Evaluation of Information Prescriptions
Final Summary Report

March 2008
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1. Introduction

The NHS White Paper Our Health, Our Care, Our Say: a new direction for community services, committed to introducing Information Prescriptions (IPs) for all long-term 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 IPs 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 can be used to develop the final strategy to inform local and national delivery.

IPs have five main components:

- **information content** – the identification of reliable and relevant sources of information
- **directories** – repositories of information that link to individual IPs.
- **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 IP to a user or carer
- **access** – IPs 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 Two.

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. This work was overseen by a project board comprising stakeholders from DH, national voluntary and community sector organisations, and the pilots. 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 IP roll-out.
The evaluation itself was limited by the several factors. Firstly, the pilot sites started prescribing later than expected and there were lower numbers who received IPs. This meant that the response to the surveys was also much lower than expected. Secondly, assessments of long term impacts 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 trail or experimental design, which limits our ability to attribute changes to the pilot programme.

The IP 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 IPs. In qualitative interviews with pilots, there was strong support for the concept and potential of IPs, with most of the pilots continuing to implement IPs beyond the pilot funding allocation.

2. How the pilots worked

The 20 pilot sites were established in January 2007 with the aim of developing and testing the introduction of IPs within their local health and social care settings by January 2008. It is possible to identify four broad areas which the pilots experienced as they approached the task of developing and implementing IPs 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 IPs meant to them, developing local plans to implement IPs, consulting and engaging users, carers and professionals to gain their involvement and ownership over the plan, identify information sources, and develop IP templates (refer to Appendix Two for the Glossary of key terms used in this report).

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

Having developed implementation plans, pilot sites set about identify relevant information sources. In doing this some sites benefited from having pre existing information held by partner organisations, such as national charities, while others had to develop new 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, representing not just their immediate care needs, but also to help them improve their broader well-being and quality of life. In the majority of sites, pilots involved users and carers in identifying information sources, regarding it 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 can be accessed via a website.
Development stage

Through 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, providing training and guidance to professionals involved in prescribing and dispensing.

Pilot sites understood early in developing their IP approaches that professional engagement was critical to building internal and external support for IPs and to tried to ensure people were happy to take up prescribing and dispensing roles. Pilots went about engaging users in a myriad 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. Most useful, it was felt, was to use real case studies describing the benefits of IPs 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 the use of existing quality assurance processes used by partner agencies in the voluntary sector or NHS Direct, while in others using existing quality assurance tools, such as DISCERN, to conduct their own checks on information sources.

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 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 IP 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 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 IPs available to users and carers. The approaches to delivering IPs varied greatly across the pilots, and were determined by a number of factors, including, the nature of the local user and carer population (eg ethnicity, age, stage in condition, socio-economic status, disabilities), the amount of time different professionals can spend with users, local geography (eg 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 IPs are provided by a vast range of professionals and 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, how to personalise IPs so that the right information is provided at the right time, and location, for users and carers, and how to ensure that the most disadvantaged users can access and benefit from IPs. Both these aims were regarded as important, but the method for achieving them varied across sites, with some developing much more personalised approaches than others, while the degree to which disadvantaged users were enabled to benefit from IPs also varied, as demonstrated by the survey findings.

Pilots sought to personalise IPs 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, internet, email or face to face.

Ensuring that IPs are accessible to those with disadvantages is regarded as important. 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, that the information comes in the right format, language and can be understood.
- **Providing information at locations** where disadvantaged users congregate or feel comfortable – some pilot professionals spoke of the benefit of making IPs available in ‘naturalistic settings’, such as community centres, older peoples centres, or youth centres, where users who may struggle to benefit from mainstream service providers, such as GP practices, benefit from IPs.
- **Providing IPs through different channels** – Pilots felt that they could increase access to disadvantaged users by providing IPs 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** – Many of the pilots tested out different formats with different groups of users, such as younger vulnerable people or older BME users, and developed different information formats in response. 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 IPs, which involved leading, managing and co-ordinating IP systems across the local health and social care system. Such an approach helped pilots maximise the involvement of different professional groups, build most effectively on the systems, information resources, and knowledge of professionals, link IP processes to integrated care pathways, and ensure from the users' perspective, that IPs appear seamless and are easy to access where ever you are in the local care system.

**Outcomes for users, carers, the voluntary sector and professionals**

IPs aim to impact positively on 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%). 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%) and people living in disadvantaged areas (60%)

Half (52%) 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%), those in poorer general health (41%), people who got an IP through primary care (42%), those with light touch information (45%) and for people living in less affluent areas (46%). Higher figures were recorded for people living in more affluent areas (58%) and for those who received an IP through Acute settings (62%)

Two-thirds (66%) 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%), mental health patients (57%), those in poorer general health (52%), people who had light touch IPs (52%) and people living in relatively deprived areas (also 52%).

**Impact on carers**

While carers agreed that, when they had seen it, they found information useful (89%), many of those taking part in the survey (35%) were actually unaware of the IP (especially those cases from sites with light touch IPs, 44%). 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 IP with carers.

**Impact on professionals**

The majority of professionals surveyed who issued IPs in the pilots (66%) were very or fairly satisfied with how the IP process was being implemented at their site, while only 7% were actually dissatisfied, although this was notably lower (52%) amongst professionals working in primary care (notably GPs and practice nurses).
Over half of the 155 issuing professionals (57%) said that the IP process compared favourably with the ways in which information had previously been given at their site, while 5% thought it was worse than the old process and 36% felt it was about the same.

3. Process

How did pilots define information prescriptions?

The piloting process was deliberately designed to give local pilots the opportunity and the freedom to define and develop IPs in a way that made sense to local circumstances. This led to pilots developing a wide range of approaches, from producing IP systems which provide IPs largely through the internet, to highly personalised face to face processes. Some of the pilots showed great ambition in developing IP systems, taking IPs beyond the original vision set out the White Paper – to create a method for signposting people to further information and advice - towards the development of a highly personalised approach whereby users receive highly tailored sources of information through face to face engagement with professionals.

Thus, pilots arrived at different conclusions about how IPs should be taken forward and defined.

While not arriving at a shared view on the definition for IPs, there was broad consensus that IPs needed to reflect a number of broad principles. IPs 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
- **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 IPs
- **Integrated part of care** – IPs 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.

What steps are needed to ensure that people with long term conditions and/or social care needs are routinely offered an information prescription?

