues relating to eye care and eyesight disorders and in relation to this mapped out the range of information sources the users would find helpful. The Information Prescription project team leads encouraged these groups to identify not only the information needs but also the potential clinical and quality of life gains from introducing Information Prescriptions, in order to develop an approach that maximises benefits achieved through Information Prescriptions. These potential gains include users developing greater confidence, managing their own care, and improving their quality of life, although further evaluation work would be needed to assess the extent to which these were achieved.

**Isle of Wight: Identifying the focus of the project**

The Isle of Wight pilot held a number of consultations and decided to focus on older people’s needs. One of the key issues raised by older people and carers was the time expended trying to access information relating to specific needs for support. It was felt that a ‘one-stop-shop’ approach was badly needed to reduce stress and anxiety. The project would provide up-to-date accessible information, empowering older people by increasing knowledge and awareness of the services and community support available. It would help foster improved health and emotional well being through improved quality and consistency of information on relevant services for older people with mental health problems and dementia, including the provision of advice and guidance to increase awareness and accessibility. The project team decided to develop an online resource within the Isle of Wight Council website.

**Identifying information sources**

Sites needed to decide on their approach to information gathering early on in the pilot. Again, sites commenced the development of Information Prescriptions from different starting points. South Staffordshire, for example, involved a new team, working in a new centre, with
no existing database of information sources. They used the information management expertise of their project manager to create and build the directory of information. On the other hand, there were some sites that had already developed information directories prior to the commencement of the Information Prescription pilot, for example, Cambridge and Peterborough, Heart of England and Mid Trent.

Sites had to manage tension between breadth and depth of information gathering. In order to meet the needs of its target group, each site needed to choose between covering a large number of topics or building up a bank of knowledge on some key themes. Again, this was informed by the previous work they had done in this respect. In the South Staffordshire pilot, therefore, the team found it difficult to predict the profile of its users and their information needs, and therefore decided to collect information on a very wide range of topics. Some sites with experience of users’ information needs also opted for this approach, for example, where the Information Prescription scheme was aimed at offering an open-access web-based information hub, such as was the case in Darlington: in this site, the wide coverage sought to maximise opportunities for self-management through self-dispensing of information. Other sites chose a small number of conditions and explored them in depth, or used existing condition-related resources, such as those produced by cancer networks.

Heart of England

The pilot evaluated patient information delivery by seeking the views of patients and staff within the Cystic Fibrosis Department. This department then compiled a directory of information relevant to cystic fibrosis patients, highlighting what is available at various points in their care pathway. This was compiled from existing sources and an electronic information prescription pad developed from this directory. Screens are used by the health professional as part of their consultation to indicate what information is available, and the information prescription is stored on the electronic patient record (EPR) so that it can be easily retrieved. A copy of the information prescription is printed for the patient. The information requested will be put into information packs.

Sites planned their approach after having decided on the type of information-related activities required. These activities ranged from intensive information gathering across a broad range of topics to identifying gaps in current sources or poor quality data. It is important to recognise that, even at the early stages of development, sites needed to take difficult decisions about the scale and nature of their approach. This required sites to prioritise different elements of the Information Prescription development process, depending upon work already done prior to the pilot. For example, some sites needed to invest only a limited amount of time into the development of directory content, whereas for others this was a major task, involving sifting through multiple and often duplicate sources of existing information or searching for new resources.

Some sites benefited more than others from being linked at the start to networks or organisations, such as national voluntary sector organisations and local information centres that are already rich in high quality information or have good existing directories. For sites with good existing relationships with such organisations, it proved easier to generate information that covered a range of different needs and produce higher quality directories at a quicker speed.

For sites that did not have such links, information gathering appeared to take longer and the coverage achieved was often not as good as planned.
In any future plan for roll out, it would considered as highly beneficial if localities could have access to good local information providers from the beginning. The creation of a database of previously accredited and high-quality information at the national level could also benefit local sites.

To ensure that local sites benefit from ready-made information and can shortcut more time-consuming information collection, local information providers need to be built into local partnership boards.

**Building internal support**

Sites who applied to be Information Prescription pilots tended to have an enthusiastic core team able to drive the project forward. In respect of the wider team, some relied on voluntary co-operation, while others made involvement in the project a requirement of certain roles. Many of the core project teams consisted of one or two people who, on learning that they had been successful, worked to expand the team to include other colleagues.

Depending upon the setting and the focus of the project, core project team members tended to allow other colleagues to ‘opt in’ to the process or to make it a requirement. In South Staffordshire, issuing an Information Prescription was made integral to the initial assessment process for all centre staff. In Durham, the project manager was able to issue Information Prescriptions by expanding the role of existing volunteers who had already been supporting and providing information to cancer patients in an information centre.

Some adopted a staged approach to securing the ‘buy-in’ of others. In some cancer sites, for example, Clinical Nurse Specialists (CNSs) were involved in the development of the process and only later broached the idea of prescribing with the consultants. In other sites, there were one or two ‘champions’ among consultants, who led their team but did not try to influence their colleagues until a much later stage.

Of the range of processes that were used to build internal support, some general approaches seem to prove successful. The first feature of successful engagement processes is the presence of a project manager who is recognised by staff as ultimately responsible for implementation and can be approached for information and support. Among pilots, these tended to be relatively senior or middle managers, which helped as they were able to draw upon administrative support and the capacity of the teams that worked for them.

Second is the need to have a wider group of information champions who work with the project manager to spread the practice of Information Prescriptions and to persuade others to take on Information Prescription roles. Many pilots found it helpful to involve those they regarded as most interested and involved in information giving at the beginning on project steering groups, so that they could take an active role in the project and generate wider support. Crucially, the champions must be representative of the wider staff group who need to be involved. One informant commented that ‘doctors will respond to other doctors, or clinical nurses, but not necessarily managers.’

Third, it is important that existing staff networks, meetings and training sessions are used as opportunities to build in information sharing or training around information prescriptions rather than imposing new arrangements on busy staff.
Building the partnership

It was essential for most sites to work in partnership, but few had the luxury of pre-existing partnerships with a single vision and the capacity and commitment to design and deliver Information Prescriptions straight away. More often, the development of a mature, reliable and focused partnership took a slow and circuitous route. Once they were clearer about the project, sites were able to identify which additional partners they needed to strengthen the team. Other partners dropped off as the perceived ‘burden’ of participating in the project undermined initial enthusiasms. Many sites found that they needed to spend considerable amounts of time not only raising awareness, but also persuading partners with a range of incentives to participate. Partnership working is a highly important strand of activity running through the pilot work, and is picked up in later sections. For now it is simply worth noting that, in preparing the ground for Information Prescriptions, partnership building was a central but often challenging task.

The sites that found it easy to build and sustain partnerships did so by establishing project steering groups which took on a partnership function, in that they pulled together staff from different agencies and care settings to discuss and agree priorities for local implementation and to monitor progress.

Typically, the membership of local steering groups included: representatives from voluntary sector organisations; managerial and front-line level representatives of health or social care teams involved in prescribing and dispensing; and other staff with roles that are linked to information provision, such as staff from the Patient Advice & Liaison Service (PALS), Equality and Diversity Officers and staff involved in IT support or information management. These steering groups provide direction, governance, essential insights into stakeholder perspectives and needs, and practical support. Some have been used to quality assure content and the template. Others have found their primary function has been to support the project manager. The steering groups typically met once a month, sometimes more frequently in the early stages. Some pilots have both a steering group and a project board, with the former being more strategic and the latter concerned with day-to-day delivery and management of the process.

Those steering groups which were regarded as working well had the following features: a strong chair, usually from a senior management position in the lead organisation; an active membership involving all of the main participating organisations; and a committed full-time project manager, able to draw upon some basic administrative support.

However, some of the steering groups are only temporary and linked to the pilot projects. Partnerships arrangements for each locality, mirroring the role of steering groups, will need to be developed if local implementation is to be achieved nationally.
Darlington: Getting buy-in from primary care

The project manager convened a meeting of key leads in primary care and explained her vision for Information Prescriptions. She picked leads from certain conditions that did not seem to be covered by other sites at the time, namely diabetes, hypertension and depression. Having persuaded them to be involved, the project manager set up a Steering Group with representation from voluntary bodies, social services, libraries, ‘First Stop’, practice nurses and community matrons.

In ‘selling it’ to primary care practitioners, etc., the project manager emphasised the following:
– keeping it simple;
– that it is not going to increase their workload; and
– that it is not about re-inventing the wheel.

Linking to existing or future initiatives and policies

An on-going task for pilots is identifying existing or forthcoming initiatives, policies and practice which either affect or could be linked with Information Prescriptions. In many cases, the project manager needed to find out about internal systems and practice in order to spot these opportunities. Ideas which emerged from these investigations included:

• Building Information Prescriptions into existing communication strategies of a unit or centre;
• Exploring the links between world class commissioning and Information Prescriptions;
• Dovetailing the Information Prescription process with Books on Prescription; and
• Linking Information Prescriptions to a range of emerging approaches to record keeping, such as including new functions on electronic record systems.

Queen Elizabeth, Birmingham: Building on a patient information website

The site has been running a similar pilot for the DH, which the lead consultant developed in 1994. This project was about designing a website which became the main resource for cancer online and Cancer Research UK’s main patient information site (www.cancerhelp.org.uk).

Patient feedback on this project indicated that they liked having this web resource and wanted websites offering other sources of information recommended to them. The lead consultant responded to these requests by developing a forerunner to Information Prescriptions.

Setting up management and support arrangements

The pilot work highlights the need to ensure that there are robust project management arrangements in place in order to deliver Information Prescriptions. Evidence from the sites suggests that success in this area rests on:
• **Early appointment of project managers** – Many, but not all, pilots had a project manager able to support the project on a full- or part-time basis. Those pilots which had project managers in place at an early stage tended to report benefits resulting from the longer lead-in time. Some sites had difficulties in recruiting project managers, often due to internal re-structuring. These sites, therefore, reported spending more time than they would have liked on recruitment issues rather than Information Prescription work. Some sites, such as Doncaster and Mid Trent, have recruited external consultants. Others, such as Leeds Mental Health Trust and Royal Marsden, have drawn on existing staff members.

• **Taking time to analyse the skills-set needed for the role and appoint the project manager accordingly** – When recruiting, sites prioritised different kinds of expertise. Some sites prioritised sectoral experience, others information management expertise, while others focused on project management experience. For this reason, Information Prescription project managers in the pilots had diverse backgrounds and included nurses, library staff, and local government training managers.

• **Where appropriate, ensuring the project manager is supported by a dedicated IT lead** – In many cases, pilots also brought in IT support to help the sites build different parts of the necessary IT infrastructure, such as the directory or website. Later in the process, a number of sites would identify information management skills as a key area of expertise for the Information Prescription project manager. However, with the creation of a national directory and a range of IT resources to support this, the close involvement of dedicated IT experts may not be as necessary in supporting national implementation.

**Involving voluntary sector organisations and user and carer groups and representatives has proved essential.** Many sites have observed that the inclusion of the voluntary sector has been particularly helpful, both as a bridge to the user and carer perspective and in offering statutory agencies an alternative delivery model, for example, using voluntary sector helplines. Some sites also regularly engaged with existing user or carer forums, including Expert Patient programmes, to get feedback on their information needs and what information provision processes might work best. Both voluntary sector and user or carer representatives played a vital role in getting people’s views and stimulating their interest, and that of other partners, in the local health and social care economy. Later in this document, we look at the role of the voluntary sector in more depth.

**Identifying content**

Pilots were clear at the start that users wanted a wide range of information sources to support them with their care. During the preparation stage, much of the focus of pilot leads was on identifying suitable information sources to be accessed through Information Prescriptions.

The position taken by pilots appears to be supported by national research. The Picker Institute, for example, found that patients want more information and that they want the following categories covered:

• Medical information about initial diagnosis, treatment and treatment choices;
• Details of voluntary sector support groups;
• Support for the family or carer(s);
• Condition-specific services;
• Information on financial benefits available, and how to claim them; and
• Information on how to comment on or complain about services.\(^2\)

The work carried out by pilot sites about the information needs of users and carers reinforced these national research findings. Focus groups held by Leeds Mental Health Trust found that ‘people expressed how they struggled with daily living such as shopping and transport, and getting information on this was important’, while researchers working with the Mid Trent pilot, found users wanted a range of information, including:

• Medical information about diagnosis and treatment and about treatment choices;
• Information or details of how to get information regarding side effects of treatment and remedies;
• Details of local information centres and help groups and organisations;
• Signposting to specialist services and other support services including welfare benefits; and
• Information about living with cancer.

Many sites found that they greatly benefited from involving the voluntary sector, both nationally and locally, in helping to identify and source appropriate information sources. Many voluntary sector agencies are at the forefront of producing and storing high quality information on conditions and enabling users and carers to access these easily through a range of channels, including websites and telephone helplines. Those pilots with pre-existing partnerships with national charities found it much easier to identify and collect suitable information sources. In addition, these pilots were able to use their partners in the voluntary sector to access user and carer groups and involve them in identifying information sources.

**Isle of Wight: Building networks**

Project leads at the Isle of Wight pilot worked closely with local voluntary sector organisations at the outset. Local charities with large networks were critical in helping Information Prescription leads to identify the wide range of voluntary sector organisations and key contacts on the island that could contribute to the development and implementation of Information Prescriptions. The voluntary sector organisations were particularly helpful in developing and/or submitting information for the directory.

Some sites found it harder than others to identify content. Depending on the conditions they covered, some sites felt that there was a lack of existing information, even at a national level, and therefore spending time identifying content was critical to the success of the pilot. Whereas for cancer sites there was often excellent pre-existing information, this was not the case for sites dealing with conditions like psychosis, depression and bi-polar disorder.

\(^2\) The Picker Institute, *Accessing information about health and social care services*, April 2007
In other cases, while there was good national information on a condition in general, information was not always suitable for some user groups, such as those with learning disabilities and from certain black and minority ethnic groups. Thus, sites often had to try to find or develop this information themselves.

As a result of this constraint, some pilot sites recommend that the DH look towards providing additional targeted funding to enable sites to develop more specialist information sources. Initial gaps that may need to be plugged are:

- Information on a range of conditions, tailored for those with functional illiteracy and learning disabilities;
- Information on more serious mental health conditions; and
- Information for carers (which is good for some conditions, such as cancer, but less so for other conditions, such as mental problems).

Some pilots separated ‘core information’ - the absolutely essential information - from other information, i.e. information that is ‘desirable’ but not of critical importance. This involved prioritisation activity.

Core information was deemed to be: condition-specific information, especially relating to diagnosis, prognosis and how the condition will change in the future; information on where to access local services; and information about local voluntary sector organisations and self help groups.

Non-essential information typically included information that was deemed to be general, very broad and non-condition-specific, such as detail of local leisure services or local employment opportunities. It was also argued that some of this information was of lower priority for inclusion in directories as it was harder to quality assure or accredit.

Our survey findings demonstrate that the pilot sites were able to provide a broad range of information sources. When asked which kind of information they gave to people, the most common items (mentioned by at least half of respondents) were:

- Contact details for support groups (62 per cent);
- Phone/helpline (57 per cent);
- Links to other websites (50 per cent);
- Contact details for charities (48 per cent);
- Side effects (43 per cent);
- More detailed information on how the condition progresses (45 per cent);
- Contact details for information centres (45 per cent);
- Benefits available (42 per cent);
- Benefits Agency, etc (39 per cent); and
- Contact details for social services/home help/home care (39 per cent)
Deciding how much information is enough

Many professionals (41 per cent) wanted the opportunity to offer more information, with around a quarter or more of them indicating:

- More detailed information on how the condition progresses (31 per cent), a view shared by many users;
- Contact details of charities/voluntary groups (27 per cent);
- Links to NHS Choices website (26 per cent);
- Contact details for support groups for users/patients (25 per cent).

This need to provide a range of information was balanced with a concern not to provide too much information, however. For instance, 16 per cent of professionals agreed that there was too much information. The qualitative research among health care professionals – and voluntary sector representatives experienced in condition-specific information giving – found that there was some apprehension over providing users with too much information.

Developing directories

Information Prescription directories are categorised databases or lists of resources which contain the information which is provided to the user or carer. Information prescribing relies on extensive, searchable directories linked to documents, websites or organisational contacts. Information found through the directory can then be tailored to meet individual needs.

Consultation with users and professionals indicates that different methods of accessing and using directories – or ‘interfaces’ – are needed for these different groups. It is likely that both professionals and users will manage and use information in different ways, and thus require different search keywords and indexes. The information content and quality assurance processes may also vary in accordance depending upon who will be accessing the directory. These are issues that appear to have not yet been fully explored by pilots although there are mechanisms in place to restrict access as a way of ensuring that content is appropriate for the user group. For example, Oxfordshire decided to develop a web-based directory that can be accessed only by professionals. Where sites have developed directories that are open to the public (for example Darlington and the Isle of Wight), these are typically designed to signpost/link to accredited, quality assured local and national sites such as NHS Direct Health Encyclopaedia (or the NHS Direct Self Help Guide).

Almost anyone involved with information prescribing may have some need to consult a directory of sources on health and other forms of care and advice, including:

- Health and social care professionals;
- Information specialists;
- Service users and carers;
- Voluntary sector; and
- Local authorities.
Directories varied in format and structure across sites, but typically fell into one of the following categories:

- A paper list or indexed folder;
- A simple database that can be run as a ‘stand alone’ without Internet or intranet access;
- A local database accessed via Internet or intranet access, usually with web links to other sites with their own directories;
- A national site with links to other national and possibly local sites;
- Local or national search engines, with indexes based on the content of accredited sites.

Directories are used in different contexts, specifically:

- During consultation – with computer access;
- During consultation – without computer access;
- From home, over the Internet, or in other unguided settings such as Internet cafes;
- In assisted sessions in libraries or health information/advice centres;
- In the office, as part of preparing lists of information.

The directory will be consulted in order to:

- Populate a customised Information Prescription during a consultation;
- Fully or partially populate a standard Information Prescription prior to a consultation;
- Make ad hoc searches relating to unusual enquiries;
- Search generally for information on a condition, symptom or services;
- Update specific items of knowledge – e.g. find new location of a local agency.

Content of directories

Once information content was identified it was usually collected in a directory. The following table shows the main sources of information provided by the sites. This shows that all of the pilots covered information about conditions, more than two thirds of the pilots provided links to local health and social care services and voluntary sector organisations, and just over half provided more in-depth information on social care services. Half of the pilots provided information on benefits and finance and just under half of the pilots provided information for carers. The survey evidence suggests that more prominence needs to be given to both these issues.
Table 1: Information contained in directories

<table>
<thead>
<tr>
<th>Types of Information</th>
<th>Number of pilots</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Management of conditions</strong> — information on conditions, diagnoses, tests, treatments, medicines, self-care of condition, an example of which is information sources which are provided on how those with diabetes can manage their diet.</td>
<td>20</td>
</tr>
<tr>
<td><strong>Social care</strong> — in depth information on range of social care services to support self-management and wider well-being, such as respite, fittings and adaptations, learning disabilities services, housing support and bereavement services.</td>
<td>12</td>
</tr>
<tr>
<td><strong>Local health and social care services</strong> — information providing links to local statutory health and social care services, such as NHS, local government and social care services.</td>
<td>19</td>
</tr>
<tr>
<td><strong>Voluntary and community sector organisations</strong>— information providing links to local and national voluntary and community sector organisations, such as health and social care VCS organisations, self-help organisations, support groups, and advice services.</td>
<td>18</td>
</tr>
<tr>
<td><strong>Benefits and finance</strong> — links to information on benefit entitlements such as housing and invalidity benefit, access to legal support.</td>
<td>10</td>
</tr>
<tr>
<td><strong>Carers</strong> — Information for carers, local support for carers, benefits for carers, roles for carers caring for those with specific conditions.</td>
<td>9</td>
</tr>
<tr>
<td><strong>Employment and training</strong> — such as information on where to find employment, employment rights and training opportunities</td>
<td>2</td>
</tr>
<tr>
<td><strong>Leisure and other</strong> — including information about local leisure facilities, local transport, libraries, helpful local websites, community centres, clubs and societies.</td>
<td>3</td>
</tr>
</tbody>
</table>

**Management of directories**

There was a range of processes for developing and managing the upkeep of directories. Some sites relied exclusively on pre-existing directories of information held nationally by voluntary sector agencies or NHS Direct and adapted further to support the work of the pilots, while others adopted existing databases used by either the NHS Trust or local authorities, building in additional content and functionality to support the Information Prescription processes.

For the purposes of piloting Information Prescriptions, many of these directories were designed as a short-term solution for holding information content to be used in Information
Prescriptions. There was widespread acknowledgement from pilot leads that these directories would be replaced by planned national directories, scaled up considerably to hold much more information content, or significantly redesigned, particularly those with limited functionality. Continuing to manage large scale directories covering the spectrum of information required by any Information Prescription system could not be cost-effectively managed at the local area.

There was broad agreement that information specific to the management of conditions, medicines and treatments would be best collected and stored at the national levels. This would both promote patient safety and reduce avoidable effort and duplication at the local levels. National directories could also be used to store information about benefits, legal rights and other national policy statements where local variations of these information sources do not exist.

It was argued, however, that local information, such as information on local statutory services and the local voluntary sector, could be better stored and maintained at the local level. Local authorities already have an information management role, particularly in supporting local service directories and local authority websites. Local government, in particular, is well placed to understand and collect information about local services and ensure these sources are updated. In the Isle of Wight, for example, the pilot has used the existing local authority directory as a foundation on which to build the directory for information prescription.

One research participant told us:

‘Many local authorities are now working with the PCT to create a ‘one stop shop’ for all health and community information. Local authorities are the best location from which local information sources can be collected and made accessible.’

Developing templates

Designing the template

The Information Prescription template is the electronic, audio or hard copy format in which information is given to a user or carer. Typically, it will record a user’s information needs and, in some cases, will also include the information itself. In other cases, additional resources accompany the template, supplying the information requested. The term ‘information prescription’ describes this template, once populated.

Several professionals interviewed in the pilots argued strongly that engaging key stakeholders is essential in the selection of information, in developing materials, and when designing appropriate template formats. User involvement can greatly enhance the quality of information, ensure that information is personalised, and provide insights into how information can be best received and used by users and carers. Professionals need to be part of the process so they can hear how much the patients want the information and be more motivated to deliver it. For example:

‘When we involved some of our patients in discussions about information, we arrived at very different conclusions about what was needed. While we were initially focused on their direct care needs, it was clear that they also wanted information to support them with their housing, debt and jobs.’
Users were involved in the following processes:

- Identifying information sources and content for Information Prescriptions;
- Identifying information needs in relation to care pathways;
- Informing the written materials; and
- Informing the design of formats.

In addition to user involvement, involving the voluntary sector and professionals in designing information is important. The voluntary sector, in particular, is often at the forefront of working with the user to define their information need, and has a strong track record in involving users who are disadvantaged.

**North Tyneside**

In North Tyneside, the pilot held a large stakeholder event involving users, carers and professionals. At the event, users were asked to identify how information was currently given to them, how they would like information in the future, how information could be personalised and the format and approach they wanted to prescribing. As part of the event, users and carers were asked to map out the different stages they went through with their conditions and their information needs at each stage. This led them to arrive at the following stages: GP referral, diagnosis, starting treatment, maintenance, complex and advanced.

In relation to this, users wanted the information on treatment and care, carer/family, support groups, practical advice, self management, overview of information sources, planning for the future, benefits and finances, and standard diagnosis information.

Several professionals were keen to emphasise the importance of making sure Information Prescription templates and materials are in accessible formats. As confirmed by our surveys, some users, particularly those with low literacy skills, learning disabilities or highly complex mental health conditions, will struggle with more detailed and formal pieces of information. Pilots found it important to assess information in relation to the following user dimensions:

- Different levels of literacy;
- Preferences for visual and diagrammatical information;
- Users’ age and learning styles;
- Disabilities;
- Language skills – many users do not have English as a first language; and
- Levels of concentration – some people with mental ill health find it difficult to concentrate on written materials.

**Format of templates**

The paper-based Information Prescription was relatively common but varied in its design. Examples include:

- **Checklists or ‘to do’ lists** – South Staffordshire’s template included a small ‘to do’ list, with space for the professional to note down a couple of key telephone numbers or websites.
• **Carbonised, triplicate forms** – some sites produced pads in this way, which allowed for those professionals issuing the prescriptions to keep one copy for their own records, give one to the user and send the other for recording back to the core pilot team.

• **Information booklets/packs** – Some sites developed booklets which include a range of information and signposts relevant to a particular condition.

---

**Leeds Low Vision pilot**

The information directory has been updated, edited and reprinted and is a vibrant information resource, set out clearly and in font point 16. The directory is also available on audio CD. The list of organisations at the back of the document is also split into tracks. This along with the database needs to be sustained and the pilot is working with partners to achieve this. The first two pages of the Directory (contains the purpose of the document and the contents list) are also available to listen to on a freephone number, along with eye condition leaflets. The service is automated and the service user can listen to the documents or order them in a format of their choice.

---

**Some sites have experimented with audio, visual and Internet channels.** Formats included the following:

• **Simple emails** – these were similar to a hard copy template but in electronic form with links to online resources, which resulted in the Information Prescription being something of an interactive ‘experience’ rather than just requesting and receiving information;

• **Podcasts** – for example, of users talking about their condition;

• Audio versions of directories;

• **Electronic touch-screen information points** – Heart of England have developed an information point to be situated on the ward that provides users with a way of accessing information about their condition and the staff;

• **DVDs** – Several sites have provided information on DVD, including one site which provided a DVD with BSL signers who can convey information to viewers while another provided DVDs with user video diaries providing information about self management;

• **Websites** – a number of sites do not have a template as such but refer users and carers to a website for self-prescribing and dispensing, using branded products such as pens, mouse mats and postcards.

---

**South Staffordshire**

A few young people using the South Staffordshire centre observed that they did not want their Information Prescription to be written down because it might be read by other family members. Individuals who requested information about sexual health or financial matters sometimes expressed similar concerns. Some sites also tried to meet other types of need by offering templates in different forms, such as large font, young person-friendly, Braille etc. The Suffolk template also allowed the user and clinician to choose whether to access low, medium or high levels of information. After discussion, this was changed to ‘introductory’ or ‘detailed’ to remove any judgmental language.
The survey of professionals showed a wide range of information types available under the Information Prescription process, notably pre-printed and other written material but also multi-media formats. The most common formats were brochures/leaflets and other printed outputs, mentioned by some 70 per cent of professionals. Just under half (45 per cent) were able to give verbal information and one in five (19 per cent) had access to multi-media formats. The availability of formats varied across settings, with mental health professionals much more likely than other respondents to have access to printouts/written materials (96 per cent) or to be able to offer verbal information (88 per cent).

Types of templates

Several types of template were developed. These can be broadly categorised as either signposts, tailored templates and information packs.

Signposts

These templates do not seek to provide information content, but rather signpost users and carers to fulfilment points, such as websites or information centres, where more detailed information can be found. Signposting templates, as we explain later, are often used in lighter touch pilot sites and in primary care.

Many of the signpost templates have free text boxes in which prescribers can write information about websites or contact addresses for fulfilment centres. For example, professionals in South Staffordshire will generally write down one or two telephone numbers or websites, and then will guide the young person through the process of accessing that information. The example presented in figure 5 is a template which has been developed by Darlington PCT and is used to signpost users to the Healthclick website where they can learn more about specific conditions.
Tailored templates

Tailored templates provide a range of information options from which the prescriber can choose during the consultation with the user or carer. Thus, the template is used to aid a process through which different information sources are identified as required by the user depending on different circumstances and clinical judgements, such as where the user is on their condition specific care pathway.

Tailored templates can provide some basic information on conditions, but are chiefly designed to allow the prescriber to indicate to another professional what information is required during a more in depth dispensing process.

The example presented in Figure 6 has been developed by North Tyneside and presents a range of information options from which the prescribing professional can choose, depending on the user’s stage in the care pathway. There are six main stages.
Some pilot sites developed information packs which, rather than simply signposting the user to another source of information or providing a tool which professionals can use to direct users to tailored information sources, provide a full list of information sources which users can take away and keep. Manchester has developed a range of information packs, covering different long term conditions, including Parkinson’s Disease, HIV and AIDS and Multiple Sclerosis. Each pack contains the following types of information:

- Introduction to information prescriptions;
- Data protection;
- Personal details, which the user or carer completes and is kept by the prescriber as a record;
- Overview of the condition;
- Who can help;
- Useful contacts and telephone numbers;
- Charity groups and voluntary organisations; and.
- Useful publications and fact sheets.
Conclusions on the preparation stage

Success factors in the preparation stage

In considering this stage of the process, pilots identified a number of success factors:

Success factors in planning implementation of the Information Prescription programme:

- Develop local implementation proposals for Information Prescriptions;
- **Develop a communication strategy** for promoting and disseminating information locally on Information Prescriptions;
- Establish a local process for quality assuring information on local services;
- Involve the voluntary sector in local implementation;
- Ensure that IT specialists are built into local Information Prescription partnerships and delivery teams;
- Ensure that users always have the option of accessing Information Prescriptions through channels other than the web, such as helplines and face-to-face information provision.

The main challenges and responses in the preparation stage

- Planning an integrated approach to Information Prescription systems can pose challenges, especially when trying to coordinate inputs across different agencies which may have little experience of working together. Pilots found that having a single coordinator and point of contact across the pilot helped, as long as they were supported by a group of professionals to champion Information Prescriptions in their local service. Integrated project partnerships also supported joint planning and delivery.

- **Identifying and gathering local information about services proved difficult for some pilots.** Most of the pilots sought to ensure that Information Prescriptions could provide links or contact information for local health and social care services, but this was not always straightforward. One problem was that local information was sometimes out of date or not stored in an accessible place. Pilots found that they could gather better information about local services when they were able to access and use existing directories, such as local authority service directories.

Barriers and challenges to determining the purpose and scope of the project

- **Many sites found it difficult and time-consuming to scope how Information Prescription would work for them, and what it should achieve.** Although sites had developed some initial ideas about their project, it was only on being awarded pilot status that they began to flesh out their early plans and grapple with the mechanics of the Information Prescription process.

  ‘Information Prescription as a concept is simple, but it actually takes a bit to work out what we’re attempting to achieve through use of Information Prescription.’
Barriers and challenges to preparing the ground

- Pilots wanted greater clarity about how different DH policies and priorities are joined together and support the delivery of the desired Information Prescription outcomes for patients and carers. Sites believed that this would help staff to understand how and where they should focus their efforts and reduce duplication. It would also help to make the case for information prescribing, by demonstrating that it is aligned with other policy agendas and a priority at national level.

- There was evidence to suggest that sites focusing on an area that was not an organisational priority found it more challenging to get adequate support for the project than those who had chosen a topic in line with key organisational issues. A few organisations withdrew support for the project, for example by refusing or strictly limiting access to the in-house IT service, supplies and equipment. In these cases, it was expected that the project budget should fund all such expenditure which proved extremely challenging.

Barriers and challenges to setting up management and support arrangements

- Developing and maintaining robust communication between the project team and other partners proved to be challenging. Communication is essential at all stages of the project, but in the start-up phase it was thought to be particularly important, in order to establish who would be involved and in what capacity. Sites reported having to spend a great deal of time and energy trying to persuade partners or groups of staff to participate in the process. Sites working with outreach workers or across a number of locations often found it difficult to arrange meetings, which then made it harder to communicate the vision of the project to key stakeholders. Some also found that potential or existing partners were unresponsive to emails or calls, or unable to attend meetings.

- Information Prescription implementation needs to be linked to and aligned with local strategic policy making and initiatives across the whole health and social care system. In future, it would be beneficial to give Local Strategic Partnerships a clear role in monitoring the delivery of Information Prescription systems, although the more detailed management of implementation could be undertaken by a health and social care sub-committee.

- Local Information Prescription implementation needs to be informed by local commissioning strategies. These strategies can be influenced by ensuring that commissioners have up-to-date and high-quality data on the local user population and their information needs, and by integrating Information Prescription implementation into future commissioning priorities.

Barriers and challenges in identifying content and developing directories

- Some sites were surprised at how hard it was to access information on particular topics or conditions. Sites seeking to meet the needs of particular user groups such as young people or BME communities reported experiencing even greater difficulties in finding suitable material. Others had expected partners to be able to make a greater contribution.
• Not building in IT specialists from the outset can place limitations on the type and size of directory that it is possible to use. Where IT professionals had been involved, this was said to have facilitated the development of the directory and reduced the amount of time non-IT related staff had to spend on this activity.

• Pilots sometimes struggled to find information directly relevant to more disadvantaged groups, such as some black and minority ethnic communities or those with learning disabilities. It was strongly suggested that further work be carried out to generate appropriate information for disadvantaged groups and explore which mechanisms for providing information are most useful to different groups.

• While users need to have access to a range of information sources, there is feeling that some types of information are more important than others and should be seen as ‘core information’. This requires prioritisation activity, which can be challenging in terms taking into account the different contexts and aims of project partners.

### Barriers and challenges in the development of templates

• Some sites found it difficult to design a template which met the needs of users and professionals and the expectations of the Information Prescription project. In many cases, sites compromised by providing information only related to the condition, signposting to a general resource (such as a website) or providing pre-packaged resources rather than tailoring information, or relying on self prescribing and/or dispensing.