Pilot sites were clear from the start, that IPs need to be accessible to all, regardless of the backgrounds and personal circumstances of users. The survey evidence suggests that professionals felt about to offer people the information they wanted most of the time. Three quarters were able to offer people the information they wanted most of all of the time, with a quarter able to do this all of the time. In some cases Professionals felt that they were not always able to offer people what they wanted, giving the following reasons:

- Lack of information/don't have what they request (22% but 50% in mental health settings)
• Time constraints (9%)
• Need/want more specialised/specific information (9%)
• Information not always accessible/I can’t access the information’ (8%)
• The format of the information, for example, the need for sign language or sub-titles (8%)

This finding suggests that there may need to be a more consistent understanding across professionals about who should receive an IP and when.

There were a number of strategies employed to which attempted to ensure that as far as possible, pilots would make IPs routinely available by seeking to:

• Ensure that a wide range of professionals were involved in prescribing and dispensing, working out of a range of care settings
• Provide IPs through a range of channels, such as websites, phone lines, emails and face to face contacts
• Provide IPs to users at a wide range of locations, from more formal care settings, such as GP practices and hospital wards, through to pharmacies, libraries and community centres
• Ensure that those who cannot easily leave their homes are also given IPs, by providing IPs through outreach, health visiting and home visits.

**What steps are needed to ensure that people from disadvantaged groups are given information prescriptions?**

Pilots were clear that users of all backgrounds, and especially those who face disadvantages, should have access to IPs. Evidence indicates that disadvantaged patients could benefit less from initiatives aimed at improving choice and health benefits for users, unless specific measures are introduced to help disadvantaged groups interpret and make use of information about health care\(^1\)\(^2\). Pilots developed a range of approaches to prescribing and dispensing IPs that took account of the disadvantaged backgrounds of many users.

Nevertheless, despite these efforts, the survey of users found that for the piloting programme overall, fewer users living in disadvantaged areas found IPs useful as those living in more affluent areas – explanations for this difference may be to do with lower

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\(^2\) Coulter Angela and Ellins Joe, Effectiveness for informing, educating and involving patients, BMJ 2007, 11 July ;335;24-27
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 IPs, nearly a half (46%) agreed that they were now able to give better information to people from marginalised and disadvantaged groups. However, 17% disagreed and nearly 37% neither agreed nor disagreed.

IPs 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, eg physical, learning, visual, hearing
- Users experiencing serious mental ill health
- 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 attempting to ensure that IPs 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, that the information comes in the right format, language and can be understood. The survey of users found that three quarters (77%) of those who received information were given an explanation about how it should be used, and this was almost always (96%) seen as either very (58%) or fairly (37%) helpful; a finding which is reflected by a recent research study by the Picker Institute, 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 which 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, including providing support to help people use the computer, understand where to get more information and answer questions about the content of information.
- Enabling the user to contact a helpline which can offer additional support and advice to the user during the dispensing process.

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3 The Picker Institute, Patients make it better, The International Evidence, 2007
• 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 IPs available in ‘naturalistic settings’, such as community centres, older peoples centres, or youth centres rather than just via mainstream service providers such as GP practices.

Providing IPs through different channels – Pilots felt that they could increase access to disadvantaged users by providing IPs 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 – Many of the pilots tested out different formats with different groups of users, such as younger vulnerable people or older BME users, and developed different information formats in response. For example, several sites found that their users from a younger age group preferred information via video clips and snappy visual diagrams.

Pilots found the following strategies were also 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 IPs to users through home visits, drop in sessions and outreach work
  ‘I was able to give IPs 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 IPs to more disadvantaged users
Manchester: Working with Expert Patients

The pilot site co-ordinator 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 or excluded lives, and find it difficult to access mainstream services. By working through Expert Patients, the site has been able to provide IPs to a much wider range of user groups.

What principles should underpin decisions about the content for information prescriptions?

Pilots were clear at the start that users want a wide range of information sources to support them with their care. Pilots reflected this view, by building directories of information that support the breadth of user needs. The position taken by pilots does appear to be supported by national research. The Picker Institute\textsuperscript{4}, for example, found that patients want more information and that they want the following categories:

- 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
- Information on how to comment on or complain about services.

The following table shows the main sources of information provided by the sites, with the type of information next to the number that provided it in their directories. This shows that all of the pilots covered information about conditions, well over two thirds of the pilots, provided links to local health and social care services and VCS organisations while 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.

\textsuperscript{4} The Picker Institute, Accessing information about health and social care services, April 2007
### Types of Information

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

However, this need to provide a range of information was balanced with a concern not to provide too much information. 16% of professionals agreed that there was too much information. The qualitative research among health care professionals found that there was some apprehension over providing users with too much information and these
professionals felt that there was potential for what they perceived as ‘key information’ to be overlooked, if the process wasn’t streamlined.

At the same time, many professionals (41%) 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%), a view shared by many users
- Contact details of charities/voluntary groups (27%)
- Links to NHS Choices website (26%)
- Contact details for support groups for users/patients (25%)

**How do you involve users, carers and professionals in identifying information sources, developing materials, and designing IP templates?**

Several professionals we interviewed in the pilots argued strongly that engaging key stakeholders is essential in the selection of information, in developing materials, and 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.

> ‘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 IPs
- Identifying information needs in relation to care pathways
- Informing the written materials
- 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.
Yorkshire and Humberside: 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 eyecare and eyesight disorders and in relation to this mapped out the range of information sources the users would find helpful. The IP 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 IPs, in order to develop an approach that maximises benefits achieved through IP. These potential gains include users gaining more 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.

North Tyneside

In North Tyneside, the pilot held a large stakeholder event involving users, carers and professionals. At the event, users were asked 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 financial and standard diagnosis information.

Several professionals we interviewed were keen to emphasise the importance of making sure IP templates and materials are in accessible formats. As confirmed by our surveys some users, particularly those with low literacy skills, learning disabilities, or with 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
- Levels of concentration – some people with mental ill health find it difficult to concentrate on written materials
This work with users and carers, led some pilots to develop IP templates and materials in a range of formats, including leaflets, visual images, video clips, PDFs, podcasts and email bulletins.

**How can the purpose of information prescriptions for patients, social care users and carers be communicated clearly?**

Pilot sites invested significantly in communicating the purpose of IPs both to build awareness and win the backing of professionals. The pilots used a range of approaches to communicate the purpose of IP and to gain the involvement of different professional groups, such as:

- Carrying out presentations at existing partnership meetings
- Holding one to one meetings with professionals to raise awareness and build support
- Marketing through posters, flyers and postcards
- Producing news stories and case studies for newsletters and staff email updates

Pilots found that communicating the benefits for users was a helpful way of getting pressurised professionals on board. Often using case studies of users or even asking users to present to professionals was a powerful tool.

It is possible to use simple graphics and designs that explain that IPs are for everyone, and simple to use. The example below is of a template used by Darlington which uses graphics and logos to convey the spirit and idea behind IPs:
Evaluation of Information Prescriptions

Information Prescription

Prescription No.: A/00000

Your condition is:

Tick to confirm patient consent to evaluation

How to get your information

STEP 1
Go to healthclick.nhs.uk

STEP 2
Enter the condition shown in the box above

STEP 3
Click Go!
How can the quality of information used through IPs be quality assured?

The majority of pilot sites felt it was important to quality assure all information sources. Several professionals believed that it was crucial to involve users in this process, to ensure that information is useful, relevant, and speaks to their specific needs. Pilots used a range of approaches to quality assure information, including using standard tools, such as the DISCERN model, or adopting the systems used by partner agencies, such as those in the voluntary sector and NHS Direct.

The insistence by pilots on quality assurance is probably reflected in the findings in the survey that nearly all (90%) were confident in the quality of the information they were issuing in their IPs.

For some sites, quality assurance of information was a simpler process, as these sites could access substantial bodies of quality assured information. Sites dealing with cancer, for example, found that a great deal of quality assured information already exists on issue. However, some of the mental health sites found that there were real gaps in existing information and needed to conduct comprehensive quality assurance of new information.

The process of quality assurance was time-consuming and labour intensive. In addition, it was possible to identify instances when two pilots had quality assured the same information twice. Most professionals we interviewed did not regard quality assurance as something which local areas would need to do 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 planned national accreditation scheme could be adapted to accredit information for IPs. However, there were concerns that any accreditation scheme should not favour only the large information providers, such as the large national voluntary organisations, over smaller potential providers.

Several professionals we interviewed were also clear that not all information needed to be accredited. Some information on medical conditions, treatments and tests would clearly need to be accredited, while other information may not need this, such as information about local statutory services. It was suggested, that it could become the responsibility of a national information provider, such as NHS Choices, to assess all clinical information while it could remain the responsibility of local information providers to collect and check information about local services.

Who gives people information prescriptions?

The pilot sites were deliberately selected in order that a range of different professionals were involved in IP prescribing and dispensing. Pilots were encouraged to develop IP processes which would involve a mix of other agencies in the process.

Pilots were successful in engaging a wide range of professionals, including NHS staff, local government employees, and people working for the voluntary sector. Of those we surveyed who were involved, or potentially would be involved, in the IP process, a large majority (over 80%) of respondents worked for the NHS, including primary care (67
people), acute care (74) and mental health (56), although there was a minority who worked for local authorities (22) and a small number employed by charities.

In the NHS, the majority of those surveyed were nurses (83 people including 33 clinical specialists, 25 Practice Nurses and 18 hospital nurses) with doctors the second largest group, (37) followed by allied health professionals (18).

In addition to these larger and more traditional groups of health professionals, several other groups were also notably involved in prescribing and dispensing, including pharmacists based both in acute settings or in community based pharmacies, librarians based in local authority libraries, and Expert Patients, working through patient groups to dispense information.

The following professionals were involved in either prescribing or dispensing:

<table>
<thead>
<tr>
<th>Profession and setting</th>
<th>Prescribing</th>
<th>Dispensing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary and community care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GPs</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Practice nurses</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Community nurses</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Librarians</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>PALs staff</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>District Nurses</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Unpaid volunteers</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Paid VCS professionals</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Pharmacists</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Secondary care (including mental health)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital consultants</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Care Managers</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Clinical Nurse specialists</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>NHS Librarians/Information</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Nurses</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Unpaid volunteers</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Social care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care co-ordinators</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Social workers</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Social carers</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

What type of environment is best for people to receive information prescriptions in different health and social care settings?

The pilots provided IPs in a range of health and social care environments, ranging from GP consultations, hospital consultations, drop in sessions in day care units, through to home visits and self dispensing through a user’s home computer. The surveys and qualitative interviews found that there was no single setting which was necessarily better than others, only that a range of settings needed to be provided to respond to the different needs of users, such as how they like to receive information, how they come into contact with services, and what information they need.

Professionals we interviewed in the pilots strongly recommend that when users are receiving difficult or sensitive information, providing a private room or space is important. However, they also said that some of the users they worked with said that they prefer
being able to access information in an informal setting, through drop-in services, or through internet portals in libraries or from their home Personal Computer.

The majority of professionals we interviewed were clear that when users have low health literacy levels, or need the information to be explained, this should be provided face to face. Certainly recent research by the Picker Institute\(^5\) strongly supports the view that patients do prefer to receive information face to face, preferably from a doctor or nurse. However, help-lines can be beneficial to patients who feel that they want to be able talk to someone about the information.

IPs were available from the following locations:

- In patient departments
- Acute and mental health hospital wards
- Hospital health information centres
- Out patient departments
- GP practices
- Local authority libraries
- Community Pharmacies
- Local voluntary sector run centres
- Local authority community centres
- Youth centres
- Adult day care centres
- Residential care centres
- Users homes (either through visits or through self dispensing)

**Mid Trent**

This pilot issued IPs remotely as well as face-to-face to maximise access. This was particularly beneficial in rural areas. Whilst face-to-face interaction is typically more beneficial, the pilot wanted to ensure people could access information in a way that best suited their needs, and when they wanted. This led to Mid Trent developing a website so people can print off their own IP forms, or even complete them online and access information directly via the website.

**Are different approaches needed for patients, social care users and carers to receive information prescriptions?**

From the start, pilots took the view that IPs needed to respond to the diverse needs of users, and that providing a ‘one size fits all’ approach would be insufficient.

\(^5\) Picker Institute, Accessing information about health and social care services, April 2007
The majority of professionals we interviewed spoke of the need to develop a highly personalised approach to IP delivery that tailors the approach to information provision around the needs of users.

IPs were personalised to respond to the following user characteristics:

- Age
- Ethnicity
- Level of literacy
- Gender
- Where people live
- The user’s condition and stage in their treatment
- How people prefer to receive information

Once the characteristics of local users and carers was established, pilots were able to personalise their IP approach 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 (see an example developed by Mid Trent below)
• 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 a 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, internet, email or face to face.

**How should information prescriptions be offered in different care settings**

There is no single method used by pilots for providing IPs that is common to a particular care setting. In one pilot based in primary care, GPs can be involved in prescribing, whereas in another they are not. In one secondary care pilot you can find that information is provided through a dedicated local information centre, whereas in another site, NHS Direct staff are the main dispensers.