• Some sites faced delays in producing tailored templates and information. Faced with the need to engage a wide range of users and professionals in the design of templates and materials, many sites took longer than expected to produce these. Some pilots found it took much longer than planned to engage professionals in the design of templates and to create templates in different styles and formats.
Section Four: Development

This section of the report looks at how sites further developed their Information Prescription approaches, building on the work carried out in the preparation phase. This phase of piloting typically took place between April 2007 and August 2007, although the progress of individual sites varied greatly. In this phase, pilots addressed stakeholder engagement, producing IT systems, quality assurance of information, finding ways to record prescribing and dispensing, and training professionals.

Engaging stakeholders

Involving users and carers

The majority of pilots involved users and carers in the design and development of their approaches to Information Prescriptions and regarded this as essential to their success. Users were involved by sites to differing degrees: some sites involved users only in early preparation stages, while others involved users over the duration of the pilots, including at steering group meetings. Most pilots also found that users and carers were enthusiastic about becoming involved, reporting that attendance at user events was generally high.

Mid Trent, Stakeholder Event

Mid Trent spent a significant amount of time and effort involving local users. Near the inception of the project, the pilot ran a number of events, including a stakeholder event involving 20 cancer patients and carers. The event was used to generate views on:

- How Information Prescriptions could be delivered across three patient pathways, head and neck, gynaecology and lung cancer;
- Identifying the benefits to patients and carers of Information Prescriptions;
- Identifying any barriers to development and implementation;
- Identifying how individuals and organisations will be able to contribute further to this work.

Most informants argued that there were real benefits from involving users in the design and implementation of pilot activities. User involvement can greatly enhance the quality of information, ensure that information is personalised, and provide insights into how information can be best received and used by users and carers. Pilot leads spoke of how they changed the design of templates, materials and training processes, having consulted users or actively engaged them in design processes.

Users were involved in the following processes:

- Identifying information sources and content for Information Prescriptions;
- Identifying information needs in relation to care pathways;
- Informing the written materials; and
- Informing the design of formats.
In addition to user involvement, involving the voluntary sector is critical in this stage of Information Prescription implementation. The voluntary sector, in particular, is often at the forefront of working with the user to define their information need and has a strong track record in involving users who are disadvantaged.

**Some sites could not easily consult their users.** Those pilots working with people with dementia and other forms of memory loss, for example, could not consult service users directly. Some of these sites did consult carers or support workers, but they spoke of being mindful of the fact that the carer or support worker cannot speak directly for the user and may have their own priorities. Many used voluntary sector bodies to feed in the user perspective.

**Sites deployed a range of tactics for raising awareness among stakeholders.** These have included branded products, such as pens and mouse mats, articles in professional newsletters, promotional posters and leaflets and roadshows. Oxfordshire has produced a DVD, which comprises a film for young people and another for a general audience, to explain information prescribing to users. Local young people have helped to make the DVD, which was scripted by the project lead. Figure 7 shows a picture developed by Mid Trent to attract interest and awareness in the pilot amongst users and carers.

**Figure 7: Example of promotional poster**

![Promotional Poster](image)

**Involving professionals**

Involving a wide range of professionals in Information Prescription processes was a clear prerequisite for the overall success of the scheme, and the pilots succeeded to a varying degree in involving different professionals.

There were several challenges to involving professionals:

- **Lack of capacity** – pilot leads reported difficulty in engaging busy professionals who did not feel that they had sufficient time to commit to the process, in some cases assuming that Information Prescription would add significantly to their workloads.
• **Lack of buy-in at the senior level within partner agencies** – when pilots consulted users from other agencies, they often found that people would become involved only if they had a clear message from their management about the need to do so. Such messages were not always evident and there was a strong view from some professionals that ‘if they didn’t have to do it, they wouldn’t do it.’

• **Lack of awareness** – Several sites told us that the professionals they asked had no prior knowledge of this initiative, and thus either thought it unnecessary to get involved or required more information before they would make a commitment.

• **Lack of integrated working** – Many of the barriers to involving other professionals were seen as cultural and behavioural, and representative of the longstanding and deeply embedded barriers that hinder cross-agency working.

---

**Oxleas NHS Foundation Trust, Surveys with carers and staff**

Having run a number of focus groups with staff which were designed to measure their confidence in giving out information, Oxleas developed two surveys. The staff survey found that senior staff felt most confident in giving out information. Those staff lacking in confidence feared giving the wrong diagnosis to the client and worried about how to communicate complex messages effectively.

The site also ran a survey of carers, which asked for ideas on information dissemination, current levels of knowledge and information gaps. Thirty per cent of carers responded and the findings shaped information prescribing at the site.

---

**Suffolk: Making connections with stakeholders**

Having met some initial resistance from clinicians, especially GPs, the Suffolk team developed a PowerPoint ‘script of reassurance’. This script emphasised that no power was being taken away from GPs; rather, it focused on the idea that Information Prescriptions could actually improve the efficiency of GP services rather than simply extending the duration of consultations. The concept of ‘selling’ the Information Prescription, using this approach, has been successful so far, with GPs becoming increasingly responsive.

Aware that the size of the Information Prescription ‘audience’ (users, clinicians and the voluntary sector) is very large, the Suffolk team held county-wide workshops for voluntary, health and social services to raise awareness of the project. The team also made links with the Expert Patient programme, and Expert Patients now form part of the project’s user panel. These engagement activities have helped the project build strong relationships with the Alzheimer’s Society, which has facilitated user consultation, and Age Concern, a national charity that is dispensing information as part of Suffolk’s Information Prescription scheme.

---

Pilots developed a range of approaches to engaging professional groups. One clear message emerging from this work is that engagement needs to be tailored carefully to meet
the particular needs of different professional groups. Different strategies appeared to be successful with different kinds of stakeholders, as summarised in Table 2 below.

Table 2: Approaches to involving professionals

<table>
<thead>
<tr>
<th>Professional Group</th>
<th>Engagement strategies</th>
</tr>
</thead>
</table>
| 1. Senior strategic managers/commissioners | Identify and book slot within pre-organised management and partnership meetings, e.g. Clinical Governance meetings, Board Meetings, Health and Social Care partnerships meetings, Local Strategic partnership meetings, staff 'away-days'. Within these sessions, depending upon time available:  
  • Deliver short presentation providing background to Information Prescriptions, proposed local approach to/context for Information Prescriptions and **potential opportunities and benefits for stakeholders present**  
  • Facilitated group/paired discussions focused on exploring Information Prescriptions in more depth, e.g. tasks could include:  
    • asking attendees to identify local barriers and challenges, and, most importantly, ways to overcome these;  
    • high-level mapping of service user pathways and where Information Prescriptions would fit;  
    • identifying how Information Prescriptions can support the delivery of outcomes against high-level strategic priorities. |
| 2. Clinicians                          | Identify existing clinician training and development activities and (as with Group 1. note above) work to book slots within these programmes to introduce and discuss Information Prescriptions.  
  
  Securing the buy-in and engagement of relevant colleagues can be advantageous. For example, to engage GPs, it may be useful to identify other primary care practitioners, such as practice and community nurses who are in positions of influence with GPs but who are also likely to be central to the successful implementation of the project. Again, it may be useful to identify existing meetings/opportunities to present Information Prescriptions to clinical staff and encourage discussion.  
  
  The NHS Institute (NHSI) has identified seven levers to use in order to facilitate engagement.[^3] The paper focuses on GP |

[^3]: NHS Institute, NHSI, (no date) [Draft] How to engage general practitioners. A suggested guide for PCTs and SHAs. [online] Available at:
<table>
<thead>
<tr>
<th>Professional Group</th>
<th>Engagement strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>engagement, but also contains transferable elements that could usefully be applied to other health professionals within an Information Prescription system. These are listed below, along with suggestions as to what each lever might encompass in respect of Information Prescription implementation:</td>
</tr>
<tr>
<td>The Engaging parties</td>
<td>Those seeking to engage clinicians in the Information Prescription process might consider having clinician representation on the Steering Group/Management Team, making clear the benefits to particular clinical groups and minimising bureaucratic processes. Where the Information Prescription project is heavily reliant on one particular clinical group, e.g. GPs, it would be appropriate to have a ‘GP champion’ on-board at the outset.</td>
</tr>
<tr>
<td>Understanding clinicians</td>
<td>There is a need to analyse fully the range of forces and drivers acting on clinicians, recognising the differences between groups. For example, it would be important to understand the financial constraints within which GPs, as independent contractors, are working. Emphasising not only the clinical benefits of involvement in Information Prescriptions, but also translating this into terms that are meaningful to the audience in question (for example, being explicit about potential resource benefit or cost savings) may be useful.</td>
</tr>
<tr>
<td>Leadership</td>
<td>Ask ‘early adopters’, ‘thought leaders’ (NHSI, p3) or clinical champions to help influence their peers to become involved. Prioritise face-to-face contact: the NHSI paper cites evidence that suggests GPs respond well to personal approaches, i.e. face-to-face rather than email/phone contact, made by trusted peers.</td>
</tr>
<tr>
<td>Data</td>
<td>It is important to make sure data is ‘readily available, reliable, relevant and comparable’ (NHSI, p4). Present clinicians with available data that quantifies and qualifies the benefits or estimated benefits of Information Prescriptions to them.</td>
</tr>
<tr>
<td>The Attractors</td>
<td>it is essential to identify and communicate the ‘selling points’ of Information Prescriptions to the...</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Professional Group</th>
<th>Engagement strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>audience, most notably the patient benefit. The NHSI paper highlights the benefits of addressing Rogers’ five characteristics of change⁴ when working to engage GPs; these are the factors ‘likely to lead to project adoption’ (NHSI, p4). For Information Prescriptions, this might mean addressing the five characteristics in the following way:</td>
<td></td>
</tr>
<tr>
<td>• Clear advantage – How will Information Prescriptions make clinical practice and the day-to-day work of the clinician better? How will patient care/outcomes improve?</td>
<td></td>
</tr>
<tr>
<td>• Simplicity – How will Information Prescriptions be implemented so as to minimise bureaucracy and potential for complication?</td>
<td></td>
</tr>
<tr>
<td>• Compatibility – How will Information Prescriptions fit with clinicians’ current ways of working and the IT systems in use?</td>
<td></td>
</tr>
<tr>
<td>• Ease – How will Information Prescriptions be piloted with clinicians? How will the Information Prescription process be reviewed and refined?</td>
<td></td>
</tr>
<tr>
<td>• Observability – How will clinicians recognise and capture the difference Information Prescriptions are making?</td>
<td></td>
</tr>
<tr>
<td>• The Repellers – There is a need to engender trust from the outset, being clear about how Information Prescription implementation and delivery will work in a bottom-up, collaborative manner and also being explicit about what successful delivery of Information Prescriptions will mean to health professionals and patients.</td>
<td></td>
</tr>
<tr>
<td>• The process – Good project management, it is thought, requires leaders with excellent interpersonal styles who encourage ongoing dialogue. Sufficient support from respected health professionals throughout the planning and delivery cycle is also critical. Consider the competing demands on clinician time: using the example of GPs, NHSI recommend adopting a ‘just enough time’ system to keep down costs and minimise the impact on the GPs’ normal working lives by avoiding multiple meetings…’ (p8)</td>
<td></td>
</tr>
<tr>
<td>Voluntary and community sector staff</td>
<td>Many of the levers identified in respect of clinicians (above) could also be applied to engagement work with VCS groups; however, it is important to recognise the contextual factors specific to this group.</td>
</tr>
</tbody>
</table>

Voluntary and community sector staff

Many of the levers identified in respect of clinicians (above) could also be applied to engagement work with VCS groups; however, it is important to recognise the contextual factors specific to this group.
Professional Group | Engagement strategies
--- | ---
• VCS providers are a hugely diverse group, ranging from very small organisations with hugely limited resources and capacity to huge national bodies with networks across the UK.
• VCS organisations can be a valuable source of information on the service user perspective and experience in the locality. Information Prescriptions should seek to build on this knowledge as appropriate, making links early on with relevant organisations and leads.
• Many VCS organisations are experienced in thinking innovatively about service delivery models. Again, skills in this area would be valuable to an Information Prescription team, for example, in helping to think about long-term sustainability and creating a culture of capacity-building.
• While the extent of existing relationships with local and national stakeholders, including statutory agencies, are likely to be as variable as the range of VCS themselves, it is important to assess which local structures and networks, both formal and informal, the VCS in the locality are linked with, and how Information Prescription planning, implementation and ongoing delivery could be aligned with this infrastructure.

For example, VCS are often linked to thematic groups within Local Strategic partnerships or involved with national conferences that present a potential opportunity to promote Information Prescription-related work.

Principles for successful engagement

There appear to be some common principles that underpin successful engagement:

• **Keep it simple** – Most professionals were positive towards the idea of Information Prescriptions but worried about their workloads. This is reflected in the survey findings: professionals were only willing to get involved if Information Prescription systems and processes were quick, user-friendly and intuitive. They also have to minimise the time spent.
Professional involvement was treated as essential. During the design process for the templates, nurses, GPs and other staff were asked to give specific feedback on the usability, format, design and information of the Information Prescription template. This work led the site to revise the template three times, in each case simplifying the style of the template. The site has developed a simple tear-off Information Prescription template which the user is given and keeps. A duplicate is left with the prescriber. This presents simple information about the website, where to find access points in ‘community access’ sites, and other signposting information telling people where to call. These signposts are available in community languages.

The main prescribing route involves 10 GP practices across Darlington. Prescribing takes place through ‘annual patient check up meetings’. These last, on average, 30 minutes and are conducted in ‘90 per cent’ of cases by nursing staff or healthcare assistants at the primary care sites. GPs sometimes undertake a patient’s first annual health check, at which point they would then prescribe the Information Prescription. It was not seen as feasible to embed the prescribing process within the usual 10 minute consultations: GPs raised concerns that these appointment slots are too short to allow for the inclusion of Information Prescriptions and doing so would result in an opportunity cost in respect of lost consulting time.

- **Embed the Information Prescription process into existing processes and communicate the complementarity** – professionals are more likely to engage with the Information Prescription process if it is closely aligned with their existing systems and ways of working. Sites which were successful in this respect were often those that actively sought to build Information Prescriptions into performance management tools and existing administrative systems. In Oxleas NHS Foundation Trust, for example, line managers used appraisals to monitor how staff were issuing Information Prescriptions and recording issuing. In this way, they sought to demonstrate the importance of the process and the need for staff to monitor how many Information Prescriptions they were issuing. This site also embedded the process of issuing by linking the Directory to the staff intranet, which is widely used in the trust. As identified earlier, Darlington has built the issuing of Information Prescriptions into routine clinical appointments.

- **Link with existing professional networks, hubs and meetings** – pilots found it easier to engage busy professionals by identifying existing training sessions or forums and using these as opportunities to promote Information Prescriptions. For example, in one site, the Information Prescription pilot leads ran a session on Information Prescription processes at the monthly nursing staff meeting, as well as at a GP practice in-service training day.

- **Explain the benefits** – professionals tended to be responsive when the benefits of Information Prescriptions to their service users were made explicit and when they were reassured about the simplicity of the processes involved. This reassurance involved communicating explicitly, to both professionals and service users, exactly how Information Prescriptions would meet their needs. These sites enlisted the help of ‘champions’ within a particular professional group or team in influencing their peers to secure buy-in for Information Prescriptions. In communicating the benefits of Information
Prescriptions, sites also found it helpful to use ‘real-life’ case studies illustrating service user or professional benefit using quotes, case studies and scenarios.

Hammersmith and Fulham PCT

This site built on the learning from their recent experience of seeking engagement for other projects. They identified that the ways to increase engagement by GPs include:

- **Adopting a ‘pay-for-participation’ approach** – providing direct financial compensation for additional tasks may improve uptake.

- **Linking with QOF** – Linking Information Prescriptions with QOF was thought to be another way of incentivising participation. This could be done either directly or indirectly through the local assessment process.

- **Making it easy** - Ensuring that Information Prescriptions can be delivered through existing systems is likely to maximise participation. It was thought that anything that requires training lasting more than approximately 10 minutes, extra preparatory reading, or logging in or out of new IT systems would not work.

- **Showing it will reduce pressures** – There is a need to provide evidence that use of Information Prescriptions will have clinical and/or patient benefit, for example, by reducing the number of times a patient is required to visit a health professional or by helping people with long-term conditions to live more independently. This could be achieved, it was thought, through evidence-based studies (which would, of course, take time to deliver), or through case studies that named and provided photos of clinicians involved.

Quality assurance and accreditation

An Information Prescription needs to contain information which is reliable and trusted by users, carers and professionals. This requirement poses significant challenges to sites, particularly those without pre-existing information banks and quality assurance procedures. Sites were given no written, and little informal, guidance on quality assurance standards and processes, and therefore responded to the task in a variety of ways.

Even given this, the majority of pilot sites felt it was important to quality assure all information sources. In doing so, a few sites developed bespoke quality assurance processes, but the majority simply used resources which they thought were reliable. Some sites produced and quality assured their own directory and, in some cases, voluntary sector partners or user panels quality assured all content. In Evelina, NHS Direct took responsibility for accreditation. South Staffordshire adapted a number of accreditation approaches and developed a robust system for assessing content. Content was marked against a number of criteria and discarded if it fell short. Other sites were able to use existing resources which they had developed for another project, but this tended to mean that information gaps were not filled, for example, around non-condition-related information.

Some sites relied entirely on the belief that appropriate quality assurance processes had been adopted by the information provider of directory content, which might be a voluntary
organisation, government website or local council, and that the content would be regularly
updated. They did not institute any processes for checking content, nor provide guidance for
professional users in how to select appropriate content from the range of resources on offer.
A few sites produced a directory and spoke of quality assuring it ‘at a later stage’. These
sites lacked clarity regarding the purpose and appropriate timing for accreditation.

A number of sites reflected that it would be very useful to have a national databank of
accredited information resources which could be adopted and tailored by each site.
Some also had questions about data protection and copyright issues, and wanted national
guidance to help them navigate such legal complexities.

The widespread support for quality control processes, across pilot sites, may well contribute
to the survey responses in respect of assurance about the quality of information being issued
in the Information Prescription: nearly all survey respondents (90 per cent) reported being
confident in this respect.

For those sites that could access substantial amounts of information that had already
been appropriately quality assured, the quality control process was relatively simple.
Sites dealing with cancer, for example, found a great deal of quality assured information
about the condition and related issues was already in existence. This was in contrast to other
sites, particularly some mental health-related pilots, which identified real gaps in existing
information. In these sites, it was necessary to conduct comprehensive quality assurance of
newly collated information.

The process of quality assurance could be time-consuming and labour intensive. In addition,
there were instances of duplication of effort: two pilots had separately quality assured the
same information. Most professionals we interviewed did not regard quality assurance as
something which local areas would need to do for themselves in the future. This role, it was
argued, could be safely carried out at a national level as part of a national information
accreditation process. Several professionals suggested that the national accreditation
scheme could be adapted to accredit information for Information Prescriptions. There were,
however, concerns that any accreditation scheme may favour the large information
providers, such as the large national voluntary organisations, over smaller potential
providers. Appropriate measures may need to be put in place, therefore, to ensure that a full
range of information providers are able to become members and thus have the potential to
be included in information prescriptions.
South Staffordshire and Shropshire NHS Foundation Trust

The project manager for this pilot site was a senior librarian. When people wanted to know how information would be quality assured for information directories, she explained the criteria recommended within the EQUIP website's quality assurance tool (see www.equip.nhs.uk). This site offers a set of criteria for including a link to a website, which addresses:

- **Appropriateness** – content should be suitable for the audience
- **Design and navigability** – ease of use, speed and appropriate use of graphics should be assessed
- **Authorship** – the website should identify its authors and mention where others were involved in its creation (e.g. whether and how patients contributed to website development). It should also state the level of expertise of the authors and the reputation of the lead. In addition, contact details should be available.
- **Sponsorship** – sponsors should be clearly stated and suitable
- **Readability** – appropriate level of language for the audience
- **Currency** – date of update should be clear and content still valid
- **Legibility** – sites ideally should adhere to the ‘clear print guidelines’ established by the Royal National Institute for the Blind (RNIB) in this respect\(^5\)
- **Accessibility** – there should be no registration, cost or special software required to enter the site and sites should be viewable in Netscape and Internet Explorer and, ideally, fully accessible to those with a visual impairment.
- **Copyright** – the information should be in the public domain
- **Content** – this is the most important factor for inclusion. Certain aspects of poor site design may be permitted if the content is of value to the audience and is not contained in other sites.

These criteria have been compiled with guidance from Centre for Health Information Quality (CHIQ), Discern Online, Health On the Net (HON), British Healthcare Internet Association (BHIA) and Organising Medical Networked Information (OMNI)

There is an important distinction between quality assurance and accreditation. Quality assurance is the use of a process to check the quality of information against a set of criteria or standards which vary according to the process used. Accreditation is a process used to assess the quality of information against an agreed set of national standards which, if met, lead to the awarding of a formal kite mark or seal of quality.

In general, most informants argued that all of the main sources of information used as part of Information Prescriptions should be quality assured and, where possible, formally accredited. While there was acceptance that accreditation can be time-consuming and may possibly exclude some information providers, informants thought it important that users and carers were able to trust the information sources and felt that accreditation helped in this respect.

‘If users can see that a piece of information is kite marked, has a clear logo of accreditation, it will greatly strengthen their trust in the information, and the whole process.’

There was broad support for The National Accreditation Scheme to be used to accredit information providers whose information could be included in any national database of information, as proposed later in this document. Such a scheme could introduce a consistent approach to accrediting information providers to ensure that the information they produced was of a high standard. The scheme itself will most likely use ‘architectural’ approaches to accredit sources. These provide a way of scrutinising the methods by which information is produced rather than examining every item of information in detail. The majority of respondents responded positively to this approach, considering it far preferable to hand-checking every single source of information, which, they felt, would be overly prescriptive and burdensome on information providers.

There were serious concerns, however, particularly among smaller voluntary and community sector organisations, that the burden of preparing for accreditation – and the capacity and resource required to do so – would bias information provision in favour of larger providers. Concerned stakeholders felt this could limit the extent to which very local or highly specific information could be included in the Information Prescription scheme. Informants from the VCS strongly recommended that any accreditation scheme ought to be flexible enough to remain open to smaller charities and information producers.

NHS Direct uses a series of standards to appraise the quality of material to include in its Health Directory and in the NLH patient home page reports. NHS Direct has accredited 100 sites that are major providers of health-related information. These sites, in the absence of a national scheme, could provide a number of ‘safe’ information sites for use in any national directory.

There was strong support for some degree of information accreditation, where possible and appropriate. In particular, it was thought to be of critical importance to accredit information about:

- medical conditions, such as symptoms diagnosis, tests/screening, and treatment options and after care;
- drug treatments, medicines and prescriptions; and
- self-management of medical conditions.

Some sites involved users in quality assurance processes. Several sites, including North Tyneside, Oxleas, Staffordshire and Mid Trent involved users and carers in identifying relevant information sources, checking their content and testing their usability.

In this regard, there was strong support for any national accreditation process that had user engagement at its heart. Thus, in becoming accredited information providers, organisations
need to demonstrate that they involve users and carers in both information development and quality assurance, and that these users are representative of local communities and of people with particular health and social care needs.

**Oxleas NHS Foundation Trust**

In Oxleas, patients and carers have been central to Information Prescription development. The trust held focus groups with patients, carers and staff to appraise a range of possible pieces of information for inclusion in the directory. This enabled the trust both to test the applicability of information and to narrow down the number of critical information sources from a long list to a much shorter list. The trust plans to involve patients and carers in the subsequent refreshing or development of any new sources of information, thus making the directory a ‘live’ resource that is evolving in accordance with the changing needs of those it exists to support.

**Information technology (IT)**

It was regarded as important for the pilots to test how IT could usefully support information prescribing and dispensing, including how Information Prescriptions are recorded and tracked, to allow information given to users and carers to be audited for quality and consistency over time. IT can be critical to supporting a range of processes which underpin Information Prescription systems, such as the development and searching of directories, prescribing and dispensing, and the recording of information prescriptions in user records.

Sites have used IT for the following purposes:

- To compile and manage a directory of information;
- To generate tailored templates or access points, such as websites, for self-prescribing; and
- To record or capture the prescriptions and/or fulfilments.

Many pilots identified the need for IT to support their activities, but some found it difficult to conceptualise what kind of system, software or process might be suitable. Informed, flexible and imaginative IT consultants and support staff proved an invaluable resource in helping to develop appropriate IT solutions.

The use of IT was varied across the pilots. Some aimed to develop public websites and databases from the outset, others designed Information Prescription modules for their care record systems and others had no IT elements in their plans. Some of this last group took up the offer of the package (described below) developed by Map of Medicine for the programme; others were largely uncomputerised throughout.

Several factors inhibited the use of IT. Some services were peripatetic or consultations took place in settings where there was not good access to IT facilities. The duration of the pilots was short and there was pressure to deliver Information Prescriptions quickly. Decisions on the design of templates, how to engage care professionals and how to incorporate Information Prescriptions in working practice thus tended to take priority over devising new IT systems.
Some sites used IT to a very limited extent. While some sites have heavily invested in IT to support all of these processes, there are sites at the other end of the spectrum dealing with paper directories (i.e. a list of sources referring to leaflets and books) and paper templates filled in by hand and kept in a hard copy file with the patient record.

Building blocks for IT to support Information Prescriptions

The main components of an IT system to support Information Prescriptions include the following:

- A database of materials
- An interface to access the database for the purpose of:
  - prescribing (searching for the relevant sources of information and issuing an Information Prescription)
  - dispensing
- An interface or module that enables details of information needs and the Information Prescription to be stored either in a stand-alone database or an individual's electronic care record.

Databases of materials

Information Prescription directories are categorised databases or lists of resources which contain the information provided to the user or carer. The information on an Information Prescription database can be complete leaflets or booklets on aspects of conditions or interventions, or details of agencies or websites that can provide information.

Information prescribing relies on extensive, searchable directories linked to documents, websites or organisational contacts. Information found through the directory can then be tailored to meet individual needs. The pilots’ experiences of constructing and using directories are described in detail in Section Three.

Managing information

Many sites have used IT to store their directory, either in the form of a searchable database or a website. This has proved particularly useful where professionals are in different locations or organisations. For example, some sites have observed that IT can help streamline the information providing process for GPs by making it very quick and facilitating an immediate link to EPR. Oxleas wants to allow GPs access to their intranet and thus to the directory. Oxfordshire has found that a web-based resource allows all participating organisations to have access and overcomes the difficulties of incompatible systems.

Issues in designing computerised databases for Information Prescriptions

Database design is fundamental as it may limit both the types of material that can be stored and the approaches to searching.
Type of content and formats

A key issue is whether the database will store full information or just links to sources where information can be obtained.

The MoM IPG was designed to store relatively short items of information, normally descriptions of and links to other resources. The content management system used by Oxfordshire and South Essex was more flexible in that it enabled the entries to include attachments such as electronic copies of leaflets or even audio and video materials.

In any event, the stored information should be intelligible – and if the aim is to print an information prescription, the formatting and other layout features should be designed with that in mind.

Searching databases and generating Information Prescriptions

Different groups may want to search Information Prescription databases in very different ways. For example:

- Care professionals may want free text or simple combinatorial searching to find material quickly using specialist terms.
- Information professionals may want all the features of advanced search interfaces.
- Users and carers may want browse facilities.
- Several groups might want pathway-type interfaces that indicate the range of information that might be helpful at different stages in the natural history of a condition or at different points in a care pathway. The presentation and terminology of pathways may need to be adjusted for different groups of users.

Most of the pilots that used some type of computerised directory only permitted single keyword searches. However, the Isle of Wight directory supported four levels of user with different approaches to searching: those with a general interest, those who have had a diagnosis, professionals, and carers.

Controlled access

Various levels of control can be placed on accessing either directories or stored Information Prescriptions and the history of information prescribed. All the following were found in the pilots:

- Fully open systems that will generate, but not store, personalised Information Prescriptions, e.g. those at Darlington or Suffolk.
- Password or other forms of control:
  - to restrict access to an Information Prescription – even though it does not contain any personal identifiers (e.g. Isle of Wight);
  - to protect an Information Prescription that includes personal information, e.g. South Essex;
  - to protect an Information Prescription that is stored as part of a wider care record system, e.g. Heart of England;
• to restrict access to information on conditions and interventions that is not intended for lay use (Heart of England – Cystic Fibrosis pilot).

There are particular dilemmas around the storing of Information Prescriptions on care record systems where the need to protect the security of the entire system may conflict with the desire to give users access to their stored Information Prescriptions. Several of the pilots, including Heart of England, were considering whether Information Prescriptions should be stored on parallel systems that did not form part of the main care record database.

The capacity to record the dispensing of information recommended on an Information Prescription may also be restricted by not wanting to give dispensing agencies, such as patient support groups, access to care record systems where Information Prescriptions are logged.

IT, prescribing and Information Prescription Generators

Because the pilots were strongly focussed on delivering Information Prescriptions to the service users, all the computer systems used or developed for the pilots had a facility to generate an electronic or hard-copy prescription. These became known as Information Prescription Generators.

However, one of the important functions of a good database of materials and sources is to enable and encourage care professionals to check the availability of information, remind themselves what resources can be recommended, and familiarise themselves relatively easily with agencies and services.

Part of the prescribing function of an Information Prescription database is to provide a convenient method for professionals to improve their knowledge of sources of information and to help them jointly explore information needs with users and carers.

How to access an Information Prescription Generator

Pilots provided examples of several different ways in which Information Prescription Generators can be accessed, including:

• stand-alone Information Prescription Generators;

• an Information Prescription Generator module within a local medical record system such as EMIS (software used in GP surgeries) or the local implementation of EPR in a hospital; and

• an Information Prescription Generator module attached to some other package that is widely available to health (and social care) professionals or the public via the Internet or local intranet (e.g. Map of Medicine).

Reports from some pilots suggest that an Information Prescription Generator is more likely to be used if it is embedded in existing local software, rather than being located on another site.
Stand-alone Information Prescription Generators

The pilots were given the opportunity to help develop and then use a prototype Information Prescription Generator commissioned from part of the team that is developing The Map of Medicine.

The idea of making a computerised Information Prescription Generator generally available to pilots was floated at an early action learning session and taken up by the Department of Health. The Map of Medicine (MOM) team was approached to produce a prototype Information Prescription Generator whose functionality would evolve in collaboration with the pilots, but whose aim was as much to explore the issues around developing such software, and alert pilots to the potential of computerised Information Prescription Generators, as to produce the definitive package.

The choice of the Map of Medicine team was partly prompted by the potential that the MAP itself might have for Information Prescription – namely that its representations of the natural history of conditions and care pathways can help in identifying information needs for different stages.

In the event, the Information Prescription Generator was developed as a package that can function independently of the MOM, though the development team have explored forms of linkage with the MAP, such as being able to view the content of Information Prescriptions from within the MAP.

Different approaches and technical options for the Information Prescription Generator were explored at several training and demonstration sessions with the pilots. The contract with MOM covered the development of customised templates for four pilot sites (Cambridge and Peterborough, Staffordshire, North Tyneside and Doncaster) and a generic template that could be used elsewhere.

Pilot sites have password controlled access to the MoM Information Prescription Generator website via the Internet. Users can load their own directories of sources (in Excel format) into a database on the MoM site and create Information Prescriptions by selecting items either from their own directory of from those of other pilots.

The Information Prescription Generator has some features of an online shopping site. There are options to search for items and create a prescription, to issue or save the prescription in different formats, and to upload or download sets of directory items. There are also options relating to the editing and maintenance of directory items. The search produces a list of possible references and descriptions supplied by the pilot site.

An example of the results of a search (in this case for diabetes) can be seen in Figure 8 where two of the items have been selected for inclusion in the Information Prescription.
All sites were offered the opportunity to work with the Map of Medicine (MoM) team to refine the Information Prescription Generator for use in information prescribing. As noted above, some sites have subsequently populated it with their own information, and developed an adapted template, so that they could prescribe and dispense directly from the system. Others used their own systems, either because the offer was made after they had developed their own approach, or because its design appeared inappropriate for the site.

One feature of the Map of Medicine Information Prescription Generator was that it could be used in conjunction with the Map of Medicine – a pathways-based diagnosis and intervention support tool.

Sites which decided not to use the Map of Medicine tool in conjunction with the MoM Information Prescription Generator had the following concerns:

- That it is ‘very clinical’;
- That it is designed for use by clinical staff, not for non-specialists or those working in social care settings;
- The MAP’s reliance on the pathway model is unsuitable for social care settings or those with complex needs;
- That it cannot respond easily to searches on multiple conditions;
- That it is not easily searchable for the types of information needed for an Information Prescription because the search facility is not precise enough; and
- That it is not suitable for members of the public.
Other examples of web based Information Prescription Generators for (mostly) professional use

There were three other cases of pilots developing web based Information Prescription Generators to support prescribing: the PIP-OX system developed by Oxfordshire, the system used by South Essex and the model used at Heart of England.

The PIP-OX site run by Oxfordshire County Council was an example of an Information Prescription Generator with access restricted to care professional. This system enables information need assessment and prescribing to be done in a single session by participating professionals. Dispensing can be done elsewhere, at venues including the local library service. The early versions of the system provided 16 standard scripts, selected on the basis of the enquirer's age and severity of visual impairment. More powerful search options are now available using the same content management system as the South Essex pilot.

South Essex commissioned the info4U service from In Touch with Health to cover a range of services and issues relating to mental health. Professionals can log onto this system and create Information Prescriptions for named patients. Information Prescriptions can be printed or emailed. The system uses the same content management software as PIP-OX and is hosted on an external website. Searching is done via keywords, which are intended for professional use. There is public access to either browse the system or retrieve and print existing Information Prescriptions, but not to generate new Information Prescriptions. People without access to computers and printers can get their Information Prescription dispensed at designated ‘fulfilment points’.

Information Prescription Generators embedded within existing hospital systems

Heart of England has developed its own system which builds on the system used in its long-established information centre. Prior to the programme of Information Prescription pilots, the hospital information centre at the Heart of England Trust had already created a system (PID) to store information materials and was encouraging hospital staff to produce informational documents for the system. The system gives staff three levels of access: secretarial and administrative staff can view and print material; medical staff can issue items to a patient, with issuing automatically recorded on the EPR; and managerial staff can use a facility to create and edit the materials.
Heart of England: IT enabled

Heart of England has used the information prescribing project to strengthen its IT infrastructure. It has purchased twenty laptops, laptop safes and some disposable keyboards which allow patients to access the Internet. There are also touch screens on the ward and resources can be accessed via the Internet by patients from their home computer. The cystic fibrosis patient information website sits on the hospital intranet. There are plans to introduce a password controlled cystic fibrosis patient chat room or blog facility.

The Information Prescription pilot involved creating a new front end for PID (PIPS) and trialling this in the cystic fibrosis unit. Compared with the original PID interface, PIPS provides more advanced searching facilities, a facility to limit the range of materials searched to, for example, items created in a particular specialty, and the capacity to store and print lists of recommended materials - the Information Prescription. As part of the pilot, the Cystic Fibrosis Unit converted all their existing materials into electronic format. PIPs was written by the software team that supports the hospital EPR system and can appear as a part of the EPR system as well as being able to interrogate and update parts of the patient records.

Open web based systems

There are several examples of pilots developing local open websites which are open to all to access information. Some of these have been specifically designed to promote self-dispensing and are central to one of the models of delivery we describe in Section 8. The sites are designed to aid users in accessing information through a searchable interface, although the sophistication of each varies. Some enable users to develop their own Information Prescription Generator, save it and print it off themselves, while others are limited to static web pages on health related topics.

The Isle of Wight – One Link

‘One Link’ Information Prescription service is maintained as part of the LA website. Searching can be guided, keyword controlled or unrestricted, depending on the type of user. Content coverage includes both local and national sources and links to national sources. The system incorporates an Information Prescription Generator and all users can save Information Prescriptions for later retrieval or printing. Coverage is deliberately restricted to depression, dementia and related symptoms and problems. This is probably the most powerful of the local health databases in the pilot. Four levels of user are supported: those with a general interest, those who have had a diagnosis, professionals, and carers. There is extensive editorial material and the database of links and resources is maintained by an automatic reminder mechanism which periodically asks participating agencies to check the accuracy of their entries.
**Darlington PCT – ‘Healthclick’**

*Healthclick* was developed internally by the PCT software team and is a web-based system that is fully accessible to the public. It is basically designed for self-prescribing. Ensuring the system was suitable for public use was the key design criterion, but it can be used in at least two other ways:

- As a two-stage prescribing system in which the first stage involves a health care professional confirming a health problem or diagnosis and handing the patient instructions for using *Healthclick*.

- As an assisted self-prescribing system in which the patient is helped to search for materials by workers at designated support points, such as the PALS office and library information services.

The information prescription can also take a variety of forms, such as a printed list of sources and agencies, or a virtual script, i.e. a set of hyperlinks in an interactive prescribing session.

Searching for material on *Healthclick* is a simple two stage process:

– select a topic (from a short list of keywords – mostly names of conditions)

– select one or more of four types of sources: NHS Health Information, Council Information, Networks and Support Groups, and other Health Information.

Searches generate web pages of links and descriptions of materials. There is no free text search facility.

In this system, the web pages of results are produced dynamically from the underlying content management system. Records in the system are typically the name/title of an information source, a brief description and a hyperlink. Records can also contain attachments, such as locally generated leaflets.

---

**The future of open systems**

It is, of course, possible to find large amounts of good quality information on long term conditions (LTCs) on many websites, such as those of NHS Direct, BBC Health, NHS Choices and those run by professional bodies, medical charities, and patient and more generic support groups.

**Given this, why did some pilots feel the need to create their own new websites?** One reason is summarised by one of the Darlington aims ‘to create a safe health Google’.

Another reason, exemplified in the Isle of Wight approach, was the desire to produce a database that included details of services from a wide range of very local providers across many sectors, many of whom might not be recorded on a national site. In particular, pilots wanted to use the database to bring these services to the attention of care professionals as well as to users and carers.

Both of these pilots recognised that many people with LTCs will not access information from the Internet themselves. In fact, only 20 per cent of users and 33 per cent of carers in the surveys got information in this way. So any open system should be designed with the joint aim of supporting care professionals and others who will assist with prescribing and
dispensing. What this might mean for the design of the proposed national database is briefly discussed in the conclusions to this section.

**Using IT to dispense the information recommended in Information Prescriptions**

With a few notable exceptions, the pilot sites have concentrated on developing and delivering the prescription (or pre-prescription), rather than on methods for dispensing. **There are, therefore, few examples of innovative methods of information dispensing and even fewer in which IT has a major role.** The general picture is that most pilots have relied on multiple and traditional methods of dispensing, often involving outside agencies.

Some of the more common combinations of the type of dispenser and mode of dispensing are shown in Table 3. Only a minority of these combinations involve the use of IT.

**Table 3: Types of information dispenser – and the role of IT**

<table>
<thead>
<tr>
<th>Where does user or carer get the information?</th>
<th>Collects pre-printed information</th>
<th>Receiving pre-printed material</th>
<th>Receiving electronic material</th>
<th>Receiving material by post</th>
</tr>
</thead>
<tbody>
<tr>
<td>From care services at or near point of prescribing</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>From remote dispenser acting on behalf of care services</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>From other agencies – not contacted via computer</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>From emailing other agencies</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Directly from sources on web</td>
<td>x</td>
<td></td>
<td></td>
<td>x</td>
</tr>
</tbody>
</table>

**Models of dispensing supported by IT**

In the pilots, there are five models of dispensing which are supported by IT:

**Mostly manual dispensing aided by electronic catalogue**

In this model, most information is in the form of pre-printed leaflets and there is unlikely to be much additional printing of downloaded files. A local database may be used to store contact details of agencies from which materials can be requested.
**Self-dispensing**

In this model, people are able to self-dispense through an open access website, such as developed by Darlington or the Isle of Wight.

**Assisted web-based dispensing**

Assisted web-based dispensing involves a professional assisting a user or carer with finding information sources and then printing them off directly, usually to a printer linked to the computer in a consulting room, ward or facility.

**Table 4: IT and dispensing in the pilots**

<table>
<thead>
<tr>
<th>Approach to dispensing</th>
<th>Examples in pilots</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mostly manual dispensing, aided by electronic catalogue</td>
<td>QE Birmingham, Durham</td>
</tr>
<tr>
<td>Obtained via web - self or assisted</td>
<td>Suffolk, S Essex, IOW, Doncaster, Oxford, Staffordshire, Darlington</td>
</tr>
<tr>
<td>Mostly printed from local database of files</td>
<td>Royal Marsden, Oxleas, Heart of England</td>
</tr>
<tr>
<td>Can be sent electronically</td>
<td>Oxford, NHS Direct (Evelina and North Tyneside)</td>
</tr>
</tbody>
</table>

**Information materials are stored on and printed from local databases**

Several of the pilots have been based in hospitals with strong traditions of developing local information materials. In these settings, much dispensing involves printing locally-produced materials that are stored and updated electronically. For example, most of the information provided to cystic fibrosis patients at the Heart of England Trust is written locally or modified from blueprints provided by the Cystic Fibrosis Trust.

**Dispensed material being sent electronically**

Across the pilots we found examples of two types of material being sent electronically to users and carers: Information Prescriptions (i.e. lists of recommended materials) and dispensed information (booklets, etc., in electronic formats).

Very few of the pilots include an option to email dispensed information (rather than Information Prescriptions) to patients and carers. The Oxford PIP-OX system has the potential to email materials automatically to enquirers, and some of the Heart of England patients may receive their materials by this route, but NHS Direct in the North Tyneside and Evelina pilots provides the most complete example of electronic dispensing.
Prescriber and dispenser model

NHS Direct has, in effect, been operating an information prescribing and dispensing function since its enquiry line was established. Callers to the normal 0845 number can either request information from the outset or the triage process may establish that giving information is the most appropriate intervention. In either event, enquirers will be passed to an information specialist/call handler or queued for a return call from the ‘Outbound calling team’. Their information needs will be discussed and the call handler will search the NHS Direct internal Health Directory for suitable information. Callers can be routed to NHS Direct nurses or to counsellors/psychologists if additional support is required.

References or materials can be sent to the enquirer in a variety of formats. The Health Directory (a development of the DORIS system) includes both national and local sources and is maintained nationally and locally by teams in their regional units who have close contact with local services.

At present the supporting database is a call-handling support tool; there is no public or external access. The NHS Direct service includes a recording and call-back system that keeps patient records and is used for periodic follow-ups.

The Evelina pilot is an example of a bespoke NHS Direct information activity. The Information Prescription (really a pre-prescription) from Evelina permits a maximum of three types of queries on each drug being prescribed. The hospital pharmacy will remotely complete the template on the NHS Direct website, whereas participating community pharmacists will fax the completed forms.

NHS Direct staff will search both the Health Directory and other sources specially identified for the pilot. Details of information prescribed and dispensed will be entered onto a new NHS Direct record or an existing record will be updated. The identified material can be sent to the enquirer in several ways including email. A schematic overview of the process can be seen in Figure 9.
Recording issued and dispensed Information Prescriptions on IT systems

Most sites felt it was a good idea that Information Prescription issuing and dispensing could be recorded and placed in user records. Recording in this way would have the benefits of ensuring that it was possible to monitor who received Information Prescriptions, when and what type of information was given. The consistency of information giving, gaps in information giving, and patients’ use of information could be tracked over time. This has a powerful potential to look at patient outcomes, such as levels of attendance at in-patients or at GP consultations, and information giving.

However, sites struggled to develop consistent and sophisticated methods of Information Prescription recording, with practice varying greatly across sites. Barriers to detailed and systematic recording included:

- The difficulty of recording patient information in care settings where clients can be advised anonymously;
- Systems that encourage self-prescribing and dispensing may also be unable to keep detailed personalised records of information provision;
- Lack of electronic patient records in most of the pilot sites;
• Lack of care planning technology in social care settings to enable recording onto client records;

• Resistance from some care professionals about the introduction of time-consuming manual recording.

In fact, most professionals added some record of the issuing of an Information Prescription on a patient record, though this might simply note that an Information Prescription was given rather than recording details of its contents.

**Our survey of professionals involved in issuing, found that most were recording the offer of Information Prescriptions.** Two-thirds (67 per cent) of the ‘issuer’ sample said that they were in some way recording **all** of the Information Prescription offers that they made to people, while a fifth (20 per cent) were recording some of the offers. The remaining one in ten issuers (13 per cent) were not recording any of their offers.

Just under a half (47 per cent) of those who were recording the offer of an Information Prescription were also recording **all** of the Information Prescriptions offered but not accepted, while one in six (16 per cent) were recording some of the offers that were not accepted. A third (36 per cent) were not recording offers that were not accepted.

All of those who are recording the offer of an Information Prescription were asked which one of a number of statements best described the way in which the Information Prescription was recorded. Nearly a third (32 per cent) indicated the best description was named record with details of items or content. This was closely followed with more than a quarter (29 per cent) indicating the best description was named record with details of items or content and linked to other patient details in EPR or client record system.

**One pilot site had successfully embedded Information Prescription recording into existing IT processes and a number of others were building this capability.** Heartlands have fully integrated Information Prescription recording into their existing IT processes. Work is being done in Darlington to add a prompt to the Annual Health Check forms already in existence in primary care to verify whether an Information Prescription has been issued. The new user information system which is being launched in Leeds Mental Health Trust will include fields for information prescribing. Moreover, Oxleas Information Prescriptions are being tailored to the existing Care Plan Assessment (CP) and the information requested and dispensed will be recorded on the Care Action Plan (CAP). The Isle of Wight and Oxfordshire sites are both linking their Information Prescription recording process into the SWIFT system, though it is unclear whether this linkage will be automatic or done via manual re-entry.

Without a link to some form of patient or user record system or case file, recording multiple Information Prescriptions or identifying user characteristics has proved difficult. Some sites are working with users without case management processes, for example. However, others had been able to develop systems to make this work. For example, one pilot was using a system which allocated a unique user number with Information Prescription numbers (1,2,3, etc.) for each Information Prescription issued.

If the effectiveness of this new system is to be monitored successfully, it is important to be able to record not only whether an Information Prescription has been issued, but also whether the user has acted upon it. For example, if the Information Prescription is emailed to a user who then must open it and go to other websites, how can the site track whether the user has actually viewed the prescribed information? Or indeed, how can it determine
whether the user made use of the information they accessed or has all the information needed? A couple of sites, such as Evelina, are telephoning Information Prescription recipients some weeks after being issued with an Information Prescription to check if the information is useful and has been followed up. This can provide a further opportunity to ensure that individuals have what they need. However, most sites are not building in processes to pick up this issue.

**Clearly it is easiest to keep complete records if an electronically generated Information Prescription can be stored directly on a care record system.** Similar detail will be kept if a hard copy of the electronic Information Prescription is included in paper records. Systems where the issuing of an Information Prescription has to be separately re-recorded may lead to briefer records. Moreover, in most cases, the records note what has been prescribed, not what has been dispensed or whether the user has followed up the prescription by, for example, visiting the site directory online.

**Training and support**

**Training is crucial to the success of Information Prescriptions.** Most sites were able to provide support to professionals who are involved in prescribing and dispensing, with the vast majority (93 per cent) of professionals who were surveyed claiming to have either attended training (38 per cent, though higher for those in mental health settings and in local authorities) or been talked through the process (55 per cent). Over a quarter of those issuing Information Prescriptions said that they needed more training, notably those who worked in mental health settings and as non-specialist nurses in acute care.

Training programmes need to be tailored to support different levels of involvement in the process. A range of training approaches were provided, including IT training, training on information giving skills, and more informal training sessions. Training should support the development of a number of core competencies:

- **Information Prescription coordination and management** – including skills in stakeholder engagement, needs assessment, influencing skills, capacity building, communication, health information management, designing and developing databases and information quality assurance.

- **Basic introduction to Information Prescription systems** – training should be offered in using and completing Information Prescription templates, understanding Information Prescription directories, and recording prescribing.

- **Advanced information giving and support** – including skills of communication, needs analysis, counselling, advocacy and information management with an understanding of equality and diversity.

There were a number of specific training programmes developed by pilots, including the following.

**IT training**

None of the IT systems developed by or for the pilots were difficult to use. Indeed, the aim was to produce systems that were quick and easy for both public and professionals. Most resembled an Internet shopping site.
There were slight differences in complexity between the systems: in general those intended for public use were simplest, followed by the stand-alone Information Prescription Generator, such as the one provided by the Map of Medicine team. The most powerful systems - those that were integrated into the EPRs or some other method for full record-keeping, and also provided dispensing - were slightly more complex, but none should have required a major training effort. Training in the use of IT systems for Information Prescriptions was not distinguished from the overall training needs in the monthly returns, but no sites mentioned this as a major issue.

Training would be of three types: how to do basic searches; how to save, print and record; and how to do advanced searches. The former should require little effort. Basic searching, often from a database of locally selected items, would be straightforward. The second required some effort, especially where new procedures were involved. There was no demand for the third as the databases being searched were all quite small with familiar contents and keywords. However, training in advanced search techniques could be of benefit to the roll-out of Information Prescriptions as it should enable professionals, and others who may be helping prescribe and dispense, to locate material more quickly.

**Darlington PCT**

The system developed by the site for training on Information Prescriptions is deliberately simple for both professionals and users to use. The rationale behind the scheme is that take-up from other professionals would be limited if there were major training requirements. The only training that is provided is a demonstration to professionals of how to prescribe and record. This involves providing and talking through a simple script. The other strand of the training is given to nurses, libraries, volunteers and others in dispensing sites around the use of the website, log in, searching and printing. Support for those dispensing and prescribing if problems arise is provided by PALS.
Oxleas pilot

Training was aimed at members of staff coordinating care for community teams. The plan was to train the team leaders who would then be able to cascade training to their staff. Pragmatism dictated that training would concentrated on those areas where the bulk of the clients and carers were based. Two half-day training sessions were arranged, followed by a ‘mop up’ session in which staff had the opportunity to appraise information further using the agreed tools. The learning objectives of the training were for staff to:

– identify the wide range of health and social care information they would be providing, building on existing practice;
– familiarise themselves with the information appraised;
– familiarise themselves with the use of MP3 players and memory sticks on which the information for use in the files was available
– familiarise themselves with how the Information Prescriptions would be issued and recorded as part of the electronic care record CPA (the Care Programme Approach), so that they could become a routine part of clinical practice,
– have the opportunity to ask any questions they had about the process, as well as discussing any concerns they had in delivering information to clients and carers.

Training to support prescribing and dispensing roles

Most of the training offered was designed to support professionals in adopting different approaches to providing Information Prescriptions. The more complex approaches appear to require more dedicated training. Thus, there is evidence that those involved in multi-stage prescribing and complex information giving in relation to formal tailored templates and multi-level directories require more training.
North Tyneside, Training pack

North Tyneside has developed an Information Prescription training pack for staff involved dispensing information. The pack contains guidance on:

– How to use the directory/ what information to select
– Navigating around the directory
– Information categories in the directory
– Accessing local services
– How to select the right information
– Dealing with complex enquiries
– Communicating with people with Parkinson’s Disease via telephone
– Communication challenges
– Tips for communication via telephone

Training on communication, advocacy and information-giving to disadvantaged users and carers

There was a strong focus in some of the pilots on developing the capacity of staff to conduct more in-depth information provision and support to users and carers, particularly those with very debilitating conditions or facing multiple disadvantages. These users or carers often find it difficult to access information and to make sense of it. Many of these users will not understand written materials, may have several questions they want to ask, and will need further explanation. If they are facing very challenging and frightening circumstances in managing their care, such as managing cancer, they may also require additional care and support, advice and advocacy.

In light of these issues, some pilots developed training programmes aimed at advancing staff’s communication skills, focusing in particular on issues around how to support users who have received distressing and difficult information, do not understand standard and written information, or require advocacy support to help them manage their care. In North Tyneside, for example, the project manager was given training in advanced telephone communication skills using a programme developed by NHS Direct to train their health information staff.

Training for volunteers and non-professional staff

Linking in with the training already on offer in organisations central to the delivery of the Information Prescription project can be helpful in terms of minimising duplicated effort and cost, and in ensuring that those issuing Information Prescriptions and information are sufficiently knowledgeable about the condition in question.
County Durham, Building on existing voluntary sector training programme

The Information Prescription model developed in Co. Durham uses a network of volunteers to deliver the ‘supportive information’ that is key to the approach. The volunteers also work for the local Cancer Information Centre (CIC). In order to undertake a volunteering role in the CIC, there is a robust and in-depth ten-week training programme that they must undertake. This training is intended to be fairly comprehensive, covering such issues as cancer care, cancer treatments, being supported by a multi-disciplinary team, available information and resources.

As part of the Information Prescription pilot, a number of ‘add-ons’ have been developed, focussing predominantly on training volunteers to deliver ‘supportive information’ in an outreach setting. Whereas prior to the pilot volunteers would work only in the CICs, the approach to Information Prescriptions developed by this pilot site involves them delivering support in health clinics. Their training now includes such topics as: confidentiality, health and safety issues, advanced skills in communicating with disadvantaged users. As well as being informed by the experience of Information Prescription leads and the stakeholders with whom they work, the ‘add-on’ training was also determined by feedback from volunteers delivering the Information Prescription so that the volunteers could directly influence the training being offered.

Conclusions on developing Information Prescriptions

Success factors in developing Information Prescriptions

Success factors in engaging users, carers and professionals

- Engage a wide range of existing networks, patients groups, and carers’ forums to consult about Information Prescriptions and gain wider involvement
- Ensure that primary care staff, particularly GPs, are involved in developing local the Information Prescription system.
- Tailor engagement processes carefully to meet the needs of different target groups.
- Recognise the importance of local engagement and communication strategies.
- Ensure that carers are involved in the design and delivery of local Information Prescription systems.
- **Involve a wide range of stakeholders in regular and sustained engagement**, using different approaches to access and involve different stakeholders.
- Involve users directly in the design of templates and information materials.
- **Involve users from the start** of the project to inform the design of the project and key elements within it.
- **Involve the voluntary sector** in helping to identify contacts and links for local services.
- Bring in stakeholder engagement expertise to support user engagement activities.
• **Ensure that disadvantaged groups are engaged in the process.** Develop approaches which are tailored to meet their individual needs and ensure that they have greater levels of support in accessing and using information.

• **Ensure multi-agency collaboration,** and include commissioners at the outset to build support and sustainability into the process.

### Success factors in quality assuring information

• Establish a local process for quality assuring information on local services.

### Success factors in developing IT systems

• Ensure that IT specialists are built into local Information Prescription partnerships and delivery teams.

• **Involve all professionals** in designing an appropriate IT system.

• Identify ways to embed Information Prescription processes into existing IT programmes, such as care planning software and intranets.

• Explore and identify linkages between Information Prescription systems and planned improvements to IT elsewhere, such as the introduction of Connecting for Health improvements.

• Ensure than any IT systems are simple to use, quick to use and intuitive.

• Identify ways to embed Information Prescription prescribing electronically into existing patient records systems.

### Success factors in providing training

• Map out the main skill requirements across all professional groups involved in the Information Prescription process.

• **Develop a range of training packages,** ensuring that these respond to the different roles of professionals and levels of involvement.

• Ensure that existing training programmes link to, and support, Information Prescription training.

### Barriers and challenges in developing information prescriptions

#### Barriers and challenges in engaging stakeholders

• **Engaging users in Information Prescriptions is challenging, but essential.** Pilots found that some groups of users were difficult to engage, such as disadvantaged users, those with learning disabilities, parents and those who work. However, pilots were able to get high quality, rapid feedback on their plans for local Information Prescription systems when they were able to utilise existing user and carer networks, such as Expert Patient Groups, patient forums and citizens panels.

• Early and sustained engagement facilitates buy-in, whereas engaging partners late on in the delivery process is likely to be more challenging. To maximise engagement, sites highlighted the need for national awareness-raising activity and commitment from
national professional bodies. Sites that consciously worked with professionals from the beginning in the design of the Information Prescription process found buy-in and commitment was easier to achieve than it might have been had they left this activity until later on in the process.

- **Engaging disadvantaged users, especially those who do not have regular contact with mainstream services, can be challenging.** Pilots found a number of ways to successfully engage with this group, including working through the voluntary sector, working through community and faith groups, and providing payments and support to enable users to attend consultation events.

- Differences in culture and approach between voluntary and statutory agencies in some cases led to delays in developing local Information Prescription systems. Some pilots driven by voluntary sector agencies reported difficulties in getting full support and cooperation from statutory sector colleagues, especially in cases where there was no senior statutory sector champion making the case internally for the project.

- **Involving GPs and other primary care staff proved difficult.** The survey also found that those working in primary care, and GPs in particular, were less positive about Information Prescriptions and more worried than other staff groups about the potential impact on their workload. Pilot sites found it difficult to engage GPs and actively involve them in the process. Pilots which had more success in engaging this group found that it was important to consult them early, visit them directly rather than expecting them to come to external events, and focus on how Information Prescriptions can benefit user care and prevent or delay more serious ill-health.

- **Securing and sustaining partner involvement takes a great deal of time.** This time was needed partly to test and refine approaches and partly to reach and persuade other professionals and partners. Some healthcare consultants and GPs seemed to be most resistant to participating in the Information Prescription process. However, although engaging staff proved time consuming and sometimes unsuccessful, these difficulties also acted as a spur to action. Processes were designed to be as efficient as possible and roles were defined so as to minimise the burden on those with limited time or commitment. In some cases the solutions are unsuitable for national roll-out – for example, where there is an over-reliance on an internal champion or dispenser or entirely paper-based processes. Other solutions have creatively resolved a number of issues, for example by using the Information Prescription process to serve multiple functions.

### Barriers and challenges in quality assuring information

- **Quality assuring information could be time-consuming and effort was duplicated.** Pilots were clear that the role of information quality assurance could lie elsewhere and felt that national agencies, such as voluntary sector organisations, were often better placed to do this than local agencies.

- Differences in culture and approach between voluntary and statutory agencies in some cases led to delays in developing local Information Prescription systems. Some pilots driven by voluntary sector agencies reported difficulties in getting full support and cooperation from statutory sector colleagues, especially in cases where there was no senior statutory sector champion making the case internally for the project.

- Many sites were not clear about the extent to which information about local service providers, such as self help organisations and local voluntary and community groups,
should be quality assured. Many sites quality assured these sources of information by consulting user groups about the quality of these services.

- In the absence of a national quality assurance scheme, some sites spent a considerable amount of time quality assured information sources, causing them to be delayed in setting up directories. Some sites also found that there are gaps in the quality of information for some conditions and for some types of user. Sites found it beneficial to have good links with national charities who have their own quality assurance system and quality assured information sources.

- User involvement in quality assurance is important, but effective engagement requires significant resources and knowledge and skills in user engagement. In some sites, pilots were able to involve local engagement specialists who ran events and focus groups, but in other sites there was no such provision available. However, if, as strongly recommended by informants, the DH develops a national resource of accredited information and builds user engagement into this process, local user involvement in quality assurance of national information may not be necessary.

Barriers and challenges in developing IT systems

- **Chiefly, pilots found it challenging to develop their own IT systems to support Information Prescriptions.** Some pilots lacked the IT expertise to help them develop appropriate systems, while others did not have enough basic equipment, such as computer terminals in consulting rooms, to support an IT solution.

- **Care professionals from pilot sites were concerned that electronic Information Prescription Generators could both be time-consuming and detract from the quality of face-to-face engagement with the user.** The latter concern was most often reported by pilots dealing with people with life-threatening or terminal illnesses. In some cases, professionals felt it was too time-consuming to create detailed information prescriptions within the setting of a consultation, although many said that this was probably the case because they did not have a fast IT process to support quick prescribing. For this reason, pilots have tended to prefer an Information Prescription Generator that can be used for self-prescribing or assisted prescribed with people other than front line care professionals. Alternatively, they favour a two-stage model of prescribing, where a manual checklist of information requirements is completed in the consultation and taken or sent elsewhere for full prescribing and dispensing.

- **Related to the above, some professionals preferred using paper-based methods for prescribing.** Many professionals who were engaged in Information Prescription prescribing preferred to have the option of using a paper Information Prescription template. They argued that a paper approach was easier to use and would avoid IT systems becoming a barrier between the professional and the user during consultations. One senior nurse specialist noted that ‘having run focus groups with patients re. Information Prescriptions, [the patients] have said that they value the handwriting of the Information Prescription by the health professional and the face-to-face information exchange. It makes the consultation and care provided feel more personal (enhances the patient-professional relationship)’.

- Some users will not be able to benefit from web-based dispensing approaches and there is the concern that some IT approaches could limit access to disadvantaged groups. Some older service users and those who do not have access to the Internet at home will not benefit from a web-based dispensing approach. Where sites relied on web-based
approaches, they also made sure the information contained within Information Prescriptions could be accessed by other means, such as through helplines, or via supported access points.

- **Some pilots struggled to find ways to record prescribing into patient records.** It is recommended that the recording of Information Prescription prescribing, and where possible dispensing, is built into existing patient records systems, whether these are electronic or otherwise. Sites should also review the possibility of adding functions to existing practice, hospital, or social care planning and consultations software, to record Information Prescription issuing. For example, in one pilot site, additional functions have been added to the hospital software that allows prescribing details to be added to patient records.

**Challenges and barriers in providing training and support**

- **Some sites found that the professionals lacked the confidence to prescribe or dispense information.** Staff in some sites did not have English as their first language and were sometimes reluctant to take on this additional role as a result. Others felt uncomfortable responding to requests for information which fell outside the professional’s current knowledge base.

- **Some professional groups appear to need more training than others, such as nurses and hospital consultants.** Pilot sites that were successful in providing a range of training to staff carried out short and simple training needs assessments of participating professionals. This allowed them to tailor training to meet different requirements.

- **Pilot sites found it particularly difficult to involve very senior and busy consultants and GPs in training.** Pilot sites tried to counter this difficulty by finding ways to build training into pre-existing professional training programmes. For example, training for GPs in one pilot was provided during a pre-arranged INSET day which the practices hold fortnightly.
Section Five: Delivery

This section looks at how pilots delivered Information Prescriptions to users and carers. Most pilots were able to start issuing prescriptions from August 2007 and continued to issue until the close of piloting in January 2008. In the delivery phase, pilots focused on developing approaches to personalising information, establishing approaches to prescribing and dispensing, and embedding Information Prescription processes in partnership and workforce strategies.

Personalisation of Information Prescriptions

Information prescriptions aim to introduce information that is personalised and enables service users and carers to be involved in the management of their care. Pilots sought to engineer approaches to providing Information Prescriptions that would deliver information:

- **At the right time** – ensuring that information is tailored around the specific needs of users when they come into contact with service providers;
- **In the most appropriate way** – ensuring that information is provided through a range of channels and is accessible and convenient;
- **In the most appropriate format** – working to develop a range of formats to maximise the inclusiveness of the Information Prescription process, helping to make sure that information is accessible and useable for all;
- **at the right place** – ensuring information is made available from a range of access points, situated at locations convenient for the service user.

Providing the right information at the right time

Most pilots involved users extensively, from early on in the process, in identifying their information requirements (see also section on Development). Typically, users involved in this way were able to identify a wide range of information requirements, relating both to health and wider well-being and quality of life issues (see the Section Three). It was recognised, however, that personalised information provision describes not only the type of information being provided, but also the point along the care pathway at which the service user receives it.

The need to develop bespoke packages of information led many sites to create what we have called ‘tailored templates,’ as described earlier in Section Three. Tailored templates are information sheets which provide a range of information options from which the prescribing professional selects, based on their identification of the users’ information needs. This type of template can be designed to correspond either to standard care pathways or to a particular point in care. An example of a tailored template used in the Mid Trent pilot is presented in Figure 10.
Examples of care pathways used to design templates

Many of the templates are designed around well established care pathways or defined ‘points in care’, for example:

- Diabetes
  * Diagnosis – change in medicine – ongoing care

- Asthma
  * Diagnosis – asthma review – worsening symptoms

- Arthritis
  * Diagnosis – change of medicine – worsening symptoms

- Parkinson’s Disease
  * GP referral – diagnosis – starting treatment – maintenance – complex stage care – advanced stage care

- Lung Cancer
  * First presentation/attendance – diagnostics – results and diagnosis – ongoing care – worsening symptoms – palliative care

Tailored templates are seen as key to providing a highly personalised information prescription that offers the right information at the right time for all users. They can, however, also be more time-intensive to use than more generic approaches, which could be off-putting for both professionals and users.
How to develop a tailored template

Lessons from pilots show that there are a number of key steps to take when developing a tailored template:

1. Identify the LTC on which to focus.
2. Gather evidence of existing care pathways – many localities are in the process of developing improved ‘integrated care pathways’ which are likely to be useful as a starting point.
3. Identify the main professionals that are involved in each stage of the care pathway, for instance from primary care to the acute outpatient service, inpatient acute care and on to discharge back to community care.
4. Identify the main user and carer groups to be represented in and involved throughout the design and delivery process, working through existing networks such as Expert Patients, LINks and local VCS organisations.
5. Engage users and professionals in template development work. In pilots, this was often done through focus groups and/or workshops aimed at mapping the care pathway, identifying critical points along the pathway and then developing the ideal information pathway to support care.
6. Review current information-giving mechanisms in order to identify whether or not there are existing templates that could be adapted to fit Information Prescriptions.
7. Develop draft paper versions of the template. Keep the template simple.
8. Ask for feedback on the template from potential prescribers, focusing particularly on the challenges and opportunities it presents in practice.
9. Refine/re-design the paper template and re-circulate to stakeholders for comment.
10. Check that the template can help collect relevant user information for recording purposes.
11. Explore delivery options – ask how the template could be used as part of existing practice and how it would fit with local government and hospital IT systems. If the template involves manual completion, how will patient information be recorded and will the whole process be sufficiently simple and streamlined?
12. Pilot the template through consultations with existing service users, timing how long it takes to complete and identifying any problems.

In addition to tailored templates, some pilot sites also developed structured scripts to help prescribing professionals follow an ideal approach to giving information to the user. Structured scripts can come in a variety of forms including tick box checklists, detailed instructions or simple bullet list aide-memoirs. Structured scripts can help to:
• **Inform the prescribing process** – these scripts can offer prompts to professionals that help them identify the users' information needs. They can be used with a tailored template, either to help the professional complete the template in the right way or to prompt the professional to ask the right questions, but not necessarily complete a template. In a small number of cases, scripts are also given to users prior to consultation with the professional to help them think through their own information needs.

• **Inform marketing and communication activities** – there are scripts which can be used by staff to inform other staff about the benefits of Information Prescriptions and how to use them.