For a number of pilots, it was important to find ways to embed IPs into processes that already exist or are being rapidly developed in different care settings.

In social, community and primary care, care planning processes which are increasingly available to those who have both a long-term health and social care need were seen to afford a good mechanism through which to provide an IP. Several pilots sought to integrate IPs 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 IPs into single assessment processes (SAP), which are currently available to older users and will be made available for all adults in social care, with one pilot successfully integrating the processes so that a user will receive an IP as part of their standard SAP, while the other pilots hope to arrive at this point in the future.

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

One key determinant which was used by pilots to judge how IPs should be offered was the identified level of need of users. Pilot sites used different definitions for need, using a range of terms such as stable, unstable, less advanced or advanced, high risk or lower risk. 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. The Kaiser model identifies those with long term conditions as having three broad levels of need:

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6 Information can be found on Kaiser Pyramid of Care for Long Term Conditions at the following website: [http://www.natpact.nhs.uk/uploads/Pyramid%20%20Chronic%20Disease%20Management.pdf](http://www.natpact.nhs.uk/uploads/Pyramid%20%20Chronic%20Disease%20Management.pdf)
- 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, and 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.

There were a broad range of issues and challenges which pilots considered in developing their IP approaches within different care settings. In the following table we describe some of these challenges and how the pilots responded in the way that they developed IP systems.

<table>
<thead>
<tr>
<th>Care setting</th>
<th>Challenges/issues</th>
<th>How IPs are offered</th>
</tr>
</thead>
</table>
| Primary care | - GPs have been difficult to engage in the IP process  
               - Users are likely on average to spend less time with professionals than in acute, mental health and social care  
               - Users conditions are likely to be able to manage their own care at the point of making contact with care professionals (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) | - Prescribing usually takes place in GP practices, but can also take place through home visits, day care centres, and in libraries.  
               - IP templates are very quick to administer, using a simple tick box approach or signpost  
               - GPs are rarely involved directly in prescribing which is covered by practice nursing staff  
               - Dispensing options provided through self dispensing websites, pharmacies, telephone help-lines and libraries  
               - Additional support to disadvantaged groups provided by health visitors, volunteers and community nurses  
               - In care planning sessions for those with long term conditions |
| 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 IP process | - Prescribing takes place during hospital consultations  
               - IP templates are more likely to be highly tailored, with options linked to care pathways  
               - Consultants can conduct initial
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)

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

IP 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

Social care

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

Prescribing takes place in a range of situations, including care planning

Prescribing is conducted by social care co-ordinators 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 web sites and help-lines
IT and information prescriptions

How can information prescriptions help audit the information that people are given about care options?

It was regarded as important for the pilots to test how IT could usefully support information prescribing and dispensing, including how IPs are recorded and tracked, to allow information giving to users and carers can be audited for quality and consistency over time.

However, many pilots found it challenging to develop methods for recording information, with many citing the largest barrier being the lack of Electronic Patient Records (EPRs) in place to aid this. In the end, many sites used manual and paper-based methods for recording, recording by hand when an IP was issued and adding a paper note to patient’s files or inputting it into electronic care planning software where this exists.

The Heart of England has managed to develop a method for recording IPs into EPRs which allows the pilot site to record prescribing automatically and attach a record of this directly into the patient records. This greatly enhances the pilot's ability to track the provision of information to different users and ensure that the process of information giving is consistent and meets the users needs.

However the remainder of the sites would benefit greatly from any mechanism which allows completed IP forms to electronically update patient or care records, without the need for a manual system.

How has IT facilitated the delivery of the information prescription?

Although there are many ways in which information technology can contribute to information prescribing, only a few of the pilots felt they had the time or resources to develop new IP software – and some thought their focus should lie elsewhere.

There are four core ways in which computers can support IP

- By providing an interface to search for materials and sources and to create IPs. This type of interface has been described as an ‘electronic information prescription generator’ or IPG)
- By providing databases that can hold materials and details of sources
- By providing bespoke printing of information materials
- By keeping a record of information issued and dispensed.

Four types of systems were used across the pilots, not all providing all these functions. The four types are distinguished by their general characteristics and mode of access:

1. systems that are freely accessible via the internet – and mainly intended for public use
2. web-based approaches for professionals – IPG with supporting databases that care professionals can access by logging onto a remote site
3. IPGs on care providers intranets, forming part of local care record systems
4. databases with restricted access intended for use by staff handling enquiries in external agencies such as NHS Direct and some national charities.
Table Examples of IPG and supporting database systems in the pilots

<table>
<thead>
<tr>
<th>IT application</th>
<th>Pilots trialling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web-based for general, assisted and professional use</td>
<td>Isle of Wight, Darlington, Suffolk, South Essex</td>
</tr>
<tr>
<td>Web-based approach for professionals</td>
<td>West Yorkshire, Staffordshire, Cambridge and Peterborough, Doncaster North Tyneside, Oxford, South Essex</td>
</tr>
<tr>
<td>Local intranet IPG</td>
<td>Heart of England, Royal Marsden, Durham, Oxleas</td>
</tr>
</tbody>
</table>

Public web-based systems

Two examples of health information databases that are mainly intended for public use were constructed by the Darlington and Isle of Wight pilots.

The Isle of Wight ‘One Link’ IP service is part of the local authority web site. 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 IPG and all users can save IPs 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.

Although both are designed for self dispensing they can be used in assisted settings where a patient or carer is helped to search for materials by workers at designated support points, such as the PALS office and library information services.

There are, of course, many other public sites providing information relating to health and social care, both funded by the NHS and other agencies – such as the BBC Health site. None of these, as yet, include options to specifically create information prescriptions.

Web-based systems with controlled access

The main example of a web-based approach targeting professionals was the IPG that DH commissioned from the Map of Medicine team, though other examples were commissioned locally, by, for example, the South Essex Partnership Trust.
The Map of Medicine team IPG provided professionals with a way to select information sources and add these to an IP template using keyword searches on directories. Results were printed on a generic or customised IP template. This was designed specifically for professionals and was thus not made available to the general public.

South Essex Partnership Trust commissioned a web-based system for professionals whose main searching and database functions could be accessed by the general public – though the IPG function was password controlled. The system was designed to be more closely integrated with the local care records system than, say, the stand-alone IPG provided by MoM.