• **Inform the dispensing process** – scripts can provide more information to those dispensing the information about exactly what information the user needs. They can also remind the user of questions to ask and help them understand the exact nature of the information they are receiving. In particular, scripts such as these can help professionals engage more effectively with disadvantaged users, such as those with a low level of literacy level or with learning difficulties.

An example script can be seen in Table 5 below has been developed by North Tyneside to help information staff at NHS Direct follow procedures on dispensing information to users with Parkinson's Disease.

<table>
<thead>
<tr>
<th>Table 5: Example of structured script</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Question</strong></td>
</tr>
<tr>
<td>1 <strong>If post</strong> – Have you received your information yet?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>2 Have you read the information?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>3 Would you like to speak to someone to further explain the information you have been given?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Question</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>4  Would you like any additional information?</td>
</tr>
<tr>
<td>5  With your information, you were sent a leaflet about the PDS helpline. Did you telephone or email the PDS?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

**Providing information in the most appropriate way**

Information Prescriptions are available through a range of delivery channels, including various face-to-face approaches such as clinical consultations, via the Internet, through telephone helplines, and by post or email. Some of the pilot sites have concentrated on providing Information Prescriptions through standard face-to-face consultations, while others have provided Information Prescriptions mainly through websites or telephone helplines. Most pilot sites have made Information Prescriptions available through more than one delivery mechanism.

However, it is worth noting that research continues to support the view that users prefer to receive information through face-to-face engagement with a care professional, and preferably a doctor, although other mechanisms are welcome. Research by the Picker Institute, for example, found that, when asked about their preferred sources of information, 73 per cent mentioned their doctor. The next most commonly cited sources of health information were health websites (30 per cent), printed materials (23 per cent), nurses and other health professionals (22 per cent) and family and friends (19 per cent).\(^6\) Interestingly, patient groups were mentioned by only 4 per cent overall, and by only 5 per cent of respondents with chronic conditions. Other research found that patients valued face-to-face information giving, seeing it as the best way to ‘raise concerns and ask questions…. and get beyond the basics (such as contact information).\(^7\)

Most sites have developed processes which enable users to receive Information Prescriptions through face-to-face contact with users. This is achieved through a range of engagements between services and users, including standard clinical consultations, outpatient visits, tests and screening sessions, annual health checks, care planning sessions, social care assessments, drop-in surgeries and health visits.

---

\(^6\) The Picker Institute, *Assessing the quality of information to support people in making decisions about their health and health care*, Picker Institute Europe, 2006

\(^7\) The Picker Institute, *Patients make it better: the international evidence*, 2007
Information Prescriptions were made available through the web in a small number of sites, although some of these made the provision of Information Prescriptions through websites a substantial feature of their approach. Many sites originally planned to use a website as a route to providing Information Prescriptions, but found that there were significant barriers to establishing websites during the time given.

However, it is important to stress that not everyone has access to the Internet or, if they do have it, wants to use the Internet to access health information. Research by Picker found that Internet access is not universal or equally distributed and this discriminates against those who may already be ‘information poor’. Age and affluence are the two key correlates of Internet use in the UK. Of those aged over 65, 71 per cent have never used the Internet. Across all ages, just over half 53 per cent of the lowest income group (up to £10,400 p.a.) have never accessed the Internet, while the corresponding figure is 6 per cent for those earning £36,400 or more. The survey of users found that only 20 per cent used the Internet to search for materials.

Several of the sites dispense information through telephone helplines. Usually, the helplines existed before the pilots were established and were already providing a sophisticated information giving service. In interviews with professionals based in pilots, many argued that telephone helplines can be a cost-effective method for providing more support to users when they access information. Research by the Health Foundation finds that use of telephones varies between different populations. Participants were also asked about their use of telephone helplines to access health information. In a survey of over 3000 patients, the majority (62 per cent) said that they were unlikely to seek information via a telephone helpline, and only 10 per cent indicated that they were very likely to use such a service. However, the same survey found that significantly more users from lower social class backgrounds than higher wanted to use telephones to access information about their health.

Providing information in an appropriate format

The pilot sites developed Information Prescription templates and other information into a wide range of formats, ranging from standard paper leaflets and information packs through to video diaries and podcasts.

A broad range of factors influenced the choice of format used by pilots, including:

- Age of user;
- Reading ability/health literacy levels;
- Access to Internet and email;
- Disabilities – hearing impairment, visual impairment and learning disabilities; and
- Language skills.

---

8 National Statistics, Omnibus Survey Jan-Apr 2006 update.

9 The Health Foundation, How engaged are people in their healthcare? London, 2005.
Mid Trent

This pilot has issued Information Prescriptions remotely as well as face-to-face to maximise access. This is particularly beneficial in a rural area. Whilst face-to-face interaction is typically more beneficial, the pilot wanted to ensure that people could access information when they wanted, in a way that best suited their needs. This led Mid Trent to develop a website so that people can print off their own Information Prescription forms or complete them online and access information directly via the website. The detail of this is still being refined, but a web-based approach provides another way of offering choice, supplementing face to face interaction. It could also help users and carers with particular needs e.g. by including podcasts for those who are visually impaired or have literacy problems.

There were common approaches to choosing formats and developing these for particular user groups. These are identified in Table 6

Table 6: Formats used for different user groups

<table>
<thead>
<tr>
<th>User group</th>
<th>Preferred format</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older users</td>
<td>• Printed material&lt;br&gt;• Large print&lt;br&gt;• Clear numbers and contacts for support</td>
</tr>
<tr>
<td>Young people</td>
<td>• Postcards with graphics/visual aids&lt;br&gt;• Simple English with some words that young people use</td>
</tr>
<tr>
<td>Learning disabilities</td>
<td>• Simple English&lt;br&gt;• Postcard&lt;br&gt;• Visual prompts</td>
</tr>
<tr>
<td>Low literacy levels</td>
<td>• Simple English&lt;br&gt;• Postcard format&lt;br&gt;• Visual prompts</td>
</tr>
<tr>
<td>Working professionals</td>
<td>• Email format&lt;br&gt;• Links to more detailed condition-specific information&lt;br&gt;• Portable Document Format (PDF) - a document-encoding process developed by Adobe that maintains page layout, fonts and graphics.</td>
</tr>
</tbody>
</table>
How to personalise formats

• Establish local user and professional readers’ group, ensuring that they are representative of the local population;

• Develop a range of draft formats of templates and information sources, based on existing knowledge of formats used in local information;

• Run focus groups with readers’ groups to review templates and information;

• Consider involving local artists and designers in discussions to work with group to develop formats;

• Develop further drafts of content;

• Test these out on the project partnership/steering group and again with readers’ group;

• Finalise templates and information.

Providing information at the right place

Pilots have made Information Prescriptions available in a wide range of health and social care and community settings. Pilots strove to increase the range of locations through which Information Prescriptions are offered, realising that diversifying access points could increase the uptake of Information Prescriptions by different user groups. Information Prescriptions were available in the following locations:

• **Primary care** – GP practices, healthy living centres, walk-in centres, through NHS Direct helplines and community pharmacies;

• **Community and social care** – residential care homes, day care centres, youth centres, children’s centres, full service schools, community centres, through home visits and libraries;

• **Acute** – district general hospitals, inpatient wards, outpatient facilities, hospital pharmacies;

• **Mental health** – acute mental health facilities, community mental health facilities, outreach and home visits;

• **Other** – websites, local government community information points and voluntary sector agencies.

In developing Information Prescription processes that are based in a range of locations, pilot leads argued that it was important not to concentrate only on medical or social care facilities as the place where Information Prescriptions can be accessed. Many users and carers do not have regular contact with mainstream health services and it was regarded as important that Information Prescriptions were made available elsewhere.

How to make Information Prescriptions accessible from a range of locations

• Map out integrated care pathways, which should be available locally for a range of conditions.

• Make sure that the care pathways include all of the main points at which users intersect with care providers, even prior to diagnosis and after successful treatment.
• Involve users and professionals in focus groups to test out the pathways for accuracy.
• Work with the users and professionals to identify any ‘touch points’ where the user could potentially benefit from accessing information. Identifying gaps is critical as there may be several points in a typical care pathway, such as when a user picks up their medicine at the pharmacy, when users should receive information but currently do not.
• Map the touch points onto the care pathway.
• Identify which professionals are involved at these points, and what information they already provide or could provide.
• Review the potential for these professionals to take up Information Prescription roles, whether more substantial, such as prescribing, or less intensive, such as simple signposting.
• Consult and engage professionals in taking on Information Prescription roles (see sections on stakeholder engagement)

Approaches to delivering Information Prescriptions

There is no single method used by pilots for providing Information Prescriptions that is common to a particular care setting. Accordingly, a wide range of models of delivery have emerged. In one pilot based in primary care, GPs are involved in prescribing, whereas in another it is nurses who fulfil this role. In one secondary care pilot, information is provided through a dedicated local information centre, whereas in another site NHS Direct staff are the main dispensers through telephone helplines.

For a number of pilots, it was important to find ways to embed Information Prescriptions into processes that already exist or are being rapidly developed in different care settings. In social, community and primary care, for instance, care planning processes are increasingly available to those with long-term health and social care needs, and were seen to afford a good mechanism through which to provide an Information Prescription. Several pilots sought to integrate Information Prescriptions into formal care planning, thereby making information prescriptions an ‘offer’ that all those going through the process are likely to receive.

In social care, a small number of pilots looked at ways to embed Information Prescriptions into single assessment processes (SAPs), which are currently available to older users and will be made available for all adults in social care in the future. One pilot successfully integrated the processes so that users will receive an Information Prescription as part of their standard SAP, while the other pilots hope to arrive at this point in the future.

‘If you can embed Information Prescriptions into care planning, you can both ensure that the user is more likely to systematically receive an Information Prescription, see it as part of a self management process, and reduce the time professionals might spend on Information Prescriptions.’

One key determinant, which was used by pilots to judge how Information Prescriptions should be offered, was the identified level of need of users. Pilot sites employed different definitions for need, using a range of terms such as stable, unstable, less advanced or advanced, and high risk or lower risk to describe population needs. In small number of pilots, the Kaiser Pyramid of Care Model was used as a basis for identifying the level of support that
users would need to access information prescriptions.\textsuperscript{10} The Kaiser model identifies those with long-term conditions as having three broad levels of need:

- Level 1 – which they define as 70-80\% of the total population who have a chronic condition and can largely manage their own conditions with the help of primary care.
- Level 2 – which are users at high risk, who require a care management approach, often provided through both primary and acute services.
- Level 3 – which are highly complex patients, who often have more than one chronic condition and require a case management approach, often provided by primary, social and acute services.

\textbf{Durham PCT}

Users with cancer who come into contact with this pilot often face multiple disadvantages, such as low income, poor health literacy levels and lack of family support. To assist users with these additional needs, the pilot ensures that those who visit the cancer information centre are not only given the information, but also have a specialist nurse or trained volunteer available who can answer questions, explain the information, and signpost the user to other services.

Pilots considered a broad range of issues and challenges when developing their Information Prescription approaches within different care settings. In the following table we describe some of these challenges and how the pilots responded when developing Information Prescription systems.

\begin{table}[h]
\centering
\begin{tabular}{|c|p{20cm}|p{20cm}|}
\hline
\textbf{Care setting} & \textbf{Challenges/issues} & \textbf{How Information Prescriptions are offered} \\
\hline
Primary care & - GPs have been difficult to engage in the Information Prescription process
- Users are likely on average to spend less time with professionals than in acute, mental health and social care
- Users conditions meant they are likely to be able to manage their own care at the point of making contact with care professionals & - Prescribing usually takes place in GP practices, but can also take place through home visits, day care centres, and in libraries
- Information Prescription templates are very quick to administer, using a simple tick box approach or signpost
- GPs are rarely involved directly in prescribing which is covered \\
\hline
\end{tabular}
\caption{Challenges in different care settings}
\end{table}

\textsuperscript{10} Information can be found on Kaiser Pyramid of Care for Long Term Conditions at the following website: \url{http://www.natpact.nhs.uk/uploads/Pyramid%20Chronic%20Disease%20Management.pdf}
<table>
<thead>
<tr>
<th>Care setting</th>
<th>Challenges/issues</th>
<th>How Information Prescriptions are offered</th>
</tr>
</thead>
</table>
| **Secondary** | • The time spent by a user with a care professional is likely on average to be longer than in primary care  
• Consultants and specialist nurses have been keen to engage with the Information Prescription process  
• The majority of users’ conditions when they come into contact with secondary care will be high risk or highly complex (although these conditions can be less high risk or complex) | • Prescribing takes place during hospital consultations  
• Information Prescription templates are more likely to be highly tailored, with options linked to care pathways  
• Consultants can conduct initial assessment of information needs, followed by more detailed tailoring carried out by specialist nurses  
• Information is made available in information centres and users have the opportunity to have information explained |
| **Mental Health** | • The time spent by a user with a care professional is likely to be longer than in primary care  
• Mental health consultants, nurses and care managers are keen to engage with the process | • Prescribing takes place through care planning sessions  
• Prescribing is carried out by consultants, specialist nurses or care managers  
• Information Prescription templates are more likely to be highly tailored, with options linked to care pathways  
• Prescribing and dispensing can take place at same sessions  
• Information is made available in information centres and users have the opportunity to have information explained |

(although this is not to say that the conditions that users have when they access primary care do not become more high risk or complex)
<table>
<thead>
<tr>
<th>Care setting</th>
<th>Challenges/issues</th>
<th>How Information Prescriptions are offered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social care</td>
<td>• The time spent by a user with a care professional is likely to be longer than for other professionals in primary care • Social workers are keen to engage with the process</td>
<td>• Prescribing takes place in a range of situations, including care planning • Prescribing is conducted by social care coordinators or social workers as part of existing assessment processes, such as the Single Assessment Process for older people • Prescribing and dispensing can take place at the same time, with information handed out at assessment • Dispensing can take place through self-dispensing websites and helplines.</td>
</tr>
</tbody>
</table>

**North Tyneside**

North Tyneside have established a process for dispensing information which makes additional support and advice available to disadvantaged users and carers over the phone. The pilot is supported by NHS Direct who work with the Parkinson’s Disease service to help dispense information by mail or email to users. Having sent the information, however, the service then follows up each Information Prescription with a call to the user or their carer to check they have the right information, answer questions, and signpost to other services. This service is seen as particularly beneficial to disadvantaged users.
Types of prescribing and dispensing

Several different approaches to prescribing and dispensing have emerged across the pilots. The following diagrams depict the main delivery approaches:

**Prescribing and dispensing by same individual**, e.g. prescribing and dispensing by a CNS.

![Diagram showing prescriber and dispenser in the same location](image)

**Prescribing and dispensing in the same building by different individuals**, e.g. prescribing by consultant and dispensing by in-house information centre.

![Diagram showing separated prescriber and dispenser](image)

**Prescribing in one location and dispensing in another**, e.g. prescribing by GP and dispensing in a voluntary sector information centre.

![Diagram showing separate prescriber and dispenser](image)

**Prescribing in one location and dispensing in multiple locations**, e.g. prescribing by youth worker and dispensing in library, through voluntary sector helpline and Citizens Advice Bureau. In this model, self-dispensing is also possible through a website.

![Diagram showing prescriber and dispenser in multiple locations](image)
Levels of support

The pilots varied greatly in the level of direct support they choose to provide to users and carers as part of the Information Prescription process. In some pilot sites, users and carers had little direct support from professionals, with the prescribing process limited to signposting with users then expected to find their own information. In other cases, users were engaged in a much more supportive process during prescribing, being encouraged to ask questions, receiving a wide range of information sources, and receiving explanations on what the information means and how to use it.

- It is possible to group pilots into two main categories: light touch pilots and greater support pilots.
- Light touch models are those that do not undertake detailed tailoring of information or provide substantial additional support from professionals to help users. Light touch models often involve signposting approaches, rapid single stage prescribing approaches and self-dispensing through websites.
- Greater support models are those which involves a more tailored prescribing process (usually involving a multi-stage process for prescribing) followed by more extensive exploration of needs and delivery of information by hospital information centre, NHS Direct or national charity helpline, or dedicated local help centre.
- As you will read, one of the defining features of the main models of delivery identified below is the extent to which they provide support.

Main models of delivery

There was no single model of Information Prescription delivery developed by the pilot sites, with all of the sites developing their own unique approaches to Information Prescription prescribing and dispensing. However, there appear to be three high-level models of delivery across the pilots, which we now describe. The models are either light touch or in-depth and offer different approaches to prescribing or dispensing.

Model One: Light touch prescribing and self dispensing

This model operates predominately in primary care. The prescribing process is quick and involves either a simple ‘tick box’ template or signposting postcard. Dispensing is carried out by the user themselves via the Internet or through helplines, voluntary sector organisations and libraries, where support is available from a professional to help the user find information.
if requested. The pilots using this model are usually working with conditions which are relatively stable and do not require significant involvement from secondary care.

The IT systems used in these sites rely heavily on sophisticated websites that can provide open access to all. Some of the IT systems were also designed to enable users to develop their own Information Prescription Generator, save it and print it themselves, while others are limited to fixed web pages on health related topics.

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

In this model, a specialist worker, such as a care worker or case manager, completes the Information Prescription alongside the service user during a consultation session, with the dispensing taking place after the consultation at another point. Dispensing takes place externally through a range of channels, including NHS Direct and community information points.

Typically, prescribing will take place during a pre-arranged consultation session that is part of the usual service provided to someone on the care pathway in question. This could be, for example, a review session or a new referral appointment that is extended to take account of Information Prescription issuing. The service user is provided with a list of recommended sources tailored to their particular needs and condition, which they will then take to a designated dispenser.

The IT systems used to support these models varied from highly sophisticated systems to relatively manual systems. In the cases where sophisticated systems were used, dispensing was supported through a range of helplines and there was the capacity to email information to users and carers.

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

This model operates predominately in secondary care, with the exception of one pilot based in primary care. In these pilots most of the conditions being treated are either high risk or highly complex and therefore require significant care from acute services. The prescribing is predominately carried out by a consultant, care manager or specialist nurse. The Information Prescription process is usually quite structured and tailored around a care pathway. The prescribing process usually comprises more than one stage: at the first stage, a professional makes an initial assessment of the user information needs, while at the second stage another professional conducts a more detailed assessment. In this model, dispensing usually takes place in an information centre, which is staffed by a nurse, NHS information specialist or someone from the voluntary sector.

Interestingly, the survey found that professionals, users and carers at the greater support pilot sites were more likely to have a more positive view of Information Prescriptions compared to pilots with more light touch models. Users from greater support pilot sites were much more likely to find the information useful (97 per cent) than people attending light touch pilot sites (79 per cent). Professionals at greater support pilot sites were also more satisfied with the way the Information prescription process is working at their sites compared with professionals in light touch pilot sites (74 per cent compared to 52 per cent respectively).

Prescribing in most of these sites was usually manual, with paper templates often used by prescribers rather than electronic Information Prescription Generators. Heart of England was
one notable exception and was able to develop an electronic Information Prescription Generator linked to an electronic directory and electronic patient records. Dispensing, however, would often be supported through an online directory that could be accessed at terminals in on-site information centres, linked to printers so that information could be dispensed to the user immediately.

Table 8 below identifies the classifications of pilots in relation to the three models. Please note, however, that some of the pilots can be placed under more than one model:

<table>
<thead>
<tr>
<th>Model One</th>
<th>Model Two</th>
<th>Model Three</th>
</tr>
</thead>
<tbody>
<tr>
<td>Darlington</td>
<td>Cambridgeshire</td>
<td>Durham</td>
</tr>
<tr>
<td>Hammersmith and Fulham</td>
<td>Doncaster</td>
<td>Heart of England</td>
</tr>
<tr>
<td>Isle of Wight</td>
<td>Evelina</td>
<td>Mid Trent</td>
</tr>
<tr>
<td>Suffolk</td>
<td>Leeds</td>
<td>North Tyneside</td>
</tr>
<tr>
<td></td>
<td>Manchester</td>
<td>Oxleas</td>
</tr>
<tr>
<td></td>
<td>Oxford</td>
<td>Queen Elizabeth</td>
</tr>
<tr>
<td></td>
<td>RNIB</td>
<td>Royal Marsden</td>
</tr>
<tr>
<td></td>
<td>South Essex</td>
<td>Cambridgeshire</td>
</tr>
<tr>
<td></td>
<td>Staffordshire</td>
<td></td>
</tr>
</tbody>
</table>
Activities and resources to develop and deliver information prescribing

Introduction and aims

Aims of this part of the report

The pilots provided details of the activities and resources they used in developing and delivering information prescribing. The information they supplied is being used in three ways:

- To identify the approaches that are most likely to be effective. These are reported widely throughout this report.
- To provide quantitative data on the possible resource implications of a national roll-out. This has been reported separately to the DH and will be used in building their impact assessment of a national roll-out.
- To summarise the activities carried out by the pilots, their use of resources and the likely types of resources required for roll-out. This is the task of this section of the main report.

Data from the pilots on resource use

The pilots provided two types of data on the resources they used to set up and run these models of delivery:

- Monthly returns on the staff time devoted to different activities, including details of any special or recurring purchases;
- Reports of the type and approximate scale of information delivery prior to the pilots, collected using methods including baseline and stock take forms.

Both of these are described in more detail in Appendix 2. In addition, site visits, personal contacts with the pilot teams, and discussions at national workshops provided invaluable feedback on the resource needs of different approaches to Information Prescriptions.

Reports of resource use from the pilots may not always be good predictors of the resources required to roll out Information Prescriptions more widely. Pilots were quite heavily funded, not least to support activities that would not need to be repeated in a national roll-out, such as the development and piloting of models that could be used more widely, and a variety of recording and reporting exercises linked to the evaluation.

There are a number of other difficulties with simply extrapolating from the resources used by the pilots to predict the scale of resources needed for roll-out. In particular:

- The lack of data from the pilots on the additional costs (or even economies of scale) of managing the introduction of Information Prescriptions across a variety of specialties, conditions or settings.
- The lack of detailed or quantitative data on the extent of existing information provision – especially across the wide range of organisations that already provide relevant information, such as CABs, local support and advice agencies and libraries – leading to difficulties in estimating what new effort would be required for Information Prescriptions.
• The lack of data on the extent to which the demand for information could decline over
time when Information Prescriptions were effective.

For these and related reasons, this report does not include any estimates of the costs of
different approaches to delivering information prescriptions, though the evaluation team have
been helping DH to construct an impact assessment for the national roll-out.

Making sense of the data on resource use – different models of delivery

Pilots were chosen, in part, to cover a range of different care settings and need, and
consequently chose to deliver Information Prescriptions in different ways with different
implications for resource use. Rather than separately describe the activities of every pilot,
this section tries to summarise the main activities required for several distinct approaches to
Information Prescription delivery.

When developing Information Prescriptions to meet local needs, pilots tried to take account
of the following: the type of care setting; which professionals were involved; the nature of the
condition; the formats and ways in which people wanted information; and any special needs
of the individuals or community.

The two key features determining what resources are required for any approach are:

• What is the role of care professionals in delivering Information Prescriptions?
• What other types of agencies and mechanisms are involved?

Role of professionals

In theory, care professionals could carry out all the following aspects of Information
Prescriptions in a single consultation, but in practice these will rarely all be done at the same
time by the same person

• Signposting (directing someone to a source of information or to a site or agency that can
  help refine the questions and provide information)
• Pre-prescribing (a preliminary exploration of information needs, concluding with
  recommendations on the agencies or resources that will be most relevant
• Prescribing (identifying the actual pieces of information that will be required – a particular
  booklet, set of web pages, or a referral to an individual or agency for specific advice)
• Dispensing (provision of information in formats ranging from personal advice though
  booklets to electronic media)

Roles of other agencies

Other agencies can help when care professionals are not doing all the prescribing and
dispensing. Their input could be part of an agency’s established function, not specifically
developed for Information Prescriptions, or an agency may agree to be a designated
dispensing or prescribing point. Individuals may also do their own prescribing and dispensing
using the Internet.

Most of the following mechanisms for additional prescribing and dispensing could be found
somewhere in the pilots:
• Self-prescribing and/or dispensing using recommended website/s

• Local agencies such as offices of medical support charities, Citizens Advice Bureaux, etc. providing additional prescribing and/or dispensing, but not as a pre-arranged, linked or commissioned service

• National helplines of charities or NHS Direct providing additional prescribing and/or dispensing, but not as a pre-arranged, linked or commissioned service

• Dispensing and additional prescribing carried out by local agencies such as offices of medical support charities, Citizens Advice Bureaux, etc., providing additional prescribing and/or dispensing as part of a pre-arranged or commissioned service

• Dispensing and additional prescribing carried out elsewhere in the care provider or other parts of the statutory care delivery services, such as a hospital information service, a social services information centre or a PCT PALS information service

• Linked helpline, where details of the enquirer and information needs are sent to a helpline run by a national charity or NHS Direct. The helpline then contacts the user or carer to discuss further information needs and arrange for the supply of information

• Outreach or some other visiting service to help with the provision and interpretation of information

Different ‘models for delivering Information Prescriptions’ can be formed by combining elements from these two lists. For example, a very simple model is one in which the care professional signposts a user to a national website and the user then retrieves the appropriate information via the Internet. Many more or less plausible combinations can be constructed, but eight distinctive approaches were found in the pilots. These 8 models were used for analytical purposes in the evaluation, but were compressed to the following three for the reporting.

1. Light touch prescribing and self-dispensing
2. In-depth prescribing and linked dispensing
3. In-depth prescribing with information centre

It should be stressed that these models are intended to clarify questions about resources. Other schemes may be more appropriate to choosing what methods will best meet the needs of specific groups of users and carers.

**Table 9**

<table>
<thead>
<tr>
<th>Model 1. Light touch prescribing and self-dispensing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activity in consultation</strong></td>
</tr>
<tr>
<td>The prescribing process is quick and involves either a simple ‘tick box’ template or signposting postcard.</td>
</tr>
</tbody>
</table>

Typical settings for model 1: GP consultations in primary care, some outpatient clinics
Table 10

Model 2: In-depth prescribing and linked dispensing

<table>
<thead>
<tr>
<th>Activity in consultation</th>
<th>Mechanisms for additional prescribing and dispensing</th>
</tr>
</thead>
<tbody>
<tr>
<td>A specialist worker, such as a care worker or case manager, completes the Information Prescription template alongside the service user, during a consultation.</td>
<td>Dispensing takes place externally through a range of ‘linked’ channels including NHS Direct and community information points. In the strongest form of linkage, the name and details of the client are passed to the dispensing agency; weaker forms involve external agencies agreeing to act as designated dispensers.</td>
</tr>
</tbody>
</table>

Typical setting for model 2: GP consultations in primary care, some outpatient clinics

Table 11

Model Three: In depth prescribing with information centre

<table>
<thead>
<tr>
<th>Activity in consultation</th>
<th>Mechanisms for additional prescribing and dispensing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prescribing usually involves more than one stage. In the first, a professional such as a consultant, care manager or specialist nurse makes an initial assessment of the user information needs. In the second, another professional conducts a more detailed assessment.</td>
<td>Dispensing usually takes place in an information centre, which is staffed by a nurse, NHS information specialist or someone from the voluntary sector.</td>
</tr>
</tbody>
</table>

Typical setting for model 3: Hospitals – both inpatient and outpatient care.

The remainder of this section will discuss the activities and resources that the pilots used to deliver these models and what might be required for a wider rollout. Where possible, the discussion will include estimates of likely demand, as well as separating the resources needed for development from those required for later, more routine, delivery. This section will also consider the extent to which the introduction of Information Prescriptions will require new resources.

Before that, there is a brief note on the type of national resources that might support the local implementation.
The role of statutory national resources to support Information Prescriptions

Local resource use can be influenced by the type and scale of any national provision. The main national resource commissioned by the Department of Health for the pilots was the web-based Information Prescription Generator from the Map of Medicine team, though pilots also made extensive use of national information from the Department of Health and sources commissioned by the Department, such as materials produced by NHS Direct.

Pilots were largely agreed that national resources were essential to support Information Prescriptions, though there was considerable debate on what form these should take.

One of the schemes being considered at the time of writing is a web-based store of accredited information and Information Prescription templates for long-term conditions. Many agencies are likely to contribute material, including NHS Direct, NHS Choices, national charities and the existing Information Prescription pilots.

Present thinking is that different methods will be provided for accessing this information to suit the needs of different groups of users. These methods could include:

- A pathway-structured interface for non-professional use (pointing people to types of question and information source appropriate to different stages in their condition)
- Free-text and other fast search options, including a facility to generate information prescriptions
- Facilitating third party access to the structures of the national database, so that it can be directly accessed from within the patient and client record systems currently used in health and social care
- A national telephone line where all the most commonly used information sources are presented in recordings for blind users
- Ensuring that pre-developed templates and other materials are available in large print, easy-to-read language and in the most widely used community languages

The role of non-statutory resources

National medical charities and support groups such as the RNIB and Cancer Backup were active partners in many of the pilots. Most of these organisations are continually reviewing their approaches to providing information and increasingly developing detailed websites to complement their helplines and local offices. They have an existing infrastructure for delivering information, an increasing range of information materials, and knowledge of the types of information that are likely to be needed at different stages of conditions and care pathways. They have great potential to support Information Prescriptions through both national and local activities.

In relation to the use of resources in the pilots, there were various arrangements for involving non-statutory agencies. These included:

- Unfunded effort from volunteers and local or national staff in developing templates, pathway models and plans to integrate Information Prescriptions into the delivery of care
- Funding for posts and staff time to contribute to or coordinate individual pilots
• Linked arrangements in which agencies agreed that helplines or local offices could be identified as sources of assistance with additional prescribing or dispensing

Much of the contribution of these agencies was done as part of their existing activity and not funded from the pilot budgets. Arguably, this is reasonable as it is very unlikely that the number of new enquiries generated by the pilots would have substantially increased the workload of a national support service, though the situation might be different for an office providing linked local dispensing.

Later in this section we use results from the survey of users to predict the numbers of enquiries that might be generated to non-statutory agencies if the first model were widely adopted in primary care. There are, however, severe limitations in using the figures for this purpose without data on major issues, such as the possible rate of decline of enquiries over time or what proportion of people with LTCs already get their information from non-statutory agencies.

One of the outstanding questions for the roll-out of Information Prescriptions – and one that cannot be answered from the pilots – is whether non-statutory national or local agencies should be funded to support the roll-out of Information Prescriptions, particularly where they are performing core functions that would otherwise be done by NHS staff in some models for delivering Information Prescriptions.

The resource implications of the three models

Resources for Model 1. Light touch prescribing and self-dispensing

Introduction

In this model, the prescribing process is quick and involves either a simple ‘tick box’ template or signposting postcard. Service users either dispense the information themselves via the Internet or approach agencies such as helplines, local information points, voluntary sector organisations and libraries.

<table>
<thead>
<tr>
<th>Model 1. Light touch prescribing and self-dispensing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activity in consultation</strong></td>
</tr>
<tr>
<td><strong>Mechanisms for additional prescribing and dispensing</strong></td>
</tr>
<tr>
<td>The prescribing process is quick and involves either a simple ‘tick box’ template or signposting postcard.</td>
</tr>
<tr>
<td>Dispensing and more detailed prescribing carried out by the user themselves via the Internet, helplines, local information voluntary sector organisations and libraries.</td>
</tr>
<tr>
<td>Typical settings for model 1: GP consultations in primary care; some outpatient clinics</td>
</tr>
</tbody>
</table>
**Typical users and settings**

The model is intended for relatively low need users. The pilots using this model are usually working with conditions which can be stable with good management, are not immediately life-threatening and do not require significant acute interventions.

As the model is intended to minimise the input from care professionals, it is suitable for settings with high volumes of short consultations, such as primary care, some outpatient clinics and community pharmacies.

**Patterns of resource use by pilots adopting this model**

Five of the pilots adopted key features of this light touch model: Darlington, Isle of Wight, Hammersmith and Fulham, Suffolk, and Oxford.

The main feature common to these pilots is the aim to minimise the burden on care providers by limiting their role to signposting.

Other shared other priorities are:

- To ensure the signposting system is acceptable to professionals, users and carers
- To promote Information Prescriptions amongst the public as well as professionals
- To develop or identify a stock of suitable information materials (i.e. to build a directory)
- To set up mechanisms to give good public access to these materials, perhaps by building new web-sites
- To train and encourage care professionals to signpost people to these mechanisms
- To ensure there are clearly identified help points for people without their own Internet access

Most of the development effort of these pilots was concentrated on these six tasks.

The pilots in this group had a strong focus on health and well-being in the community and wanted to point people to a wide range of community-based support that could help with all aspects of their condition. Although health care professionals and patient support groups contributed to these projects, they were not, in the main, run by care professionals or based in health care organisations. The Isle of Wight, Oxford and Suffolk initiatives were run by local authorities and the Darlington project was based in the PALS unit at the PCT.

Information was aimed at the general public, as well as at people with specific medical questions.

Although these projects were part of the DH-funded Information Prescription pilots, they often saw themselves as having a wider role: to create a local information database on services related to health in its broadest sense. As such, it is unclear who should take the main responsibility for resourcing and developing such work in the future – whether this is more a task for local authorities than PCTs, especially if the former already compile directories of public and voluntary sector agencies.