Systems on local intranets – integrated to care record systems

One pilot site has managed to develop an approach to recording IP prescribing that is linked to Electronic Patient Records (EPRs). Prior to the programme of IP 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. It was also one of the pilots for ERP, which meant it had a good existing system on which to build a recording facility. The system gives staff 3 levels of access: secretarial and administrative staff can view and print material; medical staff can issue items to a patient (and the issuing is automatically recorded on the EPR); and managerial – includes the facility to create and edit the materials.

IT support for help lines

Several pilots linked their local IP systems to national helplines, which provided an avenue through which IP information was dispensed. In several cases, these helplines are provided by national voluntary sector organisations, and build on existing helpline services.

On-line prescribing from a hospital bed side – the Evelina Children’s Hospital NHS Direct pilot

NHS Direct runs a web site that holds blank information prescribing templates that can be accessed by participating care providers. Pharmacists in the Evelina Children’s hospital can access these templates via wireless links and their notebook computers. The prescription is logged at NHS Direct – who then contact the service user or carer for more details of their information needs and dispense the materials electronically or by post.
Professionals based in pilots raised some concerns about the level of duplication of effort that was taking place in the gathering and quality assurance information sources, many of which they felt could be generated at a national level. They also felt that at times that the lack of expertise and existing systems locally made it difficult for localities to produce directories that were sophisticated enough to store complex and multiple sources of information.

In light of these concerns and issues, many of the professionals we interviewed wanted to see the creation of a national directory in the future which would collate and store information sources on a range of conditions and keep these in an accessible format which could be downloaded and used locally, either by the user themselves or a professional through the prescribing or dispensing process. Such a Directory, if created, could store accredited information on the full range of conditions, removing the need for local services to produce quality assured information. The Directory could also be designed to contain ready to use templates in a range of formats which could be used locally.

**Conclusions on developing and delivering IPs**

**Success factors in developing and delivery IPs**

- Engage a wide range of existing networks, patients groups, carers forums to consult about IPs and gain wider involvement.
- Ensure that primary care staff, particularly GPs, in developing local IP systems.
- Ensure that carers are involved in the design and delivery of local IP 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.
- Develop local implementation proposals for IPs
- Develop a communication strategy for promoting and disseminating information locally on IPs;
- Establish a local process for quality assuring information on local services;
- Ensure multi-agency collaboration, and include commissioners at the outset to build support and sustainability into the process.
- 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
- Involve the voluntary and community sector in local implementation
• **Ensure that IT specialists** are built into local IP partnerships and delivery teams.

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

• **Ensure that users always have the option of accessing IPs through channels other than the web**, such as help-lines and face to face information provision.

**Barriers and challenges to developing and delivering IPs**

• **Engaging users in IPs 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, and more rapid, feedback on their plans for local IP systems when they were able to utilise existing user and carer networks, such as Expert Patient Groups, patient forums and citizen’s panels.

• **Early and sustained engagement facilitated 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 IP process found buy-in and commitment was easier to achieve than had they left this activity until later on in the process.

• **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 by providing payments and support to enable users to attend consultation events.

• **Some sites found it difficult to develop templates and materials that would suit different users' needs and preferences.** Many sites found their progress was delayed by having to revisit formats and designs regularly during the planning phase. It is important to develop information sources directly with a range of users, carers and professionals. Different styles of templates and information need to be designed for different users.

• **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.

• **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.

• **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 IPs and more worried than other staff groups about the potential impact on their workload. Pilot sites found it difficult to engage GPs and to 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 to focus on how IPs can benefit user care and prevent or delay more serious ill-health.

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

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

- **Pilots found it challenging to develop their own IT systems to support IPs.** Some pilots did not have IT expertise in place to help them develop appropriate systems while in other cases, the pilots did not have enough basic equipment, such as computer terminals in consulting rooms, to support an IT solution.

- **Care professionals will often not have time for full prescribing with an electronic IPG in a consultation.** There were several reasons for this, including the view from professionals that using an IPG could restrict the quality of the patient engagement, restrict the time of professionals that is used to fulfil other objectives, and take too long, particularly if the system involved complex computer software.

- **Some professionals preferred using paper-based methods for prescribing –** Many professionals who were engaged in IP prescribing, preferred to have the option of using a paper IP 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.

- **Identifying and gathering local information about services proved difficult for some pilots.** Most of the pilots sought to ensure that IPs 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.

- **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 IPs could be accessed by other means, such as through helplines.

### Recommendations

#### National implementation priorities

- Make pre-developed templates for the all of the conditions available in large print, easy to read language, and in the most widely used community languages
• Establish a national telephone line where all the most commonly used information sources are presented in recordings for blind users
• Conduct regular surveys which provide national and local data about users’ preferences for receiving different types of information. This could be achieved by including further questions on information use in annual patient surveys.
• Provide a technical interface which allows local electronic delivery systems for prescribing and dispensing to interface with the national directory
• A National directory is developed with a bank of tailored templates that can be downloaded and used by local sites
• The National directory should hold quality assured information on all the main conditions, structured by care pathways
• Use the national accreditation scheme to accredit information providers who will contribute to the directory
• Information on the quality and standards of local service providers should be clearly displayed in directories and dispensed information
• Produce a national kite mark to be placed on all IP materials to show that the information is accredited

Local implementation priorities
• Health navigators are established in areas with high levels of deprivation to help users with their information needs and to ensure that they access the right information in the right format, understand the information, and know how to use it.
• Carry out research with local users to access their information preferences
• Build local directories to house local service information, such as contacts, emails and websites
• Establish local directories, building on other existing directories, such as children’s services directories
• Build in capacity to conduct six monthly reviews of content and link information to check and update information
• Develop local models of delivery that provide a range of channels for accessing information, but ensure that additional support is available to ensure all users and carers have equal access
• Involve users and professionals in designing care pathways so people can plot what information they want, when and from whom
• Develop scripts and prompts to help professionals provide a consistent approach to asking users about their information needs so that the full range of information options are made available.
4. Delivering information prescriptions within the system of care

How can local partnerships and health and social care support networks be incorporated into 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. These were regarded as critical to ensuring that IP 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 IPs as a whole systems approach, requiring joint decision making between health and social care providers, multi-disciplinary working, and partnership working.

The pilots were given funding to support them during the year-long piloting process. This meant that the issue of how IPs 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 IPs are supported through future commissioning strategies. The argument made by many is that future IP systems, which will need to be developed across health and social care systems, will need to be supported through joint commissioning arrangements between health and local government.

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 IPs will need to build the case, and clear service options relating to the local development of IPs, to inform the decisions of local commissioning boards.

'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 IP service, whereby users can benefit from the combined expertise of all agencies.'