It can be a major task to develop directories of local services and agencies that can help with all the consequences of LTCs, from concerns about medical topics, prognosis, medicines and their side effects to queries on all aspects of life, including relationships, finance, pets,
gardening, shopping and transport. The monthly returns showed that directory development consumed a significant proportion of the efforts of this group of pilots, not only in identifying relevant agencies, but also in ensuring that descriptions and contact details were accurate and intelligible. Several pilots mentioned the work required to liaise with groups providing services in order to ensure they provided and checked directory entries.

Creating systems to store and deliver directories was also a major task. In the Isle of Wight, the in-house team that developed their Council web site did this. In Darlington, the PCT contracted out programming, as did Oxfordshire County Council for their website for people with hearing difficulties. Suffolk developed a rather simpler system, using fixed web pages rather than an active database, and the Hammersmith and Fulham pilot eventually opted for a paper-only approach. However, all these projects put considerable effort into designing interfaces or materials to point people to appropriate sources.

Two of the three other main areas of resource use in these projects were concerned with involving local health care professionals, especially GPs and practice nurses, in the idea of information prescribing, and then familiarising them with the templates, directories and delivery systems. Even after identifying care professionals prepared to champion Information Prescriptions locally, wider recruitment and engagement in primary care proved very time-consuming and involved coordinators in many trips to local practices. To be credible to this constituency, coordinators need some combination of medical and management skills, so should be a middle grade appointment.

Much of the remaining development effort involved liaising with agencies that could provide support to people who were unable to use the Internet to search for information. Work involved both recruiting agencies to the scheme and ensuring they understood their role – whether it was to provide an existing service, such as the help given by patient support groups, or to do something new, such as helping people interrogate the local Information Prescription directory system. Events and other activities to raise public awareness also consumed significant resources in several of these projects.

Because of the nature of the commissioning organisations and the range of agencies providing services, coordination was complex and involved dealing with a wide range of statutory and non-statutory support agencies as well as care professionals.

**Resourcing the roll-out of model 1 in primary care**

Reports from the pilots, including the monthly returns, give a picture of the types of resources that may be required for roll-out. One of the key issues is whether a national database of materials would substantially reduce the local effort required for directory development, or whether local authorities and PCTs would want to maintain directories of local resources.

Another key issue is the level of demand that can be expected. Prevalence and general practice attendance rates for LTCs, the monthly returns, and results from the surveys of users and carers have been used to compute some approximate estimates.

**Estimating demand in primary care**

The number of consultations at which Information Prescriptions might be offered and accepted in primary care can be estimated by combining prevalence and general practice attendance rates for various LTCs. More details of the calculations are shown in Appendix.
But the overall prediction is that more than 12,000 consultations per year will relate to LTCs in a practice with a list of 10,000 and rates of morbidity and patient age/sex distribution in line with national averages. Because numbers are approximate and averaged, this figure needs to be treated with caution and is the predicted number of attendances, not the numbers of consultations at which Information Prescriptions are either offered or accepted. Monthly returns from the pilots suggest that when Information Prescriptions are first introduced, approximately 65 per cent of primary care consultations will involve the take-up of an offer of information – equivalent to 7800 offers of information per year per 10,000 registered patients. It is reasonable to assume that this number will decrease as people become better informed.

**Resources for the development phase of model 1**

**National resourcing**

A national database of materials with an interface suitable for public use would be an obvious choice for a central resource to support this model. It would contain material on medical and social aspects of all LTCs and provide information and contact details for local statutory services and national and local services run by medical charities and support groups.

Local involvement may be required to support this national development, for example, by:

- Checking details held nationally on local services
- Deciding whether some local services would be better recorded on a local rather than a national directory, and whether existing PCT or LA websites are suitable for this purpose
- Establishing mechanisms to maintain details of local services
- Deciding whether it would be more effective for local providers to access the central database of materials directly from within their own care delivery software, such as general practice systems.

Alternatively, it may be more effective to maintain local directories of local services.

**Resources for local development**

New posts will be needed to support the introduction of Information Prescriptions in primary care. The reports from the pilots suggest that to introduce Information Prescriptions to primary care in a small to medium-sized PCT, at least one full time senior coordinator is required, with another more junior post in support. The senior post could be a joint PCT/LA appointment whose functions would include: facilitating early discussions, identifying primary care leads, organising consultation events, devising an implementation plan, liaising with local and regional representatives of patient support groups and charities, devising and piloting local materials such as templates and posters and, above all, encouraging local GPs to participate.

In addition, this coordinator or a local implementation group would have the task of alerting and recruiting agencies to provide prescribing and dispensing for users and carers not using the Internet.

Since most general practices use proprietary patient record systems, there is an argument for national discussions between the Department of Health, representatives of GPs and...
primary care system suppliers on methods for recording the issuing of Information Prescriptions and information needs on practice computer systems. A recording facility might be included on a national database and, where local systems are used to generate Information Prescriptions (as in the Isle of Wight), the local coordinator may want to discuss methods for storing details of Information Prescriptions with users, local IT staff and care professionals.

**Resources for the delivery phase of model 1**

**Coordination in the delivery phase**

The duration of the pilots was too short to reach a mature stage of delivering Information Prescriptions and even the latest activity data will only refer to the level of coordination required at the early stages of routine delivery. Moreover, the effort required is likely to depend on the nature of the local populations and the attitudes of local voluntary sector and GPs. That said, there would be a core requirement to monitor performance, collect feedback and fine-tune the service, as well as checking that local services are accurately recorded on local and national directories.

**Input from care professionals**

Even in the lightest touch models, where a patient or carer is signposted to a web site or support agencies, the care professional will need to spend some time in the consultation exploring information needs and may need to check that the user is able to access the recommended resources. Pilots that adopted this model report that a care professional typically spends between three and five minutes on this type of signposting, though this may decrease when users and carers are more familiar with the process.

Given the large number of primary care consultations relating to LTCs, practices may arrange for some of this to be done by other practice staff, perhaps as part of periodic LTC reviews.

**Other contributors to delivering model 1**

The light touch model presumes that many users will obtain the prescribed information for themselves via the Internet. However, not everyone has access to or experience of using the Internet and may not choose to get information in this way.

The ONS Omnibus Survey shows strong associations between Internet use, age and income. In 2006 just over half 53 per cent of the lowest income group (up to £10,400 p.a.) have never accessed the Internet, while the corresponding figure is 6 per cent for those earning £36,400 or more.11 In the 2007 survey, the proportion of those aged 65 and over who had never used the Internet was 71 per cent, compared to 4 per cent of 16-24-year-olds.

These associations with age and income are likely to mean that people with LTCs, who tend to be older and poorer than the population as a whole and may have more limited experience of or access to the Internet. **Appendix 2** describes the results of combining the ONS 2007

---

11 National Statistics Omnibus Survey Jan-Apr 2006
Omnibus figures with age profiles of those with common LTCs. For the LTCs that often occur in younger as well as older people, such as asthma and depression, predicted experience of Internet use (based on age) is high at around 80 per cent; however, for angina, CHD and stroke it is under 45 per cent. Results for other LTCs are also shown in the Annex. Across all LTCs, the Omnibus figures and age profiles suggest that, on average, approximately 55 per cent of service users with LTCs will have Internet experience.

Again, these are estimates of potential rather than actual use. The survey data from the pilots suggest that actual rates of information seeking via the Internet will be lower, though it is unclear whether the survey refers to all information seeking, only those instances where an Information Prescription was issued, or all consultations including some signposting. Moreover, the number of respondents is too small to give separate estimates for methods of information seeking for each of the three models, so the figures cited here relate to the entire sample.

In the survey of the Information Prescription pilots approximately 20 per cent of patients/service users reported getting their information via the Internet. Assuming these are all people who had previous experience of the Internet, this suggests that 38 per cent of those who have experience of using the Internet and are signposted to Internet sources will actually look for information about their LTC on the web. Carers are more likely to seek information via the Internet: 33 per cent reported getting health related information in this way, corresponding to 45 per cent of all those carers with Internet access.

The same approach can be used to predict how many of those who do not use the Internet will approach local or national agencies for information. The survey of users (across all models of delivery) reports that 20 per cent contacted or joined charities or user support groups; 11 per cent contacted a benefit office and 5 per cent visited the library. When these rates are applied to the number of offers, they suggest that, over a year, a practice of 10,000 could generate approximately 1600 enquiries to charities and support groups, 900 benefit enquiries and 400 library visits.

Again, it is important to stress that these are based on offer and take-up rates reported by the pilots when Information Prescriptions are first introduced. Take-up rates are relatively low and might be higher if the roll-out is well publicised. Conversely, over time, both offer and take-up rates could decline as people acquire and act on information. The pilots were too short to provide estimates of the rate of decline.

The results from the user and carer survey make it clear that even with a model of delivery focussed on self-dispensing via the Internet, a majority of people will get information from other sources such as NHS Direct, medical and patient support charities, and libraries. These agencies may not be formally linked to local Information Prescriptions, but will be expected to provide both prescribing and dispensing and provide staff or volunteers who can discuss information needs, search the national database or a charity information system, and provide materials in suitable formats. Local funding or some form of commissioning arrangement may be necessary if there are substantial increases in workload, and part of the coordination effort will be to ensure that these agencies can provide the support required. The need for this support is even greater for model 2, where these agencies are formally part of the Information Prescription process.
**Summary of Typical Activities to Introduce Model 1 to Primary Care**

(N= national; L= local)

**Table 13**

<table>
<thead>
<tr>
<th>Main tasks during development phase</th>
<th>N or L</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Develop the national information resource</td>
<td>N</td>
</tr>
<tr>
<td>• Develop interfaces for the national resource suitable for lay use (pathway and simple search) and for use by agencies providing local support to those without Internet access</td>
<td>N</td>
</tr>
<tr>
<td>• Establish whether there is a need for directories of very local services that are not covered by the national database.</td>
<td>L</td>
</tr>
<tr>
<td>• Explore whether and where it might be practical to maintain such a local database</td>
<td></td>
</tr>
<tr>
<td>• Establish PCT/PALS Information Prescription facilitator post/s</td>
<td>L</td>
</tr>
<tr>
<td>• Local mechanisms – such as a forum – to help decide on the scale of information activity required, based on both need and existing service capacity to be undertaken by general practices, e.g. whether their input is limited to signposting or some skeletal form of Information Prescriptions (how to ensure existing information methods are best integrated and impact is manageable)</td>
<td>L</td>
</tr>
<tr>
<td>• Develop appropriate templates for signposting and skeletal prescribing</td>
<td>L</td>
</tr>
<tr>
<td>• Explore potential for noting an information enquiry or signposting on existing practice patient record systems</td>
<td>N+L</td>
</tr>
<tr>
<td>• Develop mechanisms, including identifying suitable GP or other practice leads, to encourage the take-up of Information Prescriptions in the service</td>
<td>L</td>
</tr>
<tr>
<td>• Develop mechanisms to monitor and more formally encourage participation, such as local QOF for PMS practices</td>
<td>L</td>
</tr>
<tr>
<td>• Map distribution and volume of needs using combination of QOF registers and other local data</td>
<td>L</td>
</tr>
<tr>
<td>• Agree local guidelines for instances when Information Prescriptions should be offered</td>
<td>L</td>
</tr>
<tr>
<td>• Identify local agencies that can provide routine support with prescribing and dispensing for people unable or unwilling to access the Internet (undertake commissioning if required)</td>
<td>L</td>
</tr>
<tr>
<td>• Devise mechanisms for the participation of these agencies and whether any commissioning or other additional resourcing is required</td>
<td>L</td>
</tr>
</tbody>
</table>
### Main tasks during development phase

<table>
<thead>
<tr>
<th>Activity</th>
<th>N or L</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify scale of special activities required to deliver information to groups who have special needs or are particularly at risk. Develop any commissioning plans for special support</td>
<td>L</td>
</tr>
<tr>
<td>Decide whether and how the introduction of Information Prescriptions is to be phased</td>
<td>L</td>
</tr>
<tr>
<td>Commission any training for the service and agencies involved in supporting dispensing</td>
<td>L</td>
</tr>
<tr>
<td>Develop and/or commission software interfaces for practices to access the new national database of materials from within the general practice care record systems. This would provide an alternative to the patient information leaflets (PILs) that EMIS users can provide to their patients.</td>
<td>N</td>
</tr>
<tr>
<td>Produce a local implementation plan</td>
<td>L</td>
</tr>
</tbody>
</table>

**Typical Activities in Delivery Phase of Model 1 in Primary Care**

**Table 14**

<table>
<thead>
<tr>
<th>Main tasks during delivery phase</th>
<th>N or L</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide continuing coordination, review and audit mechanisms to:</td>
<td>N or L</td>
</tr>
<tr>
<td>• Assess any additional time care professionals are having to commit to delivering Information Prescriptions – and ways this can be best used</td>
<td>N+L</td>
</tr>
<tr>
<td>• Assess level of any additional activity experienced by support agencies providing dispensing and supplementary prescribing to those not self-dispensing via the web</td>
<td></td>
</tr>
<tr>
<td>• Collect feedback from service users and information providers on methods of fine-tuning and developing the service</td>
<td></td>
</tr>
<tr>
<td>• Review services provided to people with special information needs</td>
<td></td>
</tr>
</tbody>
</table>

Ensure there are adequate local delivery mechanisms, both in the service and in agencies that provide dispensing and additional prescribing for those not using the Internet.

This may require:

- Local commissioning of services
- Additional staffing in practices and health centres
- Additional input from voluntary sector agencies
Costs of routinely providing materials such as:

- Templates and aids to consultations
- Dispensed information

Taking account of existing activity

Regardless of the approach to delivering Information Prescriptions, two key issues will influence the resources required:

- How much of the activity to delivery and dispense Information Prescriptions is new, rather than a rationalisation or formalisation of existing provision
- To what extent the demand for information will decrease over time as people acquire and act on the material dispensed.

How much new activity is required to develop model 1 locally

Clearly some of the development effort will be through the proposed national resources that could be developed, such as a central database and resource pack; this has the potential to reduce some of the local input needed. For some conditions, notably cancer, local networks may have already identified likely information needs and devised suitable templates and materials. However, in most places, substantial and new efforts will be needed for the various elements of development, such as coordinating meetings to discuss implementation, drawing up a plan, recruiting lead professionals (and subsequently others), and engaging with local agencies that will play a major part in the prescribing and dispensing.

How much new activity is required to subsequently deliver model 1

Despite periodic surveys of GP workload, there is no national data on the time GPs currently spend on different parts of their consultations, so we do not have a quantitative baseline. At least one of the general practice care record systems (EMIS) has a linked arrangement with a set of web-based information leaflets (the PILS materials), and data on the use of this system by GPs might be a guide to current activity. The pilots have not surveyed their GPs to collect systematic information on prior information giving, but there were some anecdotal reports: one GP was reported as using the PILS materials, while others were described as providing some information on medication. Information was frequently limited to verbal advice and written materials such as leaflets from a practice stock, but there were problems with maintaining stocks due to cost. Some practices also had lists of external agencies, either prepared in-house or by local PCTs. Overall, pilots generally reported the level of information provided as limited and highly variable.

There were also reports of local funding to support information provision in primary care: for example, PALS workers may be funded to provide information as part of their core activity, but most of this funding was to prepare materials rather than support routine delivery.

Pilots that commented on the relatively sparse information provided by primary care noted that much of the demand was currently picked up by the medical charities and other voluntary sector agencies, such as the Citizen’s Advice Bureau (CAB), with a smaller role played by some libraries. Comments from both national charities and members of the pilots....
suggest that there is little systematic referral to these agencies from primary care, so it is
difficult to tell how much new demand might be created if the process became more
organised. Equally, it is difficult to tell what proportion of potential demand for information is
currently being met by NHS Direct through their triage service, and whether GPs will refer
patients to NHS Direct for information rather than to medical charities.

Pilots generally welcomed the idea of an accessible central resource of materials, though
patients and carers with Internet connections can already access numerous websites on
health and health services. The most distinctive features of the new site could be a pathway
interface, guiding people to information relevant to different stages of their condition, and
mechanisms enabling direct access to the materials from local EPR systems.

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

**Introduction – description of model**

This approach to delivering Information Prescriptions has two key features:

- A specialist worker, such as a care worker or case manager, completes the Information
  Prescription alongside the service user during a consultation or assessment
- Most Information Prescriptions are taken for dispensing, and any additional prescribing,
  to a designated (linked) agency such as a national or local charity, NHS Direct or
  community information points

In some instances the prescriber or another member of the prescriber's team will also do the
dispensing.

Compared to the first model, there is greater input from the care professional, so the effort of
prescribing and dispensing is shared more equally between care professionals and other
agencies.

**Table 15**

<table>
<thead>
<tr>
<th>Model 2: In-depth prescribing and linked dispensing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activity in consultation</strong></td>
</tr>
<tr>
<td>A specialist worker, such as a care worker or case manager, completes the Information Prescription template alongside the service user, during a consultation.</td>
</tr>
</tbody>
</table>

Typical setting for model 2: GP consultations in primary care, some outpatient clinics
The linkage between the prescribing and dispensing agencies can take several forms. At its loosest, the dispensing agency simply agrees to accept referrals, provide information and publicise its availability. The Evelina Children's Hospital pilot is an example of the other extreme, where the prescriber enters details of the user/carer and Information Prescription on the dispenser's website and the dispenser (NHS Direct) contacts the user to complete the prescribing and dispensing.

In some settings, when the bulk of the prescribing and dispensing is done by care professionals, this model and model 3 converge.

**Typical users and settings**

This model is most appropriate for community-based services such as:

- Mental health care delivered by community and partnership trusts
- Other community health care services commissioned by PCTs
- The assessments carried out by children and family, young adult and older people's social services teams and a variety of teams supporting people with special needs
- Day, residential and other forms of social service care.

It could also be used in hospital settings, such as in the joint NHS Direct and Evelina Children's Hospital project.

**Experience of the pilots in developing and implementing model 2**

**Pilots with features of Model 2** were Doncaster, South Essex, Manchester, Oxfordshire, Leeds RNIB, South Staffordshire, and Evelina Children's Hospital.

Although these seven projects approximate to this model, few are pure examples and several, notably Doncaster and Leeds Acute Mental Health, could equally be grouped under model 3 because all prescribing and dispensing is done in-house by care professionals. For the purposes of reporting, Doncaster is included here because it takes place in a community setting, and the Leeds Mental Health Project is described under model 3.

South Essex provides one of the purest interpretations of model 2. Consultants, psychiatrists and mental health nurses create the Information Prescriptions in the consultation, using a computerised directory and Information Prescription Generator developed specifically for the project. Service users find the recommended materials either on the local website, elsewhere on the Internet, or at designated dispensing points, where they will be assisted by voluntary care sector staff, members of primary care teams or mental health clinic administrators.

The other pilot that most closely corresponds to model 2 is the joint Evelina Children's Hospital and NHS Direct project. Here an Information Prescription is completed by a pharmacist on the ward in consultation with the patient and the parents. The Information Prescription is transmitted electronically to NHS Direct which carries out the remaining prescribing and dispensing.

The Manchester pilot (mostly covering Parkinson's Disease, HIV and AIDS) includes a variety of mostly community-based prescribing and dispensing mechanisms in which both
functions can be performed either simultaneously or separately by people including social care professionals, expert patients, community nurses and voluntary care sector staff.

The South Staffordshire pilot used a similar variety of approaches, where the prescribers are youth workers, CAHMS professionals and YOT staff. The same individuals may also do the dispensing, as may their colleagues. Clients may also self-dispense via the Internet or visit designated library dispensing points.

The Oxfordshire pilot shares some features with model 1 in that the project developed an Information Prescription website that minimised the input from care professionals or other prescribers and only required them to identify the level of hearing impairment. The website provides lists of recommended sources for each level. These sources can then be obtained from some prescribers or from designated points, including libraries, or downloaded from the Internet. The main prescribers are audiology consultants, social workers and voluntary care sector staff. When materials are not self-dispensed, the main dispensers are social workers, voluntary care sector staff and librarians.

In the Doncaster mental health pilot, care professionals do all the prescribing and dispensing, though not necessarily in one consultation. Service users can also self-dispense from the Internet. Some of the professionals doing the prescribing in the West Yorkshire Low Vision project will also dispense information; other clinic staff will also assist with dispensing.

This is a varied group of projects with equally varied patterns of resource use, but the following resourcing issues are common to most of the group.

- Prescribing and dispensing take-up considerable quantities of care professionals time, though development effort could reduce the burden on professionals, if:
  - Prescribing is designed to be part of process of delivering care;
  - Dispensing can be done by other groups, such as voluntary care sector staff.
- Care delivery settings are often geographically dispersed so there may be particular benefits in having remote access to a common directory of sources and links or an easily interrogated portable database.
- Prescribing arrangements can be diverse and complex, involving different groups in different settings, hence the need for considerable coordination and training both during development and delivery.
- Dispensing arrangements are also potentially complex, require close coordination and may rely heavily on the support of outside agencies.
  - If dispensing is done internally, this will require clear division of responsibilities for dispensing;
  - If done externally, there needs to be well-established arrangements with other agencies.
- Coordination is required to ensure a good, consistent supply of materials to both internal and external dispensers.

Of all the approaches, this may require the most ongoing coordination and support.
Resourcing the roll-out of model 2

General issues in estimating resource use and demand for model 2

Compared with primary and hospital health care, the community and social health care sector has much more diverse organisational arrangements and includes peripatetic, drop-in, day care and residential care settings.

It also has an extremely diverse range of clients, from those with relatively undemanding information needs that might be addressed in a single meeting, to those with complex but stable conditions, who may need long-term information and help with accessing a range of support services, and finally those whose needs are both complex and acute. Estimating the resources required to introduce Information Prescriptions is further complicated by local variations in the organisation of social and mental health services and types of care provided.

Evidence from the pilots is patchy for some of these services. The main omission is the lack of a pilot based in a generic social work setting.

Given all these factors, it is difficult to generalise about the scale and types of resources that will be required to roll out this model to the many settings to which it can be applied. Three different settings are briefly considered: generic social care, community mental health and specialist social care, and hospital-linked dispensing.

In generic social care

Estimating demand

The annual Referrals, Assessment and Packages of Care (RAP) returns report the numbers of adult clients seen by social services; more detailed information is available for children in the Children in Need Census. However, the figures for adults divide clients into categories of need that mostly do not indicate whether the client has a LTC and whether this is the reason for the referral. Estimates of possible numbers of Information Prescriptions issued and offered can only be obtained by applying some heroic assumptions to the RAP figures. For example, the RAP returns show that generic social work teams with, for example, 50 workers supporting a population of 100,000 will see 400 new clients per month or 5000 per year. They also indicate that 45 per cent of these clients will only require a single contact.

There is no data from the pilots on Information Prescription offer rates in generic social work settings, but as one of the aims of the service is to provide information, initial demand could be high, perhaps 85 per cent of new contacts. Although many of these clients will have LTCs, especially the elderly, it is unclear whether they should be offered Information Prescriptions unless the referral specifically relates to a LTC. Guidance on this issue may be required for the rollout.

Although referral to an external agency for dispensing is a core feature of this model, some clients may find it more convenient to get their information via the Internet. This is most relevant for those services that mainly deal with younger people, such as some mental health teams, where as many as 75 per cent of clients might have experience of Internet use. In contrast, 70-75 per cent of clients for generic adult services are aged 65 and over, and their experience of Internet use is unlikely to be more than 30 per cent.
Generic social care: coordination and involvement of care professionals in delivering Information Prescriptions

Social workers are mostly employed by local authorities, but their work places can be dispersed and include team and patch offices, day centres, hospital offices and residential units. For this reason, considerable effort may be required to engage the workers and sustain and coordinate Information Prescriptions, perhaps requiring at least one full-time coordinator with support to develop Information Prescription in a service that sees 400 new referrals per month.

Other development work will include:

- Deciding how best to present Information Prescriptions;
- Whether these can build on lists of sources already given to clients establishing arrangement with other agencies (including other local authority services) to provide dispensing;
- Determining how far local client record systems are capable of generating Information Prescriptions and recording their issue.

Agencies providing linked dispensing may be other local authority services, such as housing departments, aids and equipment departments, and libraries. Outside agencies that may dispense information on LTCs will include the CAB, local and national charities, and generic support groups such as Age Concern. Part of the local coordination effort will involve recruiting and maintaining contact with these agencies, monitoring the impact of Information Prescriptions on their workload and publicising their involvement in the scheme.

There is no directly relevant data from the pilots on the time it takes a social worker or other care professional to establish information needs and issue an Information Prescription in these settings, but figures of 15-30 minutes per contact are reported from analogous settings. Some services will already be devoting this length of time to giving information during an assessment session, but the reports on baseline activity (see below) suggest that present provision is uneven.

In community mental health

A variety of services and clients come under this heading, from CMH teams with a watching brief over people with dementia to those that treat and manage acute forms of mental illness.

Estimating demand

Estimating demand for Information Prescriptions in community mental health care is more difficult. There are no national figures except those based on the HES data for inpatient and outpatient attendances, which will only partially cover the activities of community mental health services. Combining QOF and HES data could provide rough national estimates, but local demand is best estimated from local activity data. The situation is further complicated by local differences in the respective roles of primary care and community services in supporting people with mental health problems.

Clients for some community mental health services – but not those with dementia – will be younger than many people with other LTCs. As a result, they may be able to use a version of model 1: referral to a linked dispensing web site.
**In community mental health and specialist social care**

Activity reports from the pilots are as varied as their settings. Care managers dealing with high volumes of relatively routine mental health problems reported taking 10-15 minutes to identify information needs and issue Information Prescriptions signposting people to suitable agencies. Staff dealing with people with more complex conditions could spend between one and two hours on Information Prescriptions, though in some cases this included dispensing.

Reported take-up of initial offers varied from 50 to 90 per cent in the pilots in this group, though it is not known how many of these resulted in visits to a linked dispenser. The lowest rates of take-up were associated with clients who were mid-treatment and those complaining of information overload.

The agencies providing dispensing to these clients will include some of the more generic bodies, such as the CAB and local authority, but also local branches of mental health support groups, and groups and services relating to addiction and substance misuse.

Staff in the linked agencies will need to be familiar with the details of the approach to Information Prescriptions and introduced to national and local resources. They may need additional training and support if they encounter more demanding client groups through their involvement in Information Prescriptions.

Again, given the rather younger profile of some of these groups, Internet-based dispensing may be an attractive option.

**In other community health services**

Estimating demand for Information Prescriptions in other community health services is, if anything, even more difficult as there is very little robust and detailed national activity data for these services.

**In hospital settings**

The use of a dedicated external dispensing arrangement (model 2) was successfully trialled by one of the hospital pilots and could be applied to other tertiary centres where very specialised information has to be provided to patients who live remotely and may not regularly visit the hospital. This, or other less technologically advanced forms of linked dispensing, might also be used in any hospital where it is impractical to develop new information centres.

In the Evelina Children's Hospital pilot, the development effort was shared between the hospital and NHS Direct and resulted in an Information Prescription template for use in wards – either as hard copy or on a laptop – and a set of secure pages on the NHS Direct web site for entering details of the patient and the Information Prescription. The web pages and interface could be easily adapted for other groups. During delivery, approximately 75 per cent of patients took up the offer of an Information Prescription. It took the pharmacists 10-15 minutes to enter the information requirements on the Information Prescription before further prescribing and dispensing was done by NHS Direct.

The type of service provided by NHS Direct might also be delivered as a commissioned service by other agencies, such as national charities.
**Indicative list of tasks to implement model 2**

Table 16  
(N= national; L= local)

<table>
<thead>
<tr>
<th>Development Phase for Model 2</th>
<th>N or L</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Develop interfaces for the national information database suitable for professional use and by agencies doing local dispensing</td>
<td>N</td>
</tr>
<tr>
<td>• Establish whether there is a need for directories of very local services that are not covered by the national database.</td>
<td>L</td>
</tr>
<tr>
<td>• Explore whether and where it might be practical to maintain such a local database</td>
<td>L</td>
</tr>
<tr>
<td>• Establish Information Prescription facilitator/ coordinator post(s) for each of the care providers: local authority social services (may need coordinator for different parts of the service); care trusts providing community mental health services; PCT-based coordinator for other community health services</td>
<td>L</td>
</tr>
<tr>
<td>• Local mechanisms for each of the care services to review their existing information provision and liaise with users on how best to integrate information provision into care services and identify appropriate agencies to provide the linked dispensing</td>
<td>L</td>
</tr>
<tr>
<td>• Develop appropriate templates for prescribing for each service, with possible variations for different conditions groups within a service. Ensure these are compatible with any assessment of need recording in existing procedures</td>
<td>L</td>
</tr>
<tr>
<td>• Explore potential for recording the Information Prescription or information needs on existing care</td>
<td>N+L</td>
</tr>
<tr>
<td>• Develop mechanisms, such as identifying suitable lead professionals, to encourage the take-up of Information Prescriptions in the service</td>
<td>L</td>
</tr>
<tr>
<td>• Map distribution and volume of needs using social services activity data, mental health trust activity data and any data on patterns and levels of delivery of community health care</td>
<td>L</td>
</tr>
<tr>
<td>• Agree local guidelines for instances when Information Prescriptions should be offered – may be condition-specific within services</td>
<td>L</td>
</tr>
<tr>
<td>• Identify local agencies that can provide linked support for dispensing and any additional prescribing</td>
<td>L</td>
</tr>
<tr>
<td>• Devise mechanisms for the participation of these agencies and whether any commissioning or other additional resourcing is required; this could range from posters labelling an information point</td>
<td>L</td>
</tr>
</tbody>
</table>
### Development Phase for Model 2

<table>
<thead>
<tr>
<th>Activity</th>
<th>N or L</th>
</tr>
</thead>
<tbody>
<tr>
<td>to development of web site to receive details of clients and Information Prescriptions</td>
<td></td>
</tr>
<tr>
<td>• Identify scale of special activities required to deliver information to groups who have special needs or are particularly at risk; develop any commissioning plans for special support</td>
<td>L</td>
</tr>
<tr>
<td>• Decide whether and how the introduction of Information Prescriptions is to be phased</td>
<td>L</td>
</tr>
<tr>
<td>• Commission any training for the service and agencies involved in supporting dispensing</td>
<td>L</td>
</tr>
<tr>
<td>• Develop and/or commission software interfaces for agencies that want to access the national database directly from their care record systems</td>
<td>N</td>
</tr>
<tr>
<td>• Produce local implementation plans for each of the services</td>
<td>L</td>
</tr>
</tbody>
</table>

### Resources for delivery

#### Table 17

<table>
<thead>
<tr>
<th>Activity</th>
<th>N or L</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide continuing coordination, review and audit mechanisms to:</td>
<td></td>
</tr>
<tr>
<td>• Monitor extent of Information Prescription delivery, offer rates, etc., across the often complex patterns of services</td>
<td>N+L</td>
</tr>
<tr>
<td>• Assess any additional time care professionals are having to commit to delivering Information Prescriptions and ways this can be best used</td>
<td></td>
</tr>
<tr>
<td>• Assess level of any activity in the linked agencies. Collect feedback from service users and information providers on methods of fine-tuning and developing the service</td>
<td></td>
</tr>
<tr>
<td>• Review services provided to people with special information needs</td>
<td></td>
</tr>
<tr>
<td>• Carry out ongoing consultations and possible commissioning to ensure continuity of linked services.</td>
<td>L</td>
</tr>
<tr>
<td>• Ensure that local delivery mechanisms and agencies that provide the linked dispensing and prescribing are clearly identified to users.</td>
<td></td>
</tr>
<tr>
<td>Meet any costs agreed with services or linked agencies for materials such as:</td>
<td></td>
</tr>
<tr>
<td>• Templates and aids to consultations</td>
<td>L</td>
</tr>
</tbody>
</table>
Dispensed information

Support mechanisms in model 2

The distinguishing feature of almost all implementations of model 2 is the idea of a linked dispenser, either part of the prescribing organisation or an external agency, that agrees to take responsibility for providing the information cited on Information Prescriptions. The two key questions as far as resourcing are concerned are therefore:

- How to find sufficient development effort and coordination to recruit dispensers and ensure their role is clear and acceptable
- How to resource this linked dispensing. Does this require commissioning arrangements, or payments to cover costs of dispensed materials?

Existing information provision in services for which model 2 is appropriate

Although providing information should already be a priority in many of the services that could use model 2, the pilots reported that the current situation was varied and could be patchy.

For example, two units in the same service were contrasted. In one a form was available with several prompts and contacts of appropriate sources of information to use as a checklist as part of the consultation process. This was placed in the back of the medical file and dates written next to the appropriate leaflets/booklets, etc., when provided. The details of information given was also written in the letters to GP and copied to appropriate parties as per the CPA Process. Most of the service users received information pre-pilot as most of the clinicians had access to the files used as a resource and routinely gave the information out when appropriate.

The provision was very different at another unit in the same service. No formal arrangements were in place to develop and provide information and no mechanism existed to systematically deliver information to service users. This resulted in a very small proportion of users actually being offered information.

Reports from elsewhere indicated the following:

- All staff could point people in direction of information but this is no one person’s individual responsibility. However, the need for such position is seen as very high.
- Excellent information and support are available from the voluntary sector, health and social services, but people often do not know where or how to obtain the help they need.
- A report on a feedback event prior to one of the pilots noted that ‘service users and patients in general felt that information in both health and social care was very scarce. Some groups said there is no set pattern to information and it was very difficult if you didn’t know what to ask for. Other people attending the event said that, where they do ask for information, it is a slow process and they then end up doing it themselves or going through family support networks or websites, which can be quite frightening.
- Patients and carers reported having little or no information at diagnosis, certainly nothing written down, and being left to look it up for themselves.
Prior to the pilot in one service area, approximately 60 per cent of clients were offered information or pointers to information either on request or following an event such as a change in care management. Information would be specific and include signposting to specialists and support groups. In addition, virtually all clients with depression are given a ‘recovery workbook’ containing relevant information.