The following factors were suggested as useful to developing a whole systems approach

- **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.

- **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 IP 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.
- **Co-ordinated management** – Pilots argue that it is important to have a single point of management and co-ordination to ensure that partnerships deliver across the local system.
- **Involving the voluntary and community sector** – Establishing clear and ongoing relationships with the voluntary sector is crucial to shaping the long term involvement of local networks
- **Build IPs into integrated commissioning** – Develop a clear commissioning plan for IP implementation and embed this into local joint commissioning strategies
- **User engagement** – Involving LINks and other user forums should add value to the work of IP partnerships, and build local awareness and ownership

**How can an information prescription help people navigate through the health and social care system?**

In the pilots, there was a strong commitment to making sure that IPs can be used to help users and carers make better sense of what local services are available and how to access these. In the majority of cases, pilots aimed to do this by making sure that information was clear, that links to the full range of local services was clearly presented, and that users were given clear explanations of how to use the information.

‘IPs are about promoting choice. This can only happen if the information is clear and easy to understand and has all the right links’

The following actions were seen as helpful:

- Ensuring that the IPs clearly explain what the information is for, who provides it and how to find out more
- Clearly present named contacts, phone and web-pages and visual maps on IP templates and dispensed materials.
- Ensuring that users can always call or see someone who can explain what IPs are for and where they can be received
- Providing clear organisational logos for participating NHS trusts and the local authority on all templates and materials

**Darlington PCT**

In the Darlington pilot the local PCT PALs team was responsible for co-ordinating the implementation of IPs. In addition to this, the PALs unit was also given responsibility for signposting users to the right place when they either received an IP, did not understand it, or wanted to know more about IPs. The PALs team telephone number was clearly displayed on the IP template to aid access.
**What is the impact and benefit of giving people an information prescription on professional practice in health and social care and in motivating staff to provide relevant, trustworthy and timely information using jargon-free explanations?**

The majority of professionals surveyed who were involved in the pilots (66%) were very or fairly satisfied with how the IP process was being implemented at their site, while only 7% were actually dissatisfied. Satisfaction increased with volumes of IPs 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 where light touch IPs.

Over half of the 155 issuing professionals (57%) said that the IP process compared favourably with the ways in which information had previously been given at their site, while 5% thought it was worse than the old process and 36% felt it was about the same—respondents in acute (63%) and local authority (73%) settings were more positive than those working in mental health (50%) or primary care settings (52%).

The survey findings also indicate that many professions feel that IPs will improve their professional practice. Among the issuers, 42% agreed that IPs will help them do their job better while 19% disagreed and 39% opted for a mid point on the scale. Furthermore, some of the professionals who took part in qualitative interviews argued that IP systems helped to provide a more structured approach to providing information that provided users with information ‘in one go’; provided a more standardised approach to information providing, and help professionals ‘see what available for the patient.’

‘IPs 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 IP systems would impact on their workloads. Almost a third (36%) of those not yet offering IPs agreed that they were worried about the potential impact on their workload; a concern which was slightly higher (at 41%) 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% agreement compared with 36%). 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 IPs 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 generally worthwhile from either their own or the user perspective.

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 IP prescribing processes which were short and simple, developing multi-staged processes for prescribing, whereby different parts of the process are conducted by different professionals – sharing the workload.

**What are the different models of delivery?**

There was no single model of IP delivery developed by the pilot sites, with all of the sites developing their own unique approaches to IP prescribing and dispensing. However, there does appear to three high level models of delivery across the pilots, which we now
describe. The models are either light touch or in-depth. Light touch models are those which do not undertake detailed tailoring of information or provide substantial additional support from professionals to help users understand the information, whereas in-depth models provide this level of tailoring and support.

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, helplines, local information voluntary sector organisations and libraries. The pilots using this model are usually working with conditions which are relatively stable and do not require significant involvement from secondary care.

Model Two: In-depth prescribing and linked dispensing

In this model a specialist worker – such as a care worker or case manager – completes the IP alongside the service user, during a consultation session and then the dispensing takes 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 IP 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.

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 tend to be either high risk or are 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 IP process is usually quite structured and tailored around a care pathway. The prescribing process usually involves more than one stage, with the first stage involving a professional making an initial assessment of the user information needs, and a second stage during which 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 users and carers at in depth pilot sites were more likely to find the IPs useful as compared to pilots with more light touch models. Users from site with in depth IPs were much more likely to find the information useful (91%) than people attending sites where there was less support (76%). Professionals at in depth site were also more satisfied with the way the Information prescription process is working at their sites compared with professionals in light touch sites (74% compared to 52% respectively).
What are the costs of giving patients, social care users and carers information prescriptions in different settings?

Estimating the costs of introducing IP in a social and health care community could be achieved by the following processes, illustrated in Figures A and B.

The first task is to estimate demand: the number of times people with long-term conditions will contact health and social care services. The next stage is to try to estimate the nature of the demand from what the pilots report as the typical information needs of people with different conditions. For example, some people may require additional support to make sense of relevant information, while others may be able and happy to retrieve materials themselves from the internet.
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. Comparing 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.

Costs of local implementation can be approximated using predicted patterns of delivery with estimates of the unit costs of the various methods of providing information. The full report will look at costing issues in more detail.

**Costing the range of services required to meet local needs**

- Nature of existing health and social care services – and other services that can potentially contribute to IP
- Pattern of methods of IP delivery to meet local need
- Volume of activity required by each method
- Estimated gross costs of introducing IP as a new service
- Estimated net costs of introducing IP
- Estimated net long-term recurring costs of IP

**Nature and volume of need**

- What balance of information delivery is required

**Estimates of cost of existing information activities**

- Long-term savings predicted by modelled or otherwise estimated impact of IPs on future need for information and care

**What training and education is needed for professionals to give people information prescriptions?**

Training is crucial to the success of IPs. Most sites were able to provide support to professionals who are involved in prescribing and dispensing, with the vast majority (93%) of professionals who were surveyed claiming to have either attended training (38%, though higher for those in mental health settings and in local authorities) or been talked through the process (55%). Over a quarter of those issuing IPs 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 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:

- **IP co-ordination and management** – including skills in stakeholder engagement, needs assessment, influencing skills, capacity building, communication, health information management, designing and developing data bases and information quality assurance.

- **Basic introduction to IP systems** – they should be offered training in using and completing IP templates, understanding IP 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.