Resources for Model 3: In-depth prescribing with information centre

Introduction to the model

In this model, discussion of information needs and prescribing is mainly carried out by a consultant, care manager or specialist nurse. The Information Prescription process can be quite structured and designed to address different information needs at different stages in the care pathway. Prescribing may be done in several stages: for example, a professional makes an initial assessment of the user's information needs and another professional does the more detailed prescribing. Dispensing usually takes place in an information centre, which is staffed by a nurse, NHS information specialist or someone from the voluntary sector.

This approach is mostly found in secondary care in the pilots, though there is one example in the primary sector.

Table 18

<table>
<thead>
<tr>
<th>Model 3: In-depth prescribing with information centre</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activity in consultation</strong></td>
</tr>
<tr>
<td>Prescribing usually involves more than one stage. In the first a professional such as a consultant, care manager or specialist nurse makes an initial assessment of the user information needs. In the second, another professional conducts a more detailed assessment.</td>
</tr>
</tbody>
</table>

Typical setting for model 3: hospitals – both inpatient and outpatient care.

Typical users and settings

The main difference from the previous model is that dispensing and any additional prescribing is done in-house, rather than by external agencies such as designated dispensing points or national charity help lines.

The justification for the relatively heavy involvement of care professionals and other NHS staff is to give a full and integrated information service to people with complex and/or life-threatening conditions, including interpersonal support in both obtaining and interpreting information.
As this is demanding of medical as well as information centre staff time, it is not surprising that the model seems to have been most acceptable in those pilots where specialised teams have high levels of contact with relatively small groups of patients, as in the Heart of England Trust Cystic Fibrosis Unit. Other pilots implementing this approach were based in hospital cancer teams or their associated information centres, working in conjunction with medical charities or patient support groups. Such groups may have a long history of developing protocols and mechanisms for providing information to patients and carers. In the pilots, they demonstrated that delivering information could be integrated into the care process and that an information centre could act as a catalyst in encouraging a culture of information giving, not least by providing a focus for staff to review and develop their practice.

Although one pilot applied this model to inpatient care and one to cancer in primary care, it was more widely found in outpatient settings.

This is a challenging approach, requiring considerable resources and staff with special skills and specialist knowledge of conditions and treatments and good access to medical teams. For these reasons it may only be practical in certain specialties and large hospitals. The previous approach (model 2) may be more appropriate for many hospital settings.

**Pattern of resource use of pilots implementing this model**

Eight pilots included at least one key feature of this model, though only one, Queen Elizabeth Hospital Oncology Unit, implemented it in full. At QEH the clinical teams did the initial prescribing and the in-house information centre completed the prescribing and dispensing.

**Pilots using major features of model 3** were Heart of England, Royal Marsden, North Tyneside, Mid Trent, Queen Elizabeth, Oxleas, Durham, Cambridgeshire, and Leeds Mental Health.

The hospital information centre had a facilitating role in the Heart of England Trust pilot – where it created a computerised Information Prescription system that gave access to a stock of locally created materials and provided facilities for recording details on the hospital EPRs. However, ward staff in the cystic fibrosis unit did most of the dispensing in this pilot.

Ward and outpatient staff were both prescribers and dispensers in the Cambridgeshire and Huntingdon pilot. The Information Prescriptions were created from a locally produced directory using the Map of Medicine Information Prescription Generator and materials (generally leaflets) were dispensed from local stocks. Relating to people with dementia receiving periods of inpatient care, Leeds Mental Health Trust also operated a model in which prescribing and dispensing was done in wards or outpatient settings. The bulk of prescribing was done by consultants or nurses and nurses completed the dispensing.

At Oxleas, the medical staff generally do both prescribing and dispensing in the consultation. The directory of mainly locally-produced materials is accessible from the care planning software.

In Mid Trent, members of the relevant hospital teams mostly carry out prescribing and dispensing, though the pilot has been trying to introduce Information Prescriptions to general practices. Medical staff also do most of the prescribing and dispensing in the cancer Information Prescription pilot at Royal Marsden.
At the North Tyneside pilot, prescribing is carried out by two sets of professionals: Parkinson’s service consultants and specialist nurses. A nurse and the project manager do the bulk of the dispensing. They collect the information identified on the Information Prescription and dispatch this by post or email. There is a follow-up phone call to check whether the information has been received and whether it proved useful. NHS Direct provides additional dispensing for this pilot, especially for people in more rural areas.

Durham provided the one example of an information centre supporting information prescribing in primary care. Here, a nurse in a primary care setting does most prescribing and the information is dispensed at a local specialist cancer information centre using a database developed for the project.

Given the diversity of approaches grouped under the heading of model 3, it is difficult to generalise about patterns of resource use. Broadly speaking the aspects of development requiring most work were:

- Devising a process and template that was acceptable to clinical teams as well as service users. Making maximum use of existing staffing and integrating Information Prescriptions as closely as possible into care provision
- Developing directories, though several of these projects already had lists of recommended materials.
- Constructing databases to hold materials and links to other resources, and associated programming tasks such as creating an Information Prescription Generator and facilities for electronically recording information issued.

Resources to roll-out this model

Estimating demand

Hospital Episode Statistics are the obvious basis for estimating demand for this approach to Information Prescriptions as they record the numbers of hospital attendances and admissions, but this is not unproblematic. For example, it is not straightforward to map the HES ICD diagnosis codes to specific LTCs. Codes are also often missing from the outpatient records, so there is a difficulty identifying the number of attendances and admissions relating to LTCs.

The monthly returns from the pilots indicate that there will be major variations in take-up rates: in the pilots these ranged from 25 to 97 per cent. The lower figures were in settings where patients were attending for routine follow-up visits or regular treatment. The highest were in consultations where a first diagnosis was made and the aim was to provide Information Prescriptions to everyone, unless they declined or were too distressed or anxious to cope with information.

HES outpatient data shows that the proportion of first outpatient attendances, when an Information Prescription is most likely to be issued, varies substantially between conditions and specialties. For some long-term conditions the outpatient unit has a ‘watchful waiting’ function and the proportion of attendances that are new patients could be as low as 15 per cent. This is the case for many oncology and rheumatology departments. In other specialties, such as dermatology and neurology, the proportion of new patients could be 40 per cent.
Pilots reported take-up rates for inpatient offers of 80-90 per cent, but most of these relate to very specialised low-volume care settings.

**Is this model suitable for all hospital settings?**

It is debatable whether the pure model 3 could be applied across an entire hospital trust because of the scale of investment required to establish new information centres. One of the key questions is whether there should be separate information facilities and coordination for each specialty or whether Information Prescriptions in hospitals would be better supported and coordinated by a central information team. Pilots provided examples of both approaches: an information centre that only supported an oncology unit and a trust information centre that was intending to facilitate the introduction of Information Prescriptions across various specialties.

The choice of approach is a complex question, influenced by factors such as the layout of the trust's premises, the location of any existing information centres and the relative enthusiasm for Information Prescriptions in different specialties and teams, not to mention the needs of different groups of patients.

**Summary of typical activities to introduce Model 3 in hospital and other settings**

<table>
<thead>
<tr>
<th>Tasks during development phase for model 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Nominate or employ coordinator to oversee design stage</td>
</tr>
<tr>
<td>• Recruit key professionals for each specialty</td>
</tr>
<tr>
<td>• Use hospital activity data to estimate levels of need and throughput for information centres</td>
</tr>
<tr>
<td>• Consult management care professionals and information staff and other interested groups on the degree of centralisation to adopt</td>
</tr>
<tr>
<td>• Consult with care professionals, patient groups and others on template design for each condition; also consider how Information Prescriptions can be best fitted into existing practice and incorporate existing functions</td>
</tr>
<tr>
<td>• Involve external networks and other hospitals in consultation if services operate as networks, spokes and hub or other multi-agency arrangements</td>
</tr>
<tr>
<td>• Assess need to supplement the proposed national database with local materials – assign responsibility for producing materials and decide on suitable methods of delivery</td>
</tr>
<tr>
<td>• Arrange for national materials to be accessed via local EPRs</td>
</tr>
<tr>
<td>• Devise local enhancements to EPR to record the issuing of information</td>
</tr>
<tr>
<td>• Plan locations, details of premises and staffing for any new information centres</td>
</tr>
<tr>
<td>• Establish whether voluntary agencies, local networks or volunteers should play a role in the implementation</td>
</tr>
</tbody>
</table>

OPM page 117
role in running the centres and whether any of this input needs to be commissioned

- Assess any new IT hardware needs either to support information centres or facilitate the issuing of Information Prescriptions in outpatient units or wards
- Set up mechanisms for stocking information centres with materials
- Decide where to refer people for information who are unable to use the hospital information facilities

### Main tasks during delivery phase

**Table 19**

<table>
<thead>
<tr>
<th><strong>Main tasks during delivery phase</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide continuing coordination, review and audit mechanisms to:</td>
</tr>
<tr>
<td>- Assess any additional time care professionals are having to commit to delivering Information Prescriptions; assess whether the Information Prescription activities can contribute to other aspects of care delivery, such as providing formal records that patients have been notified of a diagnosis</td>
</tr>
<tr>
<td>- Monitor workload on information centres and review location and staffing arrangements</td>
</tr>
<tr>
<td>- Collect feedback from service users and information providers on methods of fine-tuning and developing the service</td>
</tr>
<tr>
<td>- Review services provided to people with special information needs</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Main tasks during delivery phase</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Confirm that patients and carers who cannot use the hospital information centres are getting information elsewhere</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Main tasks during delivery phase</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Liaise with other members of networks or other joint care arrangements to ensure consistency and synchronisation of information provision</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Main tasks during delivery phase</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Meet running costs for materials including:</td>
</tr>
<tr>
<td>- Templates and aids to consultations</td>
</tr>
<tr>
<td>- Stocks of booklets from external agencies</td>
</tr>
<tr>
<td>- Paper and print cartridges for ad hoc printing of materials</td>
</tr>
</tbody>
</table>
Developing the model

National and local directory development for model 3

Given the specialised nature of many of the conditions and interventions likely to be supported by this model of delivery, and the patient and carer interest in very specific local information, such as hospital parking charges, there may be a substantial and continuing role for local specialists and administrators, as well as national charities, to develop materials of both national and local interest.

The question of whether to use national or locally developed materials on more generic topics is a potential source of tension, especially in hospitals with a strong history of developing such materials.

A related issue is whether to maintain a hospital database of local materials and how this would relate to local databases to support model 1, such as information on local groups kept by PCTs or local authorities.

Any national database should be made as accessible as possible to local care and information staff, which could involve developing an interface in the local EPR system to access it directly alongside local materials. The EPR system should also include a facility to store details of an Information Prescription. From the experience of the pilots, suitable modifications to the local EPR system are easiest to achieve when an in-house team maintains the system.

Increasing access to IT

Some pilots used their funding to make computers more accessible, so that Information Prescriptions could be issued on wards and patients and carers could access the information databases from terminals in the hospital. Examples included providing laptops for use in wards and community settings and touch screen consoles in both wards and public areas. In several cases, the pilot funding was used to increase access to printers, enabling Information Prescriptions to be printed in or near consultations.

Planning the implementation

A recurring theme from the pilots implementing some aspects of this model is the very detailed planning required to ensure not only that the process meets user needs, but also that it integrates closely with the processes of diagnosis and care delivery. Drawing up an implementation plan is likely to be a major task involving consultation with professionals, information staff, and patient and carer groups. Consultation will cover issues such as the role and design of information centres and how the model of Information Prescription delivery should be varied to take account of factors such as the nature of conditions, the type of care, staffing levels and the availability of premises.

Although this model relies on the availability of hospital information centres, as far as we know, there are no national statistics on the number or scale of such centres. A small national survey or supplement to the ERIC returns would help establish the feasibility of rolling out this approach. Widespread introduction of new centres would be costly and finding space could be difficult in existing premises.
Coordination with other care providers will be required when designing Information Prescriptions for services that operate in network or hub and spoke arrangements involving other trusts and outside agencies. Pilots have also shown that some parts of this approach might be contracted to national charities.

The hospital Information Prescription pilots that used this model were mostly based in specialist teams that already had a strong commitment to information provision and key members of staff who were keen to promote Information Prescriptions. It is therefore difficult to use data from the pilots to predict the effort that would be required to engage and train staff in Information Prescriptions in higher volume settings or those without an existing commitment to providing information. However, one message from the pilots is that the process is more likely to succeed if medical professionals are heavily involved in coordination, rather than this being left to management or information staff.

The main question for the local development of model 3 is whether trusts can afford new information centres or whether model 3 can only be implemented for certain groups of patients, with the remainder receiving information by other routes, such as linked dispensing in outside agencies.

**Delivering the model**

Unsurprisingly, the two key resources for delivery of this model are staff time and materials costs.

There are several components to staffing, depending on the method of implementation.

The returns from the pilots indicate that, in the early stages of delivery, as much as 1.5 FTE of staff time (some of which would need to be medically qualified) would be needed to supervise and coordinate the introduction of Information Prescriptions in an outpatient unit that sees around 35,000 people per year. The same would be required for implementation in several inpatient wards with a total bed capacity of 100-150 serving specialties with relatively short average lengths of stay, i.e. 2 weeks. Again, there are difficulties extrapolating from the pilots, as this level of input would also have supported development work and various recording exercises for the evaluation. The start-up effort may therefore be lower or higher depending on the nature of the user and carers needs and the local attitudes to information provision, while lower levels coordination may be required once Information Prescriptions are established.

The staff resources required for prescribing and dispensing depends on who does the initial consultation and whether this includes detailed prescribing. Pilot returns report that that a preliminary discussion of information needs – and the creation of an Information Prescription that lists those needs – could take 15 minutes of a nurse specialist or consultant's time. More detailed prescribing and assistance with interpreting information is likely to be undertaken in an information centre and can take much longer, at least 30 minutes. This could be done by an information worker with medical knowledge, a nurse specialist, or perhaps an expert patient or volunteer with knowledge of a specific condition. The time to finish the prescribing, dispense information and provide additional help will vary greatly with individual needs and the nature and stage of the condition. Experience from the pilots suggests that more than one full-time member of staff will be required in an information centre to support a large high-volume out-patient department.
Material costs can also be considerable for hospital information centres. Pilots report that charities charge for supplying booklets in bulk to Trust information centres and significant printing costs will be incurred if they are providing paper copies of items from the national database.

**Existing information provision in hospital settings**

Baseline provision is extremely variable. Some pilot sites were already providing information by mechanisms similar to information prescribing, but only to small groups of patients. In these cases, the pilot funding permitted this activity to be refined and expanded. What is clear, even from these sites, is that additional resources would be required to cover all LTCs.

Accounts from the pilot sites of their prior information provision reflects their relative sophistication and interest in ensuring information is suitably targeted. However, the following comments from the baseline returns suggested that, even here, prior activity was variable.

- The care planning process (for intensively supported patients) has always had a focus on providing information
- Existing information protocols were not always adhered to and standard packs might be issued when it was more appropriate to provide selected items based on need
- At times, there was too much information and it tended to be repetitive and inappropriate to the stage of their condition
- Information in outpatient areas consisted of displays of leaflets covering most topics

**Conclusions and a brief guide to estimating local resource requirements**

**Conclusions**

This section of the report has described some of the activities and resources employed to implement three different approaches to Information Prescriptions and has indicated, where possible, the pilots’ level of input into these activities.

**Resourcing the three models**

The three models are an inevitable simplification, designed to highlight some of the resourcing issues experienced by the pilots and likely to be encountered in a national roll-out.

**Model 1**

This is the approach intended to minimise the input on care professionals, in which they signpost people to appropriate sources. National or local websites are established to store downloadable information for people who choose and are able to get information by this route.

Some of the key tasks to successfully implement this approach include:

- To develop a signposting system that is acceptable to professionals, users and carers
- To promote its use amongst the public as well as professionals
• To develop or identify a stock of suitable information materials (i.e. to build a directory)
• To set up mechanisms to give good public access to these materials, perhaps by building new websites
• To train and encourage care professionals to signpost people to these mechanisms
• To ensure there are clearly identified help points for people without their own Internet access

The approach is particularly suited for primary care and, as such, has the potential to deliver Information Prescriptions to everyone who presents with a LTC to a GP.

Key resourcing issues for the rollout of this approach are:

• How far it will be able to rely on any new national resource to be a central repository of accredited information on all LTCs
• Whether there will continue to be a need for local databases of materials and links to very local services
• If this is mainly intended for primary care, how to encourage GPs and other primary care staff to adopt the model
• How to ensure that people without Internet access are well-supported
• How to provide services for people who experience difficulties interpreting and understanding the information

The last two points are critical. The number of Information Prescriptions that could potentially be delivered by this approach is very large. Many of these will be given to people without Internet access or experience and they will need to know how to get information by other routes. The process will need careful monitoring to ensure suitable mechanisms are available both to this group and to those who have difficulties interpreting any information they receive. It is unclear who will do this monitoring if the role of the care professional is limited to signposting.

**Model 2**

In this model, the care professional plays a greater role in the prescribing and issues a full Information Prescription that is taken to linked dispensers, such as local information points, libraries, offices of local support groups and national helplines run by charities or NHS Direct. In some settings, the prescriber may also dispense; in others, the materials will be obtained by self-dispensing via the Internet.

This model is suitable for most community settings and some hospital care, especially when the third model proves too expensive.

Some of the main resourcing issues associated with the approach are:

• The prescribing and dispensing will take-up considerable quantities of care professionals time, though this could be reduced if:
  • Prescribing is designed to be part of the process of delivering care
  • Dispensing can be done by other groups, such as voluntary care sector staff
• Care delivery settings are often geographically dispersed, so there may be particular benefits in having remote access to a common directory of sources and links or an easily interrogated portable database

• Prescribing and dispensing arrangements can be diverse and complex, involving different groups in different settings, hence the need for well-organised supplies of materials to dispensers and considerable coordination and training during development and delivery.

Some of the main uncertainties around rolling out this approach concern the logistics of coordinating prescribing and dispensing across disparate services and ensuring that multiple agencies are committed to the process.

Given the commitment required from the support agencies that provide the linked services (additional prescribing and dispensing), there may be an argument for specifically commissioning these services in some settings.

Model 3

The overriding questions of resourcing associated with the third model – prescribing carried out by care professionals and dispensing done in a dedicated information centre – are:

• Whether it is only practical in teams that provide long-term intensive support for relatively small numbers of patients

• How to fund the development of hospital information centres, and what type of centre is best suited to Information Prescriptions

One of the most important tasks in implementing this approach was to devise a prescribing process and template that was acceptable to clinical teams as well as service users. This aimed to make maximum use of existing staffing and integrate Information Prescriptions as closely as possible into care provision.

Some pilots using this model developed databases of information materials and integrated Information Prescriptions into existing EPR systems. This could involve considerable local programming effort and raises the issue of how any national database should be accessed from with local IT systems.

The scale of investment required to establish new information centres may rule out the full implementation of this approach in most hospital trusts. One of the key questions for these trusts is whether to establish separate information facilities and coordination for each specialty, or whether Information Prescriptions would be better supported and coordinated by a central information team.

The choice of approach is a complex matter, influenced by factors such as the layout of the trust's premises, the location of any existing information centres and the relative enthusiasm for Information Prescriptions in different specialties and teams, not to mention the needs of different groups of patients.

This is a challenging approach, requiring considerable resources, staff with special skills and specialist knowledge of conditions and treatments, and good access to medical teams. For these reasons it may only be practical in certain specialties and large hospitals. The previous approach (model 2) may be more appropriate for many hospital settings.
National and non-statutory resources for the roll-out

The possibility of national resources to support Information Prescriptions has been widely welcomed by the pilots and many expressed an interest in having access to an online national repository of accredited materials that was also suitable for use by users and carers.

Many non-statutory agencies contributed to the pilots and several played major roles in running or supporting individual projects. Much of the contribution of these agencies was made as part of their existing activity and not funded from the pilot budgets. One of the outstanding questions for the rollout of Information Prescriptions – and one that cannot be answered from the pilots – is whether non-statutory national or local agencies should be funded to support the roll-out of Information Prescriptions. Data from the pilots was insufficient to accurately predict the workload that Information Prescriptions could create for these agencies and how that demand might change over time.

Predicting future resource needs from the experiences of the pilots

There are several reasons why the monthly returns from the pilots might not be an accurate guide to the resources required for roll-out. Some of these have been mentioned earlier and include:

- The pilots generally had quite a small scale and narrow focus and hence do not indicate the additional costs or economies of scale of managing the introduction of Information Prescriptions across a variety of specialties, conditions or settings.
- Pilots were relatively heavily resourced
- The pilots may have been unrepresentative in being unusually advanced in their commitment to, and experience of, providing service users and carers with information
- Nevertheless, in many cases they were developing Information Prescriptions from scratch and had to do early piloting and development that may not be required in the national roll-out
- Pilots had to carry out additional tasks to support the evaluation
- They were too short to reach a stable delivery phase, so reported activity will tend to be dominated by the development activities
- They were also too short to detect the rate at which the demand for information might decline over time as people receive and act on the information they need

For these reasons, and because the details of implementation will differ from one place to another even when the same approach is used, this discussion has not tried to precisely predict the scale of resources that would be required, nor to compute any costs. There is the further complication that, even in the units running the pilots, there is little detailed data on the scale of information that was routinely provided before these projects, nor on the time that care professionals spent on these activities. It is therefore difficult to generalise how much new effort will be required to develop and deliver Information Prescriptions and how much will be a restructuring or rationalisation of existing activity.

That said, this section ends with a brief guide to the main factors to consider when estimating the resources required for local implementation. In practice, there will not be data on many of these for some care settings and local knowledge will be needed to make more or less
realistic assumptions on factors such as levels of special need, likely take-up rates, and how far the delivery of Information Prescriptions will represent new effort or a restructuring of existing activity.

**A brief guide to estimating resource needs for a local implementation of Information Prescriptions**

The first task is to estimate the volume and nature of demand.

- From prevalence or attendance data compute the number of times people with long-term conditions will contact the service.

- Estimate the nature of the demand, by considering the types of LTC being presented, their stage and what proportion of users and carers will require additional support in retrieving or interpreting information. For example, some people may require quite intensive interpersonal support to make sense of relevant information, while others may be able and happy to retrieve materials themselves from the Internet.

**Figure 11**

The nature and accessibility of local health and social care, as well as other services such as branches of local and national charities, will limit the ways in which information can be delivered. Combining estimates of need with known patterns of service delivery can produce rough estimates of the balance of services and approaches to information delivery that will
be required locally. This may be some combination of the three models described in this section.

Resource implications and costs of local implementation can be approximated by combining predicted patterns of delivery with estimates of the unit costs of the various methods of providing information.

**Figure 12**

<table>
<thead>
<tr>
<th>Costing the range of services required to meet local needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nature and volume of need</td>
</tr>
<tr>
<td>What balance of information delivery is required</td>
</tr>
<tr>
<td>Pattern of methods of IP delivery to meet local need</td>
</tr>
<tr>
<td>Volume of activity required by each method</td>
</tr>
<tr>
<td>Estimated gross costs of introducing IP as a new service</td>
</tr>
<tr>
<td>Estimated net costs of introducing IP</td>
</tr>
<tr>
<td>Estimated net long-term recurring costs of IP</td>
</tr>
<tr>
<td>Nature of existing health and social care services – and other services that can potentially contribute to IP</td>
</tr>
<tr>
<td>Estimated take-up rates for each type of delivery</td>
</tr>
<tr>
<td>Unit start-up costs of different methods for delivering IPs</td>
</tr>
<tr>
<td>Unit running costs for these methods</td>
</tr>
<tr>
<td>Savings due to making use of existing information delivering mechanisms</td>
</tr>
<tr>
<td>Long-term savings predicted by modelled or otherwise estimated impact of IPs on future need for information and care</td>
</tr>
</tbody>
</table>

Finally, it is a question of deciding what components of information prescribing are new inputs and what can be delivered by activities that are already funded.

**Working in partnership to deliver Information Prescriptions**

In the vast majority of pilots, partnerships between different agencies were essential to the success of the endeavour. The majority of pilots established steering groups or partnership boards made up of the full range of stakeholders involved locally, including NHS partners, local government, the voluntary sector and local users and carers. These were regarded as critical to ensuring that Information Prescription systems were developed across the local health and social care system, involved a wide range of professionals, and were made accessible to users in different service settings.

Most pilots regarded Information Prescriptions as a whole systems approach, requiring joint decision-making between health and social care providers, multi-disciplinary partnership working with significant input from the voluntary and community sector.
The pilots were given funding to support them during the year-long piloting process. This meant that the issue of how Information Prescriptions could be supported through commissioning was not immediately addressed during the pilots. However, in interviews with pilot professionals, the majority regarded it as critical that Information Prescriptions are supported through future commissioning strategies. The argument made by many is that future Information Prescription systems, which will need to be developed across health and social care systems, will require support from joint commissioning arrangements between health and local government.

'We had a very active steering group, made up of all the key stakeholders from the local authority, NHS and elsewhere. This provided the framework in which we could establish an integrated Information Prescription service, whereby users can benefit from the combined expertise of all agencies.'

In future, it will be essential to establish detailed needs analysis for local areas which can be included into wider needs analysis to inform commissioning. In addition, partnerships responsible for the implementation of Information Prescriptions will need to build the case, and clear service options relating to the local development of Information Prescriptions, to inform the decisions of local commissioning boards.

The following components were regarded as essential to the successful delivery of Information Prescriptions in a local area:

**Clear local leadership**

In pilots where there was clear leadership from the top, pilots found it easier to involve a wide range of stakeholders and acquire the crucial local buy in. One informant told us ‘having the director of nursing involve was helpful; where barriers arose, her help could unblock these.’

Some sites did not have high-level senior support. For these sites, this led to some problems being encountered in building up sufficient internal support, particularly from other managers and senior clinicians.

If Information Prescriptions are to be adopted more widely through a scaling up and roll out of Information Prescriptions then senior commitment will be critical from senior managers. In national events with pilot participants, it was suggested that there needed to be at least two committed champions at the senior level for a whole systems approach to be successful, a Director on the PCT Board and a Director at the local authority.
Darlington PCT

In Darlington PCT, the Chief Executive was closely involved in developing the pilot bid, helping set up the project Steering Group, and in identifying local champions. When problems arose, such as in getting other agencies to sign up, the Chief Executive was able to broker a deal or raise the issue at partnership meetings. The Director of Nursing was also closely involved, taking a key role in getting the nursing staff involved and giving support where necessary in winning over GP support.

Integrated whole systems governance

Where pilots could establish steering groups and delivery partnerships incorporating a range of partners, they found it easier to manage implementation over time. While in most cases pilots did not formally link up to existing partnerships, and instead established new partnership arrangements, many of the professionals we interviewed in the pilots felt that in the long term those implementing local Information Prescription systems would benefit if they linked up to existing cross sector partnerships, such as Local Strategic partnerships, which have a huge amount of influence over the local development of health and social care services.

Coordinated management

Pilots argue that it is important to have a single point of management and coordination to ensure that partnerships deliver across the local system.

In many of the pilot sites, project managers with the sole responsibility for implementing local systems were identified as useful in coordinating local delivery. For those fulfilling this role, project management skills were seen as important, as was access to some administrative support. Those with an in-depth understanding of health and social care partnership working were particularly helpful to local implementation.

Involving the voluntary sector

The voluntary sector was closely involved in the development and delivery of Information Prescription systems, in many cases having a central role in local pilots as information provider, prescriber and dispenser.

In qualitative interviews with voluntary sector representatives, there were generally high levels of support for the notion of Information Prescriptions and where these interviewees had been involved in the partnership, there was reported satisfaction with the process. In summary, Information Prescriptions helped voluntary sector bodies by:

- Giving them a bigger role in providing information to users and carers, especially to those facing disadvantages;
- Enhancing the professional skills of voluntary sector staff, by enabling them to become more closely involved in the detail of providing information and additional support to users who face disadvantages; and
- Building more closely aligned and productive partnerships between the statutory and voluntary sector.
The value of involving the voluntary sector, however, was clearly understood by respondents from organisations of this type and from statutory services. In particular, voluntary sector representatives can bring to Information Prescriptions:

- A strong understanding of user needs and a well-established history of delivering services in a way that places service users at the centre of the process;
- Significant condition-specific knowledge and experience, both related to medical and non-medical issues. In some cases, those who deliver or support the delivery of voluntary sector work have had first- or second-hand experience of the particular condition in question, and therefore have invaluable insight into the service user perspective;
- Extensive experience of useful approaches in accessing hard-to-reach groups;
- Innovative thinking, for example, in respect of managing limited resources, or taking a capacity-building approach to involving users in order to co-deliver support.

Site feedback identifies that involvement of the voluntary sector has been central to the delivery of many Information Prescription projects. In particular, it has been significant in the following areas:

- Producing and providing tailored information for Information Prescription directories. Many pilot sites relied heavily or entirely on partnerships with the voluntary sector to produce quality assured information on a range of conditions;
- Informing the design of Information Prescription templates, directories and other materials to ensure that these can be of benefit to a range of users, including those with complex needs, black and minority ethnic users and those with mental health and learning disabilities;
- Providing Information Prescription dispensing services through national websites and helplines;
- Providing volunteers to help dispense information in information centres, community centres and/or through outreach.

Hammersmith and Fulham PCT

In Hammersmith and Fulham, three national voluntary sector organisations came together with the PCT to form a single partnership to develop Information Prescriptions for those with diabetes, arthritis and asthma. The partners made the following contribution to the pilot:

- Helped to provide high-quality, accredited information
- Provided access to user groups and carers to inform design of information materials
- Provided high-quality helplines and websites to use for dispensing information
- Identified local contacts and supporters to be engaged.
- Provided advice on local implementation.
- Took a significant role in the project steering group.

It is of critical importance that the voluntary and community sector is involved in the future development of Information Prescriptions nationally. More specifically, the voluntary sector needs to help the DH and other national organisations:
• Ensure that the service user view, and outcomes for service users, are explicitly recognised in national roll-out and continue to be central to ongoing implementation;

• Inform and assist in the design of local approaches to delivery and provide a ‘voice’ to local community groups;

• Inform the commissioning decisions and priority-setting to ensure that Information Prescriptions – and specifically, the role of different stakeholders in the delivery of Information Prescriptions – can contribute to key local and national agendas; and

• Work to ensure that Information Prescriptions make provision for the most hard-to-reach groups.

Interview feedback suggested that it was important to engage the voluntary sector in a way that was meaningful, not tokenistic. A number of sites made clear their commitment in this respect by involving the sector actively in steering group meetings, stakeholder engagement events, designing templates, and issuing itself.

**Isle of Wight: Making clear the centrality of the voluntary and community sector in the Information Prescription delivery plan**

Of the four Isle of Wight key objectives, two were hinged on engaging and working closely with voluntary sector organisations.

– ‘Develop information in a variety of formats and consider innovative methods of dissemination to ensure availability through a number of outlets, including Isle of Wight Council Information Centres, libraries, Age Concern Isle of Wight (including the mobile information vehicle to reach out to more isolated communities), rural post offices etc.’

– ‘Provide a ‘Search, press and print’ facility to all cross-sector professional and voluntary agencies ensuring that the information prescription is tailored to the individual, freely available to the older person and delivered in a timely, user-friendly manner.’

– The project management arrangements within this plan also make clear the commitment to ongoing liaison with the voluntary sector.

– ‘The local Dementia Carers Group and other appropriate support groups will also be consulted with regard to content of the information prescription, self-help booklet and best methods of delivery, receiving monthly progress reports.’
Suffolk: Clarifying the role of the VCS

In Suffolk’s delivery plan, key VCS organisations to be involved on an ongoing basis were named and given the task of ‘critical friend’. Suffolk’s Information Prescription was aimed at promoting the independence of older people and the key ‘critical friends’ were identified as Suffolk Family Carers, Age Concern, Alzheimer’s Society and Diabetes UK. While these were not the sole VCS organisations involved, it was thought to be important to identify – and build in a clear role at the outset for – the lead agencies representing the interests of the user group in question.

Information Prescriptions in social care

The social care sector has been closely involved in many of the sites. In some sites the local social care services have taken a lead role in developing and implementing Information Prescriptions locally. The evidence from this evaluation points strongly to the need for both adult and children’s social care services to be at the forefront of local partnerships. Sites have demonstrated clear benefits from involving social care.

Manchester: Joint social care and health project leadership

Information prescriptions were delivered jointly by the City Council and the PCT. This gave a clear message from the outset about the importance of cross-sector joint working and the key leadership roles played by both health and social care in the successful delivery of such a project. This was supported by the ‘whole-system’ approach to Information Prescriptions taken by Manchester, which, in combination with the joint leadership, enabled them to maximise the networking opportunities across the City. This resulted in the involvement of library services, advice and support organisations, voluntary agencies and in links being made with existing schemes such as ‘Expert Patients’.