Professionals need to be supported if they are to successfully adopt prescribing and dispensing roles:

**Ensure that staff are informed at all stages of the implementation of IPs** – regular and meaningful engagement with all staff involved in IPs throughout the roll out of new approaches is critical. Update staff at training sessions, staff networks and other get togethers. 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 IP systems in different service settings.

**Provide opportunities for staff to work with users and carers** – User involvement, as we have said, is critical to the success of IP process. Involve as many professionals as possible in working with users to design IP processes, develop templates, directories and training processes. Involving staff directly with service users can help both users and professionals understand each others’ needs and develop shared approaches to providing IPs that work.

**Integrate IPs into existing protocols and processes** – Staff are accustomed to using protocols and processes as part of their jobs. The more that IP processes are embedded into these processes, the more likely they will adapt to using IPs. Pilots explored a number of ways of doing this, including integrated IPs into care planning processes, single assessments and information sharing protocols.
Conclusions on delivering IPs within a system of care

Success factors which enable the delivery of IPs within a system of care

• **Build on existing networks and partnerships**, both within the health and social care sector and beyond, for example with LSPs

• **Work with well established and comparatively small teams** – makes the process easier

• **Identify local professionals to co-ordinate delivery of IPs** across the local health and social care system

• **Develop a local partnership arrangement to support local implementation**, involving all of the main partner agencies and user representatives

• **Link IP 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 IP plans

• **Engage professionals in all services, and at all levels**, in developing and implementing local IP systems

• **Identify a network of local ‘champions’** to promote and implement IPs across different professional groups and services.

• **Identify opportunities to align and adapt existing and planned training** to support IP skills

• **Build IP processes into existing protocols and processes**, such as single assessment processes, common assessment framework, care planning protocols and annual health checks.
Barriers and challenges to delivering IPs within a system of care

Pilots did not always have enough high quality data to make judgements about the needs of the local population. Personalising IPs 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 from. Pilots found it helpful when there was high quality data on the local population.

Pilots found that they had to balance providing a personalised service, with the need to protect professional’s time. Many of the more tailored approaches, involve a greater time commitment from professionals. Initially some pilots tired to involve professionals in complex assessments using tailored templates, but found that there was great resistance to such an intensive approach.

Engagement between health and social care sectors was often problematic. While Pilots regarded it as important to involve different sectors in developing a seamless local IP system, often it proved difficult to get professionals from social care and health together to discuss shared approaches and solutions to problems.

There is no single approach to developing IPs. IPs developed a wide range of approaches to delivering IPs to local users and carers. While three high level models of delivery can be identified, the differences within these are substantial. Some models appear better placed to respond to different user needs and local operating context. However, it is likely that any locality will require a combination of models, covering primary care, community care and more specialist and acute services.

Recommendations

National implementation priorities

- Develop guidance to help local areas develop local commissioning strategies
- Examine ways to build IP skills and competencies into consultant, nursing and social work education
- Establish how Skills for Care, NHS Institute, NHS Employers and Strategic Health Authorities and others can support local training for IP systems.

Local implementation priorities

- Commission and deliver suit of training tailored for different level of involvement and roles
- Local directories should clearly present the full range of service providers by condition and stage in pathway
- Develop local IP partnerships linked to the local health and social care thematic partnerships.
- Involve health and scrutiny committees in regularly assessing the impact of IP systems locally
5. Impact on users, carers and professionals

What is the impact of giving people information prescriptions on providers of information, including the voluntary sector, NHS and other non-statutory providers?

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

In qualitative interviews with the voluntary sector, there was generally high levels of support for the notion of IPs and where they were involved in the partnership, satisfaction with the process. The voluntary sector felt that it could benefit them by:

- Giving them a more central role in providing information to users and carers, especially those facing disadvantages
- Enhance the professional skills of many staff in the voluntary sector, who have the possibility of becoming more closely involved in providing information and additional support to users who face disadvantages.
- Building more closely aligned and productive partnerships between the statutory and voluntary sector.

However, concerns were raised by the sector about the potential costs of IP systems, and that they may become overloaded with requests for information.

The sector is credited with offering pilots:

- A strong understanding of user needs.
- Providing and advising on approaches for accessing hard-to-reach groups.
- Providing innovative approaches to meeting user needs – often ‘joining-up’ needs across different services areas such as health, education and social care etc

The role of the voluntary sector has been significant in the following areas:

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

The sector needs to be involved in the future development of IPs nationally. Specifically, the role should include:

- Designing local approaches to delivery, and providing ‘voice’ to local community groups
• Informing commissioning decisions and priorities
• Providing services, particularly for disadvantaged users

**Do patients, social care users, carers and professionals find information prescriptions useful and help them get the information that they need?**

**Were users satisfied with IPs?**

The sample of users included almost 300 people who had been identified by pilots as having been given an IP. 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 who were linked with pilots where light touch IPs were issued. More generally, users from these two groups were generally less positive about information, so it is quite likely that the survey results overstate positive views of the IP process, reinforced by a lower response rate from disadvantaged users and the fact that some professionals targeted information at people they thought had most capacity to make use of it.

Almost all (95%) of users in the IP surveys had made some use of the information they were given and were also quite positive about IPs, 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 IP agreed that they found the information useful (88%, with 49% agreeing strongly – there was 100% agreement among cancer patients).

It is clear that people living in disadvantaged areas found the information less useful than those living in more affluent places (76% v 91%). Some of the factors that associate with more positive views were having explanations about how to use information, receiving greater support/tailoring in the IP, getting information on (state) benefits available and on how the condition progresses across time. Almost all of those receiving IPs from acute settings (97%) agreed that the information was useful, compared with 81% for people who got the IP from Primary Care.

The main reasons people gave for finding their information prescription useful were that it:
• Helped me understand/told me about the condition/explained my problem (42%)
• Was informative/useful (18%)
• Was easy to understand (13%)
• Many users also said that the IP 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.’
  (MS patient)

From the professional point of view nearly two thirds (63%) agreed that the patient or service user had found the information useful. Professionals in primary care (42%) and those in light touch sites (42%) were the least likely to indicate that the users had found the information useful. In Acute settings, 71% agreed, the same percentage as in pilots with an in depth approach to IPs.
About half of the users and patients indicated that they would have liked further information. Among this group, 29% would have liked information about benefits available and 28% 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 being positive parts of the IP process. Other relatively common requests were for information about different medication available (21%), details of side-effects (17%) and support groups (14%).

Are information prescriptions clear and straightforward?