Isle of Wight: Linking Information Prescriptions to existing social care access points

User feedback provided to Information Prescription leads at the Isle of Wight suggested that working with Social Services to make the Information Prescription information available via the Council’s website helped people to have confidence in it, given that they are already familiar with the Council’s services. They also reported that locating it on this website also helps users to identify clear lines of accountability for the information, giving it credibility as well as raising its profile.
Social care professionals were involved in several dimensions of prescribing and dispensing, as shown in Table 20.

**Table 20: Social care involvement**

<table>
<thead>
<tr>
<th>Prescribing</th>
<th>Dispensing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social care professionals prescribe through home visits</td>
<td>Social care information is made available through directories.</td>
</tr>
<tr>
<td>Social care professionals prescribe during single assessment process meetings with users and carers</td>
<td>Social care professionals dispense in day care centres, youth centres and residential care homes</td>
</tr>
<tr>
<td>Social care professionals prescribe when developing integrated care packages</td>
<td>Social care dispensing through information centres located in social care facilities, such as day care centres</td>
</tr>
<tr>
<td>Social care professionals prescribe during drop-in services</td>
<td></td>
</tr>
</tbody>
</table>

There were a number of challenges encountered by pilots in engaging social care professionals:

**Lack of inter agency working between health and social care** – of the teams of professionals that pilots wished to engage with Information Prescriptions, not all were integrated across the two sectors. This made communication difficult and the development of joint processes a challenge.

**The NHS and medical focus of some Information Prescription processes on 'medical conditions'** made the notion of an information prescription seem remote and less relevant to some social work staff.

**Lack of senior leadership in social care** – Information Prescriptions are not currently viewed as a priority for some social care managers and awareness of the initiative was low across many professional groups. There will be a need to ensure that Information Prescriptions are seen as more of a priority in the sector.

**Fragmented information provision in social care** – some information provision was found to be very patchy across social care, with many social care professionals informing us that they did not have good existing directories and had to store information ‘in their heads’. There are many mechanisms to be more fully developed across adult and children’s social care which offer a good opportunity for Information Prescription issuing to be embedded in the practice of delivering social care. These include the creation of single assessment processes for all adults with long term conditions, the creation of comprehensive assessment processes for all vulnerable children and young people, and the development of integrated care packages for those receiving social care.

The CAF process, for example, uses a standard form which will be available online or in paper format for social services and other professionals to complete. This provides a comprehensive picture of the child’s needs, including information requirements. Information
Prescriptions could be developed so they are provided through this process and added to the assessment that is then recorded in the child’s case file.

**Developing a robust proposals for implementation**

Most of the pilots were informed by a clear proposal for implementation that was developed by project steering groups in consultation with wider stakeholders. While some pilots strayed from core dimensions of their plans, they regarded robust planning as crucial to the success of the pilots.

**Partnership responsible for implementing Information Prescriptions locally needs to develop clearer proposals for local implementation.** While any emerging proposals should not be too long and onerous, nor duplicate other existing plans or strategies, the proposals will need to clearly:

- Set out the local aims objectives and priorities for Information Prescriptions in the local area;
- Outline how the local strategy links to national developments, such as NHS Choices, World Class Commissioning and the development of integrated care pathways;
- Link to the Sustainable Communities plan, the organisation’s business and financial plans and workforce strategies;
- Identify clear commissioning priorities and funding streams; and
- Identify clear timescales, outcomes and indicators

**Building user and carer involvement**

Pilots were keen to identify processes through which to ensure that user involvement occurs on an ongoing basis through a range of engagement mechanisms.

It was argued that users need to be involved on an ongoing and regular basis, to assist professionals leading Information Prescription implementation to:

- Identify and share users’ needs and gaps in services in order to inform commissioning decisions;
- Shape the priorities for local implementation and long term performance indicators;
- Help design information templates, materials and marketing tools; and
- Evaluate and scrutinise the impact of Information Prescription systems and inform future service redesign.

Pilots emphasised the importance of using a range of existing processes to gain the involvement of users in Information Prescriptions, including citizen panels, PALS, local user surveys and neighbourhood forums. All of these should be utilised to help boost awareness of and involvement in Information Prescription systems locally.

They also emphasised that in the future, LINks will provide an important forum through which to engage users.
Several professionals identified the need to involve NHS Health Trainers, who are being recruited in many PCTs. NHS Health Trainers will provide advice, motivation and practical support to individuals in their local communities to help them improve their health. Health Trainers are regarded as having the potential to signpost users to Information Prescriptions and dispense information.

**Delivering effective whole systems community engagement for Information Prescriptions**

- **Involve**: Identify and involve the people and organisations that have an interest in the issues which are being explored. This could include the patient advice and liaison services, local authorities’ active communities units, local authority corporate services engagement staff, and neighbourhood renewal teams.

- **Support**: Identify and overcome any barriers to people’s involvement (transport problems, timing etc). Look in depth at the needs of groups that are likely to find accessing patient information most challenging, such as those with learning disabilities, older people and those leading chaotic lives.

- **Plan**: Gather evidence of necessary and available resources and use these to plan purpose, scope and timescale of engagement and actions

- **Methods**: Agree to, and use, methods of engagement that are appropriate and fit for purpose

- **Work together and with others**: Agree to, and use, clear procedures to enable participants to work effectively together and with others who have an interest in the engagement process

- **Share information**: Ensure that necessary information is communicated between participants

- **Improve**: Actively develop skills, knowledge and confidence of all participants. Ensure that future training programmes to support Information Prescription systems include training on stakeholder engagement

- **Feedback**: Give feedback on results to all those involved and affected

- **Monitor and evaluate**: Work together to monitor and evaluate whether engagement has achieved its purpose

- **Recognise**: people are different and processes and services should take meaningful account of those differences

**Commissioning**

In the future, commissioning will be one of the main mechanisms used at the local level to fund and plan local Information Prescription systems. Developing strong links between local planning for user information and local commissioning will be essential. While pilots themselves did not explore in great depth how commissioning can support Information Prescriptions, suggestions were made about how commissioning can have an impact in the future. Those responsible for implementing Information Prescriptions locally need to:

- Use Joint Strategic Needs Assessments processes to capture information about user and carer information needs;
• Align the implementation of World Class Commissioning (WCC) processes and competencies locally to the commissioning of local Information Prescription systems;

• Ensure that local Information Prescription partnership arrangements actively influence commissioning decisions by ensuring that they are involved in each stage of the commissioning cycle: supplying information on user needs, identifying resources and setting priorities, planning patterns of services, commissioning, and monitoring and review; and

• Develop a better knowledge and awareness amongst local commissioners in Information Prescriptions and how they can help local services achieve wider service improvement objectives.

### What are Joint Strategic Needs Assessments?

JOINT STRATEGIC NEEDS ASSESSMENT describes a process that identifies current and future health and well-being needs and, taking into account evidence of effectiveness, informs future service planning. Joint Strategic Needs Assessment identifies ‘the big picture’ in terms of the health and well-being needs and inequalities of a local population.\(^{12}\)

### How to embed Information Prescription systems into joint commissioning

The following steps can help implementers embed Information Prescription systems into joint commissioning:

1. Look at current patterns and recent trends in information provision and outcomes in their area and compare with national and relevant local comparators. What survey evidence or inspection data (such as the HCC patient survey) is there about the quality of information, gaps in information, and needs for information. How does the area compare to other localities on information provision? What are the existing examples of good practice, such as information giving in well-developed local cancer networks?

2. Look within the overall picture at outcomes for particular groups of local people, stratifying the population by the major determinants of health inequality, such as age, gender and socio-economic backgrounds.

3. Use all this data and draw on the views of local users and carers, clinicians and frontline staff to develop an overall, integrated strategic needs assessment for Information Prescriptions.

4. Agree on the nature and scale of the local challenge, identify the resources available and set priorities for action. Ask questions such as: what model of Information Prescription delivery will reach the largest numbers of local people? What models will reach those most disadvantaged?

5. Plan the pattern of service most likely to secure priority outcomes, considering carefully the ways in which resources can be increasingly focussed on self-management and less intensive interventions where they are not necessary.

---

6. Decide together how best to purchase or provide/commission those services, including drawing in alternative providers to widen options and increase efficiency. Include the voluntary and community sectors, LINks and the private sector in these discussions.

7. Develop and extend joint commissioning from pooled budgets and pooled resources.

8. Plan for the workforce development and other changes in local processes and ways of working necessary to support delivery.

9. Monitor and review to ensure services are working to deliver the ambitions set out for them.

**Using local information**

Pilots used a wide range of information sources to help inform the design of their Information Prescription systems. The following information sources were utilised to help map out user needs and identify appropriate strategies for meeting these:

- **The Health Survey for England (HSfE)** provides an overall view of risk factors and disease prevalence. Whilst this does not provide estimates at PCT or local authority levels, local synthetic estimates of some risk factors, based on the HSfE, are available from the NHS Information Centre.

- Local lifestyle surveys and primary care data can be used to support local estimates.

- **The Health Poverty Index** gives a high-level overview of each local authority area showing its ‘health poverty’; a combination of the present state of health, the root causes and intervening factors. It includes some data enabling comparison across ethnic groups. The Local Basket of Indicators for health inequalities, accessed via the London Health.

- **Observatory (LHO) website** provides a menu of indicators to examine health inequalities across a range of dimensions.
Figure 13 depicts the arrangements that may need to be put in place to promote a locality-wide whole systems approach to Information Prescriptions.

**Figure 13: Arrangements needed for whole systems approach**

- **Local strategic partnership**
  - Ultimately responsible for IPs through Sustainable Communities Plan
- **Healthy communities thematic partnership**
  - Responsible for co-ordination and strategic planning on IPs
- **Joint commissioning partnership**
  - Commissions IP services jointly
  - Responsible for day to day co-ordination and management of IP system across locality
- **Single co-ordinator**
  - Provides integrated information on user population and needs
- **Overview and scrutiny**
  - Reviews IP performance periodically
  - Scrutinises performance of IP system
  - Feeds into commissioning decisions
- **LINks**
  - Scrutinises performance of IP system
  - Feeds into commissioning decisions
- **IP Providers**
  - Prescribe and dispense IPs to users and carers

### Involving the workforce

**Identifying the different roles of the workforce**

There will not be one pattern of roles that will apply to all members of the workforce. The role of each member of the workforce will need to be determined by a range of factors, such as what model or models of delivery a locality decides to implement, what existing roles staff have in relation to information giving, the focus of local workforce planning strategies, the shape and size of the local workforce, and the scope of local training and development programmes.

While there is not one single model, the piloting suggests that the professional groups identified below could take up the following roles successfully. The policy and workforce levers, which can be used to assist with the process of engaging these strands of the workforce in prescribing, will also vary. In Table 21 we have described the roles of different professional groups in prescribing and dispensing, and suggested policy and workforce levers which may help in gaining the groups involvement.
### Table 21: potential roles and levers for professional involvement

<table>
<thead>
<tr>
<th>Profession</th>
<th>Roles</th>
<th>Levers</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPs</td>
<td>• Signposting</td>
<td>• Local QOF points</td>
</tr>
<tr>
<td></td>
<td>• Prescribing</td>
<td>• GPs with special interests could promote Information Prescriptions locally</td>
</tr>
<tr>
<td>Primary care nurses (including community nurses and health visitors)</td>
<td>• Prescribing, but only with integrated technology</td>
<td>• Clinical benefits of Information Prescriptions clearly explained</td>
</tr>
<tr>
<td></td>
<td>• Dispensing at large GP practices</td>
<td>• Nursing networks could be used to promote Information Prescriptions to nursing groups</td>
</tr>
<tr>
<td></td>
<td>• Dispensing through health visiting</td>
<td></td>
</tr>
<tr>
<td>Hospital Consultants</td>
<td>• Prescribing</td>
<td>• National professional bodies and local networks used to promote Information Prescriptions and speed practice</td>
</tr>
<tr>
<td></td>
<td>• Signposting</td>
<td>• Clinical benefits of Information Prescriptions clearly explained</td>
</tr>
<tr>
<td></td>
<td>• Updating and quality assuring information</td>
<td>• Ensure Information Prescriptions integrate with requirements of professional audit and procedures to avoid medical negligence claims around information giving</td>
</tr>
<tr>
<td>Specialist nurse</td>
<td>• Single stage prescribing</td>
<td>• Nursing networks could be used to promote Information Prescriptions to nursing groups</td>
</tr>
<tr>
<td></td>
<td>• Multi-stage prescribing</td>
<td>• Additional training around information giving</td>
</tr>
<tr>
<td></td>
<td>• Information centre dispensing</td>
<td></td>
</tr>
<tr>
<td>Non-specialist hospital nurses</td>
<td>• Prescribing</td>
<td></td>
</tr>
<tr>
<td>Social workers/carers – mostly LA-based</td>
<td>• Single stage prescribing</td>
<td>• Build Information Prescriptions into single assessment processes</td>
</tr>
<tr>
<td></td>
<td>• Multi-stage prescribing</td>
<td>• Formalise information</td>
</tr>
<tr>
<td></td>
<td>• Dispensing</td>
<td></td>
</tr>
</tbody>
</table>
Information prescriptions pilot programme – final report

NHS Librarians
- Support for prescribing
- Support for dispensing
- Need to be drawn into formal arrangements
- Involvement of librarian networks

Local authority librarians
- Support for dispensing
- Involvement of librarian networks

Officers in local authority information services
- Building and maintaining databases of local services to support prescribing and dispensing
- Providing local information services
- E-government initiatives and guidelines
- Local area agreements

Pharmacists
- Signposting
- Dispensing, where they have private space for dispensing services
- Local pharmacy contracts

Embedding Information Prescriptions into workforce practice

Information Prescription processes will only take hold in professional groups if embedded into day-to-day management and practice. Pilot sites which successfully found ways in which to use existing workforce management, supervision and performance management processes to re-enforce the adoption of Information Prescription systems seemed to be more successful.

The following avenues to embedding Information Prescriptions across the workforce should be explored:

Communication with professionals – pilots that were able to develop sophisticated plans for communicating staff found it easier to build ownership and increase involvement in prescribing and dispensing. In doing this, the following activities need to be explored:

- Use existing communication mechanisms, such as staff newsletters, email alerts, intranets and staff meetings, to promote Information Prescriptions.
- Dovetail communications about Information Prescriptions into existing communication exercises, such as community events, staff away days, training sessions, and management and partnership meetings.
- Develop a clear local image and slogan for Information Prescriptions that can be conveyed through posters, information sheets and leaflets.
- Use staff and residents’ surveys both to promote and receive feedback on information prescriptions.
Oxleas NHS Foundation Trust: Intranet to support Information Prescriptions

Oxleas NHS Foundation Trust has developed its intranet, used by staff across the site, to serve as the front page of its Information Prescription process. Professionals can access and print off all of the main information sources contained in their directory. The site is widely used and popular; building the Information Prescription process into the site is therefore a good way to reach a wide audience quickly and to standardise Information Prescriptions into daily practice.

- **Staff induction** – Build information prescribing into staff induction and training packages. Short and focused training sessions for new recruits or staff entering new roles were also helpful in sharing learning and increasing awareness about Information Prescriptions.

- **Staff supervision** – In a small number of pilot sites, managers have started to raise questions about Information Prescription prescribing and dispensing in appraisals with staff. Where this took place, it was seen as a good way to embed the focus on Information Prescriptions into daily practice and ensure that staff were accountable for their roles in Information Prescription systems.

- **Ensure that staff are informed at all stages of the implementation of Information Prescriptions** – regular and meaningful engagement with all staff involved in Information Prescriptions throughout the roll-out of new approaches is critical. Update staff at training sessions, staff networks and other meetings. Where possible, ask them to help develop solutions and approaches and solve problems. Set up a system of feedback and be welcome to receiving feedback.

- **Identify and involve champions from different service sectors** – Identify and train champions to lead the implementation of Information Prescription systems in different service settings.

- **Linking Information Prescriptions to existing processes and protocols** – There are a range of protocols and processes that govern the way in which members of staff interact with each other or service users. Some of these provide an excellent framework on which to build Information Prescription processes, although the inclusion of Information Prescription processes will need to be negotiated with senior managers and staff representatives, such as trade unions. As discussed in the section on social care, there is scope to include Information Prescription templates and questions in Single Assessment Processes for adults and older people and into the Comprehensive Assessment Framework (CAF) used to record assessments of children and young users’ needs in integrated children’s services. Other processes, such as formal information sharing procedures, staff appraisal forms, and practice guides could also be developed to include information on information prescriptions.
Darlington PCT

Darlington PCT has succeeded in embedding Information Prescriptions into the practice of GP practice nurses by making the Information Prescription process a standard part of Annual Health Checks. Now when all patients go through the check, they are given an Information Prescription and asked about their information needs.

Education and training

The roles associated with Information Prescription systems management and prescribing and dispensing, involve a range of skills and competencies, such as information management, advocacy and counselling, capacity building and stakeholder engagement. The levels of skill deployed at any one time will also vary greatly in terms of the depth and scope of involvement by a professional. Pilot sites were in favour of developing a clearer set of ‘core competencies’ for Information Prescription systems. Such a development would have the benefit of providing a clear set of dimensions against which people could define job descriptions, make recruitment decisions and provide training. It would also help to ensure high standards and consistency of approach, and would acknowledge the work of those involved in Information Prescriptions.

Training programmes need to be tailored to support different levels of involvement in the process. A range of training approaches was provided, including IT training, training on information giving skills, and more informal training sessions. Training should support the development of a number of core competencies:

- **Information Prescription coordination and management** – including skills in stakeholder engagement, needs assessment, influencing skills, capacity building, communication, health information management, designing and developing databases and information quality assurance.

- **Basic introduction to Information Prescription systems** – staff should be offered training in using and completing Information Prescription templates, understanding Information Prescription directories, and recording prescribing.

- **Advanced information giving and support** – including skills in communication, needs analysis, counselling, advocacy and information management with an understanding of equality and diversity.
Table 22 gives suggestions from pilot participants on what the competencies could include:

Table 22: what competencies could include

<table>
<thead>
<tr>
<th>Competency level</th>
<th>Core competency</th>
<th>Training provision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information Prescription system management and coordination</td>
<td>Needs assessment (using and interpreting patient, performance and demographic data)</td>
<td>Presentation and communication training</td>
</tr>
<tr>
<td></td>
<td>Stakeholder engagement (qualitative and quantitative engagement skills)</td>
<td>Stakeholder engagement processes and techniques</td>
</tr>
<tr>
<td></td>
<td>Appraising information and knowledge</td>
<td>Facilitation skills</td>
</tr>
<tr>
<td></td>
<td>Presentation skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Negotiation skills (to influence decision-making)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Facilitation skills (to build relationships and partnerships)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Up-to-date knowledge of new information sources</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Information quality assurance skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Database design and management</td>
<td></td>
</tr>
<tr>
<td>Advanced information giving, advocacy and support</td>
<td>Information sharing and record keeping</td>
<td>Equality and diversity training</td>
</tr>
<tr>
<td></td>
<td>Listening and communication</td>
<td>Advanced communication training</td>
</tr>
<tr>
<td></td>
<td>Advocacy skills</td>
<td>Basic counselling skills</td>
</tr>
<tr>
<td></td>
<td>Understanding equalities and diversity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Basic counselling skills</td>
<td></td>
</tr>
<tr>
<td>Basic information giving</td>
<td>Using database search engines</td>
<td>Basic IT training on using websites and online directories</td>
</tr>
<tr>
<td></td>
<td>Completing Information Prescription templates</td>
<td>Basic training on prescribing and dispensing skills,</td>
</tr>
<tr>
<td></td>
<td>Dispensing information</td>
<td></td>
</tr>
</tbody>
</table>
There was recognition among pilot informants that developing and building a competency framework for Information Prescriptions would not entail ‘re-inventing the wheel.’ Existing National Occupations Standards and National Workforce Competencies already cover many of the competencies listed above. An example of this is the Health Informatics suite of competencies developed by Skills For Health. This covers competencies such as ‘collecting and validating information’ and ‘appraising information and knowledge resources.’ The framework on project management also covers many of these areas.

Conclusions on the delivery stage

Success factors which support the delivery of Information Prescriptions

Success factors which support personalisation

- Establish local user and professional ‘readers group’, ensuring that they are representative of the local population
- Ensure that all templates and information sources are easy to read and understandable for people of all reading abilities
- Develop a range of draft formats of templates and information sources based on existing knowledge of formats used in local information
- Run focus groups with readers’ groups to review templates and information
- Map out integrated care pathways, which should be available locally for a range of conditions
- Make sure that the care pathways include all of the main points at which users intersect with care providers, even prior to diagnosis and after successful treatment.

Success factors in resourcing the implementation of Information Prescriptions

- Detailed planning is required by care professionals in designing and costing an appropriate model of delivery. Deciding in the case of implementing model 3 to create a single integrated information centre or a range of centres linked to specialist departments, for example, requires considerable consultation and planning.
- Ensure that someone is given the role of coordinating the development of a local delivery model, including consulting colleagues and analysing demand data to develop outline costs for implementation.
- Establishing a system of on-going monitoring is essential. If Information Prescriptions are to be supported through commissioning regimes, it is vital that data relating to Information Prescription systems is recorded. This should include reliable information about the costs associated with the model, output and outcome data. Such data can then be presented to commissioners to build the case for ongoing funding.
Success factors which support working in partnership

- Identify local professionals to coordinate delivery of Information Prescriptions across the local health and social care system
- Develop a local partnership arrangement to support local implementation, involving all the main partner agencies and user representatives
- **Link Information Prescription planning to local joint commissioning arrangements**, ensuring that user needs and priorities are fed into local needs assessments
- Map out the local policy interventions and strategies, linked where possible to local Information Prescription plans
- Engage professionals in all services, and at all levels, in developing and implementing local Information Prescription systems
- **Pool all available relevant data and evidence** on the local population and their needs in relation to information
- **Involve disadvantaged groups** in identifying their individual support needs
- **Identify a health and social care partnership** operating across the local authority to coordinate Information Prescription delivery across the locality
- **Ensure that LINks are regularly updated** on the development of a local Information Prescription system and are involved in developing the local strategy
- **Develop a clear communication strategy** which sets out how professionals and the public will be engaged
- Build Information Prescription systems into existing local assessment protocols and processes, such as the Single Assessment Process

Success factors which support engaging the workforce

- **Identify a network of local ‘champions’** to promote and implement Information Prescriptions across different professional groups and services.
- Identify opportunities to align and adapt existing and planned training to support Information Prescription skills
- **Build Information Prescription processes into existing protocols and processes**, such as the Single Assessment Process, Common Assessment Framework, care planning protocols and annual health checks
- **Map out all of the main workforce groups** who need to be involved locally and identify the main levers which can help gain their involvement
- Explore how **local workforce strategies** can link up to and reinforce local Information Prescription implementation
- **Use a range of existing communication strategies**, such as staff bulletins, staff away days, INSET days and email updates to promote and promulgate Information Prescriptions
Challenges and barriers in the delivery stage

Identifying and gathering local information about services proved difficult for some pilots. Most of the pilots sought to ensure that Information Prescriptions could provide links or contact information for local health and social care services, but this was not always straightforward. One problem was that local information was sometimes out of date or not stored in accessible place. Pilots found that they could gather better information about local services when they were able to access and use existing directories, such as local authority service directories.

Challenges and barriers to personalisation

• Pilots did not always have enough high-quality data to make judgements about the needs of the local population. Personalising Information Prescriptions is predicated on having a good understanding of the needs and preferences of local people, such as what information they want, how they want it and where they want it. Some pilots conducted user surveys to make better assessments about the local population, while others ran focus groups. Both processes should be part of the local strategy for identifying local needs. However, in future, other more quantitative data sets, which combine local intelligence about the population, will need to be drawn into local implementation strategies to help inform commissioning priorities.

• Pilots found that they had to balance providing a personalised service with the need to protect professionals’ time. Many of the more tailored approaches involve more time and commitment from professionals. Initially some pilots tried to involve professionals in complex assessments using tailored templates, but found that there was great resistance to this approach. Two strategies were deployed to ensure that a degree of tailoring was achieved, while reducing the burden on professionals: creating more simple templates that mainly comprised ‘tick boxes’, and passing the task of detailed prescribing from consultants and doctors, to those who can spend more time with users, such as mental health nurses, social workers and primary care practice nurses.

Challenges and barriers to developing models of delivery

• Pilots in primary and community settings found it difficult to provide additional support to disadvantaged users and those who require more help when receiving information. When it comes to roll-out, there will be a need to explore ways to target more disadvantaged groups through commissioning strategies so that those facing disadvantage are given additional support to meet their needs.

• In most cases, pilots were aware that their models would be insufficient on their own to reach the entire population of those with LTC locally. They were also clear that more than one model would be required to address different circumstances and reach all segments of the population.

Challenges and barriers to resourcing the implementation of Information Prescriptions

• Resources attached to some of the models could be considerable – some of the models require significant staff involvement to ensure they are set up and implemented effectively. In model 3, for instance, there is likely to be the requirement of significant
involvement from specialist clinicians both to support the prescribing function and to adequately staff the resource centres.

- **Ensuring that Information Prescriptions are supported through commissioning and other funding streams** – it will be important to link up planning for Information Prescription delivery through local commissioning regimes that are likely to be the main source of funding for Information Prescription implementation. Opportunities should be sought to link Information Prescription delivery to other existing funded programmes where there are clear overlaps in the intended outcomes.

**Challenges and barriers in working in partnership**

- **Identifying strong leaders to promote and oversee the development of the pilots was sometimes a challenge.** Pilots sought to overcome this difficulty by ensuring that there was a clear lead for the project in the main participating agencies, ensuring that they were involved in steering groups and in stakeholder workshops. In future, pilots felt that there needed to be formally designated leads at the Board level in both the local authority and PCT.

- **Involving the voluntary and community can be challenging.** Several reasons were given, including the lack of pre-existing partnerships between the statutory and voluntary sector, the concern amongst VCS that they are being asked to do more work for free, and the lack of multi-disciplinary working between the sectors. Sites engaged the voluntary and community sector by ensuring that they had a clear presence and role on steering groups, capturing their expertise in the design of Information Prescription processes, and where possible, making funding available for the services offered by the VCS.
Section Six: Outcomes

This section looks at the impact of pilots on identified outcomes for users, carers and professionals.

The impact model identified the following intended outcomes:

- Improving the health and quality of life of disadvantaged users and carers
- Increasing the capacity of users and carers to manage their own care, preventing their health from worsening
- Increasing information for carers so that they can improve their support to users and their own health and well being
- Enhancing the ability of professionals to provide high-quality, personalised and holistic information
- Increase the involvement and capacity of the voluntary sector in health and social care information giving

When thinking about outcomes, it is important to distinguish between the outcomes that can be achieved during the lifetime of the pilot project and those that might be achieved through a fully-embedded process operating over a number of years. This section looks at both the intended outcomes from Information Prescriptions, as envisaged by professionals interviewed in pilots, and evidence of actual impact as evidenced through the survey work.

Intended outcomes

When asked to articulate the outcomes they expect from the project, sites tended to speak about the long term. They emphasised in particular the beneficial outcomes of: improved patient experience for all, including hard-to-reach groups; better information provision; stronger relationships with partners; and improved clinical outcomes.

The patient experience and quality of life

- Users and carers are empowered. Information Prescription processes and culture give users and carers permission to ask for information that is specific, comprehensible and timely. Their wider information needs can then be legitimately discussed by professionals and receive an appropriate response. Questions and concerns can be addressed in a respectful and appropriate way. A greater sense of empowerment and the resulting confidence among service users and carers to question or ask for help is likely to reduce their anxiety, stress and distress.

- Information is given when needed at every point in the care pathway. Users and carers can continue to ask for and receive information at every stage and in every encounter with a professional.

- Users and carers are able to make informed choices. Users and carers can choose what information to receive, how to receive it, and what decisions to take on the basis of this evidence (for example about diet and exercise).
• **Users and carers are offered a more flexible service.** For example, users are offered the opportunity to access information outside scheduled appointments, via a website or helpline. This might reduce the number of scheduled appointments.

• **Service user interactions with services may involve less crisis management.** If service users are better able to self-manage their condition, they may be less likely to experience crises such as relapses or chronic episodes.

### Better information provision

• **Information prescribing will improve information and health literacy among users and carers.** The Information Prescription approach will help users to become better informed not only about their own condition and sources of support and information, but also about how to make sense of information and articulate their information needs.

• **Professionals will be able to access reliable information through a systematic process.** This contrasts with current practice, which sometimes involves professionals relying on their memory or familiar sources that might not meet all needs.

• **Information Prescriptions provides rigour, consistency and breadth of information provision.** The processes ensure that any user or carer meeting any professional receives high-quality, tailored information, drawn from the same accredited sources.

• **Information can be systematically updated.** Information provided can be reviewed and updated to ensure accuracy. Moreover, systems can be put in place to ensure that Information Prescription recipients can receive that updated information.

• **Information prescribing may save time.** Providing users and carers with targeted information may minimise the need for repeat visits or lengthy discussions with professionals later on. (In other instances, the process is more time-consuming. Sites have used different strategies to respond to this, as noted elsewhere.)

### Clinical outcomes

Some of the anticipated outcomes noted by sites have included:

• Reductions in repeat consultation and re-admittance

• **Reductions in prescribing** of some more acute drugs

• More patients taking the appropriate medicine(s) or treatments at the appropriate times.

• People with serious mental health conditions may have reduced instances of violence, self-harm, substance misuse, Sexually Transmitted Infections (STIs) and offending behaviour.

• **Earlier diagnosis** of other physical or mental health issues.

### Partner agencies

• The process of setting up and delivering information prescribing builds partnership across the statutory and voluntary sectors. This increases professionals’ understanding of different service areas and gives them the capacity to offer a more holistic service to users.
The Information Prescription initiative will improve the quality of information for people with long-term conditions among non-specialist services, particularly those run by GPs.

Harper to reach groups

**Individuals from harder-to-reach groups will find it easier to access services and have their needs met.** Some sites are targeting harder-to-reach groups, such as those with low levels of literacy, deprived BME communities and young people who are not in education, employment or training. The outcomes they anticipate for those people centre on access to services, beginning with accessing a service for the first time (for example attending a memory clinic or visiting a GP) and, once diagnosed, maintaining contact with services for treatment, support and care. Some of the outcomes listed earlier, such as those relating to being empowered and able to make informed choices, have particular resonance for those individuals. In some cases, more support is needed to achieve those outcomes, but the result is anticipated to be significant gains in health and well being.

Evidence of impact from the survey research

**Improving the quality of information to support improved outcomes**

The sample of users included almost 300 people who had been identified by pilots as having received an Information Prescription. However, the base was reduced after removing people who claimed not to have received information or who said that they turned down the offer: these people tended to be from more disadvantaged areas or were linked with pilots where light touch Information Prescriptions were issued. More generally, users from these two groups were less positive about information, so it is quite likely that the survey results overstate positive views of the Information Prescription process. This view appears to be reinforced by a lower response rate from disadvantaged users and the evidence that some professionals targeted information at people who they thought had most capacity to make use of it.

Almost all (95 per cent) of users in the Information Prescription surveys had made some use of the information they were given and were also quite positive about Information Prescriptions, although this finding should be viewed with some caution due to the lack of a formal control as part of the design used in this evaluation. A large majority of respondents who said that they received an Information Prescription agreed that they found the information useful (88 per cent, rising to 100 per cent among cancer patients. Forty-nine per cent agreed strongly),

It is clear that people living in disadvantaged areas found the information less useful than those living in more affluent places (76 per cent as against 91 per cent). Some of the factors associated with more positive views were receiving explanations about how to use information, receiving greater support/tailoring in the Information Prescription, getting information on available (state) benefits and on how the condition might progress across time. Almost all of those receiving Information Prescriptions from acute settings (97 per cent) agreed that the information was useful, compared with 81 per cent of people who received the Information Prescription from primary care.

The main reasons given by users for finding their information prescription useful were that it:

- Helped me understand/told me about the condition/explained my problem (42 per cent)
• Was informative/useful (18 per cent)
• Was easy to understand (13 per cent)
• Many users also said that the Information Prescription had made them more aware of the range of services that were available. One said:

‘It gives you some phone numbers that I haven’t got, you know, if I needed extra help.’
(Service user with MS)

From the professional point of view nearly two-thirds (59 per cent) agreed that the patient or service user had found the information useful. Professionals in primary care (42 per cent) and those in light touch sites (42 per cent) were the least likely to indicate that the users had found the information useful. In acute settings, 71 per cent agreed, the same percentage as in pilots with an in-depth approach to Information Prescriptions.

About half of the users and patients indicated that they would have liked further information. Among this group, 29 per cent would have liked information about available benefits and 28 per cent wanted more detailed information about how the condition progresses; as noted earlier, both of these types of information were viewed by patients and users as positive parts of the Information Prescription process. Other relatively common requests were for information about different types of medication available (21 per cent), details of side-effects (17 per cent) and support groups (14 per cent).

Providing clear and useable information

Most users surveyed agreed (93 per cent) that they understood what they had been given (though the figure was lower for mental health patients at 83 per cent). A large proportion (79 per cent) agreed that they were given about the right amount of information. Again, those with mental health conditions were less likely to agree (66 per cent), as were people who were given their Information Prescription from light touch pilots (64 per cent) and those living in more disadvantaged areas (65 per cent). Professionals held a similar view in terms of the amount of information available with just 16 per cent indicating that they now have too much to offer people.

A small minority agreed that the information was not in an easy-to-read format (9 per cent but as many as 21 per cent of people with a mental health condition). This particular finding was more positive than that recorded in the earlier survey of people given information at sites prior to the introduction of the Information Prescription process (31 per cent agreement).