Most users surveyed agreed (93%) that they understood what they had been given (though the figure was lower for mental health patients at 83%). A large proportion (79%) agreed that they were given about the right amount of information. Again, those with mental health conditions were less likely to agree (66%) as were people who were given their IP from light touch pilots (64%) and those living in more disadvantaged areas (65%). Professionals held a similar view in terms of the amount of information available with just 16% 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% but as many as 21% of people with a mental health condition). This particular finding was more positive than the views recorded in the earlier survey of people given information at sites prior to the introduction of the IP process (31% agreement).

One patient or service user in six (17%) 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 sometimes be explained by someone making active use of the information they were initially given.

From the professional perspective, nearly two thirds (65%) 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%) and in light touch pilots (55%) were the least likely to agree with this, while those in Acute settings (73%) and in sites with greater IP support (72%) were more positive.

In terms of helping with workload just under a quarter (23%) spent less time looking up information than they did before, but it is worth noting that a third of professionals disagreed with this.

Did carers benefit from IPs

While carers agreed that, when they had seen it, they found information useful (89%), many of those taking part in the survey (35%) were actually unaware of the IP (especially those cases from sites with light touch IPs, 44%). 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 IP with carers. It is also important to note that on a number of issues, there was a discrepancy of around 20% 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 for carers linked with mental health sites and pilots that offered light touch IPs.

A large majority (86%) of carers who had seen an IP thought the information was given at a good time in the management of the condition, though 12% held the opposite view.
(including 21% where the patient had a mental health condition and 22% when the IP was from a site with low-level tailoring).

Three-quarters of carers (74%) 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 (63%) 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%) and the benefits available (51%). A third (32%) wanted more detailed information on the medication available and about a quarter (27%) 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 life.

**How will information prescriptions help people get interventions and services at an earlier stage to access preventative treatments sooner?**

It is important that IP systems are an inherent component of the wider preventative agenda influencing reform in the health and social care sectors. Ultimately, IPs aim to reduce the reliance of health service and improve their capacity to manage their own care.

It is not possible within this evaluation to establish a link between IPs 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 IP 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 terms of managing their condition (76%). However, levels of confidence were lower among the under-65s (68%), mental health patients (67%), people not in good health (66%), and patients and service users who lived in more deprived areas (67%), suggesting that these groups require additional support to benefit from IPs.

IPs can also increase awareness of preventative approaches, through the information that is provided. Many pilots provided comprehensive information about approaches to self management and preventative care through IPs. Building IPs into preventative processes, such as annual health checks, can also highlight to users ways to prevent ill-health.

**How do information prescriptions support people to live with a condition including self care and managing their lives and condition?**

Three quarters agreed that they felt more confident in asking questions about their condition (73%). 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 relatively low among those with self-ascribed poorer health (62%) and people living in disadvantaged areas (60%).

Half (52%) 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%), those in poorer general health (41%), people who got an IP through primary care (42%), those with light touch information (45%) and for people living in less
affluent areas (46%). Higher figures were recorded for people living in more affluent areas (58%) and for those who received an IP through Acute settings (62%).

Two-thirds (66%) 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%), mental health patients (57%), those in poorer general health (52%), people who had light touch IPs (52%) and people living in relatively deprived areas (also 52%).

However, a majority (59%) 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%) and for cancer patients (73%), suggesting that IPs on their own will not necessarily lead to some taking on more self management of their own care.

Almost two-thirds (63%) agreed that they thought their health will benefit from the information obtained about managing the condition. The groups that were most likely to see health benefits were women (71%), those aged 65 plus (70%) and those who lived in more affluent areas (81%). Once more, there is less impact on some groups including people who said they were in poor general health (54%) and, especially, those patients and service users who lived in relatively deprived areas (49%).

Conclusions on making an impact on users, carers and professionals

Success factors on making an impact on users, carers and professionals

- Provide a range of mechanisms through which users can receive additional support, such as receiving an explanation about the information
- Target additional support at those without English as a first language, those with learning disabilities, those with mental health conditions, those who do not have good self advocacy skills.

Challenges and barriers in bringing about benefits for users, carers and professionals

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 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.

Recommendations

National implementation priorities

- Establish a longitudinal cohort study to explore relationships between IP issuing and services which prevent people from serious ill health.
• Ensure that any National Directory contains information for carers and ready to use templates for carers
• Ensure that any National Directory provides information for each condition on how the condition progresses and links to information on benefit entitlements

Local implementation priorities
• Involve the voluntary sector in local partnerships
• Consult the voluntary sector in local commissioning decisions
• Explore opportunities to engage the voluntary sector in service delivery

6. Conclusions and recommendations

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

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

2. IP directories cover a wide range of information sources which enable users to access information which can help them to self manage their condition, improve their quality of life, and enhance their wellbeing. 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, 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 IP templates in a range of formats which can be downloaded and used locally.

5. IP 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 happen. 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 IPs 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 IPs. Local models need to be designed to respond to a range of factors including local population needs, information preferences, and 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 forthcoming National Information Accreditation Scheme, 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 IPs by providing IPs through multiple channels of delivery, ensuring that information is easy to read, comes in a range of accessible formats, and that additional support in terms of providing users with explanations and advice is available.

9. IP processes need to ensure that carers benefit more fully from IP 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 IP systems need to be developed through a whole systems approach, and across the local health and social care system, preferably 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 IP delivery.

11. Identify ways to embed and support the development of skills and competencies required by professionals involved in IPs through occupational standards and competencies, professional education programmes, and continued professional development.
## Appendix One: Descriptions of pilots

<table>
<thead>
<tr>
<th>Pilot site</th>
<th>Brief description</th>
<th>Pilot site contacts</th>
</tr>
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<tbody>
<tr>
<td>1. County Durham Primary Care Trust&lt;br&gt;Macmillan Cancer Information and Support Centre</td>
<td>This pilot was based at the Macmillan Cancer Information and Support Centre, and developed information prescriptions for people with cancer, delivering the prescriptions through GPs and district nurses.</td>
<td>Fiona McQuiston&lt;br&gt;0191 587 4500&lt;br&gt;<a href="mailto:fiona.mcquiston@cdpct.nhs.uk">fiona.mcquiston@cdpct.nhs.uk</a></td>
</tr>
<tr>
<td>2. University Hospitals Birmingham NHS Foundation Trust Queen Elizabeth Hospital</td>
<td>This pilot site developed information prescriptions for people with cancer in the field of non surgical oncology. It was based on the hospital site, and information prescriptions were delivered by clinicians.</td>
<td>Lynne Dodson&lt;br&gt;0121 472 1311 Ext 51516&lt;br&gt;<a href="mailto:Lynne.dodson@uhb