One patient or service user in six (17 per cent) agreed that they had to go back and ask for more information, including a quarter of those who described themselves as not being in good health. Going back for more is not, in itself, necessarily a bad thing as it can indicate that the person is making active use of the information they were initially given.

From the professional perspective, nearly two thirds (65 per cent) of professionals agreed that they were giving information prescriptions at about the right time for people to make use of them. Those professionals who worked in primary care (52 per cent) and in light touch pilots (55 per cent) were the least likely to agree with this, while those in acute settings (73 per cent) and in sites with greater Information Prescription support (72 per cent) were more positive.
In terms of helping with workload, just under a quarter (23 per cent) agreed that they spent less time looking up information than they did before, but a third (33%) of professionals disagreed with this. However, the reasons why they disagreed cannot be established from the survey.

**Improving outcomes for carers**

While carers agreed that, when they had seen it, they found information useful (89 per cent), many of those taking part in the survey (35 per cent) were actually unaware of the Information Prescription (especially those from sites with light touch Information Prescriptions at 44 per cent). This raises issues about the extent to which pilots were systematically giving carers information, or ensuring that, where appropriate, the patient or service user shared the Information Prescription with carers. It is also important to note that on a number of issues there was a difference of around 20 per cent in responses between matched users and carers and that this divergence could limit the overall impact of the information on one or both groups. As with users, views were generally less positive among carers linked with mental health sites and pilots that offered light touch Information Prescriptions.

A large majority (86 per cent) of carers who had seen an Information Prescription thought the information was given at a good time in the management of the condition, though 12 per cent held the opposite view (including 21 per cent where the patient had a mental health condition and 22 per cent when the Information Prescription was from a site with low-level tailoring).

Three-quarters of carers (74 per cent) reported that an explanation had been given about how to use the information. Every respondent said that the explanation was very/fairly helpful and nearly two-thirds (64 per cent) rated it as very helpful. Like users, carers were more positive about the information if they were given an explanation.

Carers were asked whether there was any other information they or the person they care for would have liked to receive. Of those who answered this question, around a half would have liked more detailed information on how the condition progresses (53 per cent) and the benefits available (51 per cent). A third (32 per cent) wanted more detailed information on the medication available and about a quarter (27 per cent) details of the side effects. From their own perspective, one in seven carers said that the information had significantly improved the quality of their day-to-day lives.

**Increasing the capacity of users to manage their own care**

Three-quarters agreed that they felt more confident in asking questions about their condition (73 per cent). A cancer patient in the qualitative interviews said that ‘Anything else I want, I can get it when I go to my follow-up appointment.’ Agreement was lower among those who described themselves as having poorer general health (62 per cent) and people living in disadvantaged areas (60 per cent).

Half (52 per cent) of patients and service users who said that they had received information agreed that it had helped to improve their care. This average figure was lower for the under-65s (44 per cent), those in poorer general health (41 per cent), people who got an Information Prescription through primary care (42 per cent), those with light touch information (45 per cent) and for people living in less affluent areas (46 per cent). Higher figures were recorded for people living in more affluent areas (58 per cent) and for those who received an Information Prescription through acute settings (62 per cent).
Two-thirds (66 per cent) agreed that they now felt more in control of what was happening with their condition. There were again some marked variations across the sample with less evidence of impact for the under-65s (55 per cent), mental health patients (57 per cent), those in poorer general health (52 per cent), people who had light touch Information Prescriptions (52 per cent) and people living in relatively deprived areas (also 52 per cent).

However, a majority (59 per cent) of the sample agreed that they would rather just be told what to do by a professional rather than have to find out things for themselves; this was particularly the case for the over-75s (78 per cent) and for cancer patients (73 per cent). This suggests that Information Prescriptions on their own will not necessarily lead to users taking on more self-management of their own care.

Providing information that enables users to access preventative treatments sooner

It is important that Information Prescription systems are an inherent component of the wider preventative agenda influencing reform in the health and social care sectors. Ultimately, Information Prescriptions aim to reduce reliance on the health service and improve the capacity of people with long-term conditions to manage their own care.

- It is not possible within this evaluation to establish a link between Information Prescriptions and a decrease in the use of acute services and a higher level of self-management of care. However, in the surveys users did indicate that information (whether in an Information Prescription or from a site prior to beginning the new process) gave them greater confidence, with three-quarters of the sample agreeing that the information had made them more confident in managing their condition (76 per cent). However, levels of confidence were lower among the under-65s (68 per cent), mental health patients (67 per cent), people not in good health (66 per cent), and patients and service users who lived in more deprived areas (67 per cent), suggesting that these groups require additional support to benefit from Information Prescriptions.

- The information provided in Information Prescriptions can also increase awareness of preventative approaches. Many pilots provided comprehensive information about approaches to self-management and preventative care through Information Prescriptions. Building Information Prescriptions into preventative processes, such as annual health checks, can also highlight ways that users can prevent ill health.

Enhancing the ability of professionals to provide high quality, personalised and holistic information

The majority of professionals involved in the pilots (65 per cent) were very or fairly satisfied with how the Information Prescription process was being implemented at their site, while only seven per cent were actually dissatisfied. Satisfaction increased with volume of Information Prescriptions given out, but was notably lower amongst professionals working in primary care (notably GPs and practice nurses, perhaps because of concern over workloads, spending more time with patients and being less convinced this is always worthwhile) and at sites adopting a light touch approach.

Over half of the 155 issuing professionals (57 per cent) said that the Information Prescription process compared favourably with the ways in which information had previously been given at their site, while 5 per cent thought it was worse than the old process and 36 per cent felt it
was about the same. Respondents in acute (63 per cent) and local authority (73 per cent) settings were more positive than those working in mental health (50 per cent) or primary care settings (52 per cent).

The survey findings also indicate that many professionals feel that Information Prescriptions will improve their professional practice. Among the issuers, 42 per cent agreed that Information Prescriptions would help them do their job better while 19 per cent disagreed and 39 per cent opted for a mid-point on the scale. Furthermore, some of the professionals who took part in qualitative interviews argued that Information Prescription systems helped to provide a more structured approach that provided users with information ‘in one go’, standardised information provision, and helped professionals ‘see what available for the patient.’

‘Information Prescriptions have built on our existing processes for providing information, by making information more accessible and easier to find.’

However, concerns were raised by many professionals about how Information Prescription systems would impact on their workloads. Almost a third (36 per cent) of those not yet offering Information Prescriptions agreed that they were worried about the potential impact on their workload, a concern that was slightly higher (at 41 per cent) among those already issuing the prescriptions. There was a clear difference between the views of those issuing in primary care and professionals in other settings (50 per cent agreement compared with 36 per cent). Importantly, half of those who had issued at least 20 prescriptions agreed that they were concerned about the impact on their workload. About half of those issuing Information Prescriptions reported that they were now spending more time with their patients or service users and there were concerns, mainly in primary care, about whether the additional time was worthwhile for either the practitioner or the user. However, even with these concerns, 64 per cent of professionals always or mostly felt this extra time was worthwhile while 65 per cent of users felt the additional time being spent with them was always or mostly worthwhile.

In many of the pilots, concerns about workloads were a real challenge. However, pilots reported some success in overcoming or reducing these concerns by providing training to professionals, designing Information Prescription prescribing processes which were short and simple, developing multi-staged processes for prescribing, whereby different parts of the process are conducted by different professionals and the workload is shared.

**Improving health and quality of life for disadvantaged users and carers**

Pilots were clear that users of all backgrounds, and especially those who face disadvantages, should have access to Information Prescriptions. Evidence indicates that disadvantaged patients may benefit less from initiatives aimed at improving choice and health benefits for users, unless specific measures are introduced to help these groups interpret and make use of information about health care. 13 14 Pilots developed a range of

---


approaches to prescribing and dispensing Information Prescriptions that took account of the disadvantaged backgrounds of many users.

Nevertheless, despite these efforts, the survey of users found that, overall, fewer users living in disadvantaged areas found Information Prescriptions useful as those living in more affluent areas. Explanations for this difference may be to do with lower understanding of the information, professionals not discussing what would be useful, not always being given the right amount of information and some problems with it not being in an easy-to-use format. Also, of those professionals currently issuing Information Prescriptions, nearly a half (46 per cent) agreed that they were now able to give better information to people from marginalised and disadvantaged groups. However, 17 per cent disagreed and nearly 37 per cent neither agreed nor disagreed.

Information Prescriptions systems aimed at disadvantaged groups need to be designed in such a way that they are accessible and useful to the following groups:

- Black and minority ethnic groups, especially those who do not speak English as a first language
- Users with disabilities, e.g. physical, learning, visual, hearing
- Users experiencing serious mental health problems
- Users with low literacy levels
- Older and immobile users
- Users on low incomes

Most of the pilots carried out stakeholder engagement and consultation with local communities facing some or all of these disadvantages. This involvement of users facing disadvantages was regarded as critical in ensuring that Information Prescriptions were designed around their needs.

The following approaches have been used to reach disadvantaged users and carers:

- Providing additional support to users facing disadvantages during both the prescribing and dispensing, such as ensuring that information is explained to the user, comes in the right format and language, and can be understood. The survey of users found that three-quarters (77 per cent) of those who received information were given an explanation about how it should be used, and this was almost always seen as either very (58 per cent) or fairly (37 per cent) helpful. This finding is reflected by a recent research study by the Picker Institute\textsuperscript{15} on user and patient information which found that, ‘people valued face-to-face information giving, seeing it as the best way to ‘raise concerns and ask questions…. and get beyond the basics (such as contact information.’ Approaches that pilots used to ensure that additional support was made available included:

- Providing support at libraries or community centres to help users access websites to dispense information, e.g. providing support to help people use the computer, understand where to get more information and answer questions about the content of information.

\textsuperscript{15} The Picker Institute, \textit{Patients make it better: The International Evidence}, 2007
• Enabling the user to contact a helpline that can offer additional support and advice to the user during the dispensing process.

• Providing users with the opportunity to ask questions about their information during the prescribing or dispensing process, such as about the content of the information, which links to go to, and how to find out more.

• Providing information at locations where disadvantaged users congregate or feel comfortable: some pilot professionals spoke of the benefit of making Information Prescriptions available in ‘naturalistic settings’, such as community centres, older people’s centres or youth centres, rather than just via mainstream service providers such as GP practices.

• Providing Information Prescriptions through different channels: pilots felt that they could increase access to disadvantaged users by providing Information Prescriptions through a range of communication channels, such as through telephone helplines, a range of face to face channels, the Internet and home visits.

• Providing information in a range of formats: information materials and templates were designed in a range of formats in order to respond the preferences, backgrounds, language and cultures of different users. For example, information was translated into community languages for those who cannot speak English as a first language.

Pilots also found the following strategies useful in meeting the needs of disadvantaged groups:

• Ensuring that written information provided to those with low literacy is provided both in written and spoken format.

• Providing Information Prescriptions to users through home visits, drop-in sessions and outreach work:

  ‘I was able to give Information Prescriptions to people who have little contact with mainstream services, or who do not know how to ask for help. These are typically families leading chaotic lives, or who can’t get out their homes’

• Involving local volunteers to provide translation services to users who do not have a good command of English

• Providing opportunities for users and carers to access the support of public health and self-help groups who can provide additional support, education and advocacy to users facing disadvantages.

• Involving Expert Patients in dispensing roles to take Information Prescriptions to more disadvantaged users

Figure 14 depicts how a local Information Prescription system might operate in a way that is advantageous to disadvantaged users and ensures that there are multiple places from which to access Information Prescriptions. In this imagined local area, a local large primary care centre, or polyclinic, would act as the hub through which the local coordination of Information Prescription issuing would take place. In Durham PCT, large primary care centres were similarly used as hubs for the delivery of local information prescriptions. Within the centre, someone would be allocated the role of coordinating both internal and external delivery of Information Prescriptions, working with staff in the centre and with other local organisations.
This individual could come from a range of backgrounds, although it is likely they would be a practice nurse, NHS information worker or PALS manager.

- One suggestion made by a number of pilots was that a cadre of health navigators could be recruited to very disadvantaged areas to take a role in signposting disadvantaged groups and providing explanations and support to those with low health literacy.

- The primary care centre would be the main location through which Information Prescriptions are issued to users and carers through a range of approaches including annual health checks, GP consultations and consultations with practice nurses or other primary care staff, such as physiotherapists. Ideally, a social care professional could also operate in the centre, prescribing during discussions on the social and integrated care plan or other engagement with users. Finally, the centre could be set up to include an information centre, with users able to access Information Prescriptions through drop-in clinics.

- Externally to the centre, users would be able to access information prescriptions through a range of fulfilment points such as community pharmacies, community centres, children’s centres and local voluntary organisations, including churches and other faith centres. Over and above the provision of local fulfilment centres, Information Prescriptions would also be prescribed by community nurses, health visitors, social care professionals, expert patients and volunteers through home visits and outreach work.

- Finally, to enable users to access information out-of-hours, a telephone helpline and website would be available to receive information. This would be particularly important for users who are home-bound or may not regularly access mainstream services such as GPs’ surgeries.

- Together these strategies are likely to help increase the overall uptake of Information Prescriptions by those facing disadvantages.
Manchester: Working with Expert Patients

The pilot site coordinator in Manchester has trained up a number of Expert Patients to dispense information prescriptions, which come in the form an information pack. The Expert Patients access a wide range of patients, many of whom lead chaotic lives or face exclusion and find it difficult to access mainstream services. By working through Expert Patients, the site has been able to provide Information Prescriptions to a much wider range of user groups.

Impact on the voluntary sector

Voluntary sector representatives thought that successful implementation could result in a number of benefits to voluntary and community sector organisations, including the opportunity for them to:

- **Build closer relationships with statutory bodies** in order to provide holistic support for individual service users.
- **Raise the profile of their organisations** at the local and/or national level and, related to this, help ensure that there is greater acknowledgement and awareness of the work done by such agencies.
- **Influence the inequalities agenda** through careful targeting of interventions to meet the needs of disadvantaged groups. Voluntary sector representatives identified that users must be offered a range of channels for receiving information through Information
Prescriptions, and that some will need substantial additional support. They thought that VCS organisations were often best placed to provide more intensive support, and could thus be integral to the success of Information Prescriptions in meeting the needs of particular groups and working to address disadvantage.

- **Challenge statutory partners to think in new ways** about service delivery and their service users. In this way, Information Prescriptions could be seen as a new vehicle for multi-agency engagement. VCS providers could use both Information Prescriptions, and their understanding of statutory sector ‘language’ to identify how, by closer cross-sector working, Information Prescriptions could help all agencies to respond to key policy drivers.

  ‘When you talk about ‘life to years and years to life’ [i.e. the World Class Commissioning agenda] it’s about the quality in terms of what that patient needs… looking at where that patient is at, not where the service is at…” (VCS representative)

- **Increase, and improve the quality of user engagement:** representatives of VCS organisations reported that many of the users they had consulted about Information Prescriptions had been very positive and the user feedback seemed to suggest that Information Prescriptions met a real need, not only for information but also for reassurance and support.

- **Help make the idea of user choice a meaningful option:** in the event that Information Prescriptions work in a locality to create a locality-wide ‘menu’ of information provider options, this may support user choice in a way that a less ‘joined-up’ approach does not. Some users may prefer to receive information from statutory providers but others might feel more comfortable accessing VCS organisations.

### County Durham: Recognising the value of outreach services

Linking Information Prescription projects with outreach activities led by community-based organisations, it was thought, can help to maximise service user access into the Information Prescription system, particularly in relation to harder-to-reach groups. In County Durham, for example, while the overall management of and responsibility for Information Prescriptions sat within the public health function that worked across Co. Durham and Darlington Primary Care Trusts (PCTs), the day-to-day delivery and management of Information Prescriptions was led by a project manager sited within a local Cancer Information Centre.

Thinking about the wider determinants of health and well-being, **encouraging volunteers from the local community has the potential to improve the health and well-being of the volunteers themselves and their peers.** Furthermore, use of existing and new volunteers is a good way of tapping into local networks and engaging the local health and social care community. The **‘one stop shop’ model** was thought to work well, but it was deemed to be important not to develop new centres/models before assessing what is already in place. **Information Prescriptions have the potential to ‘mobilise existing resources’** in this way.

Volunteers, while not a panacea, are hugely **valuable when set within a robust framework for governance and performance management.** This site has built on existing protocols for volunteering developed by Co. Durham PCT that include a volunteer policy, protocols for levels of intervention, and clear procedures for monitoring volunteers. In addition, volunteers also have to meet standards and requirements of the Macmillan Cancer charity and the local
cancer network. This way of ‘covering all bases’ allows managers to feel confident in the quality of service being delivered by volunteers.

However, representatives from this sector raised some concerns about the potential costs of Information Prescription systems to those agencies with limited resources and the potential for demand to exceed capacity to supply. In particular, it was felt that the national introduction of Information Prescriptions could lead to increased costs in the following areas:

- Provision of specialist helplines
- Updating and production of specialist information
- Opportunity costs associated with VCS representatives taking part in local implementation partnerships
- Costs of developing and maintaining websites
- Cost of training staff and volunteers

**Conclusions on the outcomes stage**

**Success factors on the outcomes stage**

**Success factors in improving outcomes for disadvantaged users**

- Ensure that disadvantaged users are provided with additional support when accessing information prescriptions.
- **Target additional support** at those without English as a first language, those with learning disabilities, those with mental health conditions, and those who do not have good self-advocacy skills.
- Provide information prescriptions through a wide range of access points to ensure that users facing disadvantages can access Information Prescriptions.
- **Involve the voluntary sector** in helping the statutory sector involve disadvantaged groups and gain from Information Prescriptions.
- Evaluate the impact of Information Prescriptions on disadvantaged groups.

**Success factors in improving outcomes for carers**

- Ensure that there is a tailored information template and supporting information directed at carers
- **Involve carers in local partnerships** to implement local Information Prescription systems

**Success factors in improving the impact on the voluntary sector**

- **Involve voluntary sector organisations** in local partnerships to implement Information Prescriptions
- **Work with voluntary sector organisations** to identify ways to develop Information Prescription systems
Challenges and barriers in outcomes stage

Challenges and barriers in improving information for users with long term conditions

- Providing additional support, including explaining information when needed, can be time-consuming and resource intensive. Pilots sometimes found it difficult to provide enough support to users, especially those with additional needs and the most disadvantaged. Pilots were able to provide additional support by involving professionals as information prescribers whose time is either less costly to the organisation or who spend more time with users as part of their core jobs. Trained volunteers were also used to provide additional support in information centres and in other community settings.

- Approaches to making decisions about who gets an information prescription varied not just across sites, but also within sites, and professionals raised some concerns about the impact of inconsistent approaches. The lack of a consistent methodology could lead, according to some professionals, to some users missing out on Information Prescriptions.

Challenges and barriers in improving outcomes for disadvantaged users

- Engaging disadvantaged users can be challenging, especially those who do not have regular contact with mainstream services. Pilots found a number of ways to successfully engage with this group, including working through the voluntary sector, working through community and faith groups, and providing payments and support to enable users to attend consultation events.

- Some users will not be able to benefit from web-based dispensing approaches. Some older service users and those who do not have access to the Internet at home will not benefit from a web-based dispensing approach. Where sites relied on web-based approaches, they also made sure that Information Prescriptions could be accessed by other means, such as helplines.

- Some sites were surprised at how hard it was to access information on particular topics or conditions. Sites seeking to meet the needs of particular user groups such as young people or BME communities reported experiencing even greater difficulties in finding suitable material.

Challenges and barriers in improving outcomes for carers

- Carers may have different needs from users, and some pilots struggled to ensure that support given to carers was tailored to their specific needs. In addition, some sites were concerned about the need to treat information about users confidentially when working with their carers.
Section Seven: Conclusions and recommendations

Conclusions

Planning and development of Information Prescriptions

Pilot sites were deliberately given significant flexibility to develop and define Information Prescriptions as they went through the piloting process. This, together with substantive guidance on the development of Information Prescriptions, fostered a diversity of approaches to the preparation and development of Information Prescriptions, some of which deviated in one or more significant aspects of the core elements of Information Prescriptions. For example, there was a huge range of approaches to personalising Information Prescriptions, with some providing a high degree of personalisation, while the others provided a much less personalised service.

Sites succeeded in developing workable approaches, although the initial planning and development stages were more protracted than anticipated by most sites. The planning and development stages were more efficient where sites already had a baseline understanding of user and professional needs; similarly, sites which had in place good user and professional engagement mechanisms were able to obtain baseline needs assessment more quickly and general support for the development of Information Prescriptions.

For many sites, the development of a directory of information sources was time consuming and the quality assessment of sources was challenging. Many sites made trade-offs between the breadth of information coverage and its depth and quality. Existing quality assurance processes are more strongly developed for medical and health information sources, leading to a potential imbalance between health and other Information Prescription core themes if there is a delay in accrediting other sources. This was overcome most effectively when sites had access to national agencies (for example national cancer charities) that already were committed to assessing a broader range of information sources. The broad consensus among most of the sites was that national information provided by reputable information providers did not require additional local quality assurance. Some sites implemented local quality review panels. Many sites pointed to the importance of involving users in the assessment of information sources for their accessibility and usefulness. Several sites demonstrated the improvements to other Information Prescription processes, such as template design, achieved by direct user involvement and testing.

User evidence confirms that they expect Information Prescriptions to cover the full range of health, social and welfare information. By contrast, some professionals were concerned that users could be overwhelmed by too much information; some professional groups were also concerned that they did not have sufficient expertise to advise on information that lay outside their areas of expertise.

The development of Information Prescriptions was not only dependent on accessing diverse information sources nationally, but working closely with local partners in the social care field, local government, and the community and voluntary sector. Creating, nurturing and maintaining such partnerships was time-consuming and challenging.

Many sites demonstrated that the early involvement of service users and user groups generated insights and focus for the development of Information Prescriptions. This was
particularly strong when the approach to user involvement was shared with other agencies and involved the community and voluntary sector.

A significant accelerator to the development of Information Prescriptions was the support from local professional groups. Support was achieved more easily where core professionals already had a strong commitment to provide information as part of their existing practice and where the Information Prescription processes helped to rationalise and systematise these processes. As mentioned above, confidence in accessing, assessing and recommending diverse information sources were also key features of committed endorsement by professionals.

Pilot sites demonstrated that the wider roll-out of Information Prescriptions requires leadership from senior management and clinicians. In many sites, the scale of the Information Prescription operation was constrained because senior managers and clinicians had too little involvement. Information Prescription project managers had to rely on their own networks and persuasion skills to progress local Information Prescription processes. Where such leadership was put in place, access to essential support (for example to IT resources or to communications and training processes) was significantly improved.

**Information Prescription directories and templates**

Sites’ approaches to the development of comprehensive directories of information were severely hampered by slow access to IT solutions. Some sites hardly progressed beyond paper-based sources, while others put in place more systematic, IT-based directories, with search and tailoring functions.

The templates on which Information Prescriptions were offered to users varied greatly from paper formats to audio and a wide range of digital media. Oral and written channels were the primary delivery process for most sites.

Apart from the choice of channel, templates varied by the depth and breadth of information offered. At one extreme, information was compressed into a postcard format, signposting users to further information sources; at the other extreme, detailed information compendia with up to 50 pages of content were offered.

Some of the more sophisticated approaches to Information Prescriptions trialled by the sites demonstrated that information searching tools and skills could greatly enhance the personalisation of Information Prescriptions, but could also create demands on professional confidence, skills and time.

The survey of professionals involved in delivering Information Prescriptions showed that written information was the main medium used. The most commonly provided information offers were contact to support groups, helplines and websites of national charities.

As noted earlier, many of the pilots identified the need for IT to support their activities, but some found it difficult to conceptualise what kind of system, software or process might be suitable. The experience of the pilots, the resource pack and the work on developing a national database of materials should help managers, care professionals and support groups decide what type and level of IT would be appropriate to the roll-out of Information Prescriptions in their locality. Again, informed, flexible and imaginative IT consultants and support staff could be an invaluable resource in helping to develop appropriate IT solutions.
One of the strongest features of IT use in Information Prescriptions is that it forced pilots to analyse and rationalise their processes. The risk, of course, is that developing and then testing the effectiveness of IT to support Information Prescriptions could be a distraction as well as a drain on resources.

It should also be stressed that even though some care professionals may not have time to issue an Information Prescription Generator online in a consultation, having quick access to extensive, validated and maintained directories should help them keep track of the available information so that sources can be recommended verbally.

It is unlikely that major new IT systems will be created at local level specifically to support Information Prescriptions, though this could happen where new information centres are being developed. As in the pilots, the decision on what approach to adopt will largely be influenced by:

- The views of professionals and users who have sometimes had concerns about IT interrupting the dynamics of the consultation;
- Access to IT infrastructure (computers, printers, photocopiers) for example for outreach workers or nurses without access to terminals;
- IT skills, which can be low among some professionals;
- Compatibility with current systems, such as databases, between partners or organisations; and
- Existing paper-based systems, for example where record-keeping is paper-based.

The recording of Information Prescriptions proved to be a major challenge for pilot sites. Two major difficulties were encountered by sites: firstly, many Information Prescriptions involved partnership working across health, social care, and voluntary sector settings, with no data-sharing protocols on which to base the recording of Information Prescriptions; secondly, access to IT in most settings is extremely limited, precluding professionals from recording Information Prescriptions on established record systems and preventing the use of IT for other aspects of the Information Prescription process (which, in some sites, included an inability to access printers). Many sites had to resort to setting up spreadsheets or simple anonymised recording process to capture basic information about their prescribing activities. There was some evidence to suggest that where recording of Information Prescriptions is connected to existing client data, this has the potential to enhance assessment and care planning processes.

**Training and support**

For some professional groups and settings (for example mental health and cancer services), the provision of information was seen as a core part of service delivery. In such cases, the Information Prescription process was broadly welcomed, and few requirements for further training or support were raised. Most staff involved in the pilots had either received training (39 per cent) or at least been given an explanation about what to do (55 per cent). However, there was a need for further training for mental health professionals (46 per cent) and for non-specialist hospital nurses (64 per cent). GPs proved to be the most challenging group, with few participating in training or indeed in any major time investment in the Information Prescription process; GPs generally preferred simple, paper-based options. The survey of
professionals showed that primary care staff in general and GPs in particular were least positive about the Information Prescription process.

The key training challenges relate to assessing information needs and identifying appropriate information sources which lie outside the core expertise of different professional groups. Training in the appropriate use of IT-based processes also will need to be developed, especially where more sophisticated templates and information selection and recording approaches are implemented. The survey evidence shows that there was variation in how professionals delivered Information Prescriptions, how much tailoring they offered, and to whom they offered Information Prescriptions. Whilst some of this variability was based on professional judgements, there also was an element of unplanned inconsistency which better training would reduce.

**Delivery of Information Prescriptions**

The delivery chains tested by the pilot sites broadly fell into three groups, single stage prescribing and dispensing, multi-stage prescribing and dispensing, and signposting to information at the prescribing and dispensing stages.

The prescribing and dispensing pathways varied across the different channels. The analysis of the pilot evidence led to the creation of a ‘typology’ of three primary delivery models, ranging from signposting in different health/social care settings and self-dispensing to different combinations of prescribing and dispensing fulfilment.

User evidence shows that self-prescribing, particularly via the Internet, only meets the needs of information literate and confident user groups. Most service users prefer face-to-face approaches to Information Prescriptions, and in particular value the involvement of traditional health professionals like GPs, consultants and specialist nurses.

Users appear to be more satisfied with Information Prescriptions when they are issued by sites that offer a higher level of professional input and formal tailoring of information.

The evidence from Information Prescription users confirms that those in deprived areas take less from the Information Prescriptions than the more advantaged groups, pointing to a potential widening of health inequalities unless Information Prescriptions are supported by additional interventions aimed at disadvantaged groups, such as advocacy, outreach, and community empowerment initiatives.

The resources associated with Information Prescription implementation could be considerable, especially in settings where there is little previous history of providing users with tailored information, such as parts of primary care and in some specialist settings. It will be vital for local implementation teams to develop clear and costed business cases to feed into the commissioning function of local PCTs and Local Authorities in order to explain the intended benefits for users and the costs of provision.

Many sites raised concerns about the needs of socially disadvantaged groups - indeed the evaluation shows that the value of Information Prescriptions is lower among those living in deprived areas. This suggests that additional advocacy and other support services would be required to make Information Prescriptions succeed.
User response

Users’ views of Information Prescriptions were largely positive, with pilots that were able to provide greater levels of support, such as a more tailored prescribing process, achieving better levels of user satisfaction than the light touch pilot sites. Information items most frequently addressed the side effects of treatments, how the condition progresses, alternative medication and welfare benefits. About half of Information Prescription recipients would have liked more information, especially about how conditions progress; this also echoes the views of carers and professionals.

When users were given written information, four in five reported using it. Recommended links to websites were followed up by one third of those with Internet access.

Nine in ten recipients endorsed Information Prescriptions as useful, although the degree of positive endorsement was lower among those living in relatively deprived areas, with three-quarters describing the information as useful. The overall usefulness figure might be inflated by professional targeting of Information Prescriptions to certain people and a slightly lower response to the survey from those in deprived areas. The perception of usefulness was also lower among users of mental health services and for those who had soft touch Information Prescriptions.

Many of the Information Prescription users felt that the information had given them more confidence; half of the user group and about half of the carer group reported that the Information Prescription had improved the care of the Information Prescription recipient. Prescribing professionals reported that the Information Prescription process gave them a better opportunity to give explanations and half spent more time interacting with users, although many professionals in primary care were concerned about this extra time being worthwhile.

These reported positive benefits are in line with the wider research evidence on user responses to information provision. As pointed out earlier, many sites commented on the need to enhance Information Prescriptions through advocacy, outreach, and other empowerment processes. This need for additional support is evidenced by the variation in positive responses among some user groups, most notably those who are more deprived, users of mental health services, and those who received low levels of tailoring. There is a risk that these factors can combine to produce a lower uptake and impact of Information Prescriptions among key user groups, with an adverse impact on health inequalities.

Workforce issues

The professionals participating in the pilots were positive about the Information Prescription concept and its local application. Those in primary care indicated less satisfaction. Many professionals were concerned about the potential impact on their workload, especially those in primary care and those who have issued larger volumes of Information Prescriptions over recent months.

Two significant challenges for the wider roll-out of Information Prescriptions are the need for more systematic training (including the need to persuade professional groups to include Information Prescriptions in their practice) and the increased time demands which Information Prescriptions generate. Further workforce-related issues are the need to target deprived user groups more effectively and deliver quality and consistency.
**Recommendations**

To support national and local delivery of Information Prescriptions the following is recommended:

1. Ensure that local users, carers, professionals and the voluntary sector are fully involved in the development of local Information Prescription systems, engaging them in order to determine local needs and information preferences, to inform the design of Information Prescription delivery systems, Information Prescription templates and materials, and to ensure that they can hold the local Information Prescription delivery systems to account.

2. Information Prescription directories cover a wide range of information sources that enable users to access information that can help them to self manage their condition, improve their quality of life, and enhance their well being. Most critical is for directories to cover information about the management of conditions, information on social care services, links to a range of statutory and non-statutory care services, guidance on benefits and finance, and information for carers.

3. Develop a national directory of information that stores accredited information on long-term conditions linked to established care pathways. Ensure that this directory can be accessed by professionals involved in both prescribing and dispensing and by users and carers who wish to self dispense.

4. Provide a range of ready-to-use Information Prescription templates in a range of formats that can be downloaded and used locally.

5. Information Prescription processes should be personalised to ensure that users receive the right information to support the management of their care at the right time. Tailored templates and structured scripts can ensure this happens. Personalisation can also be widened by enabling users to receive information in a range of formats, through a range of delivery mechanisms (such as through email, the post or on the phone) and locations (such as at home, through consultations or drop in sessions).

6. There are a range of delivery models which can be used to provide Information Prescriptions and it is likely that local areas will need more than one, or a mix of models, to ensure that all local users and carers can benefit from Information Prescriptions. Local models need to be designed to respond to a range of factors including local population needs, information preferences, the quality and coverage of existing information systems, the local configuration of services, and the structure of the local workforce.

7. Ideally information on any national directory should be accredited using The National Information Accreditation Scheme, an accreditation scheme for health & social care information, thus avoiding the need for local areas to undertake their own quality assurance processes. However, local areas need to develop directories covering links to local services and find appropriate ways to quality assure this information.

8. Local models of delivery need to make provisions to ensure that disadvantaged users benefit fully from Information Prescriptions by providing these through multiple channels of delivery, ensuring that information is easy-to-read and comes in a range of accessible formats, and making available additional support in terms of providing users with explanations and advice.

9. Information Prescription processes need to ensure that carers benefit more fully from Information Prescription systems by involving carers in the design of processes, providing...
tailored information to carers, and providing additional support to carers, especially those from disadvantaged backgrounds.

10. Local Information Prescription systems need to be developed through a whole systems approach, across the local health and social care system, which should preferably be defined as falling within local authority and PCT boundaries. Local partnership arrangements and joint commissioning arrangements should be utilised to provide strategic direction, planning and commissioning for local Information Prescription delivery.

11. Identify ways to embed and support the development of skills and competencies required by professionals involved in Information Prescriptions through occupational standards and competencies, professional education programmes, and continued professional development.

An expanded set of recommendations can be found in Appendix 10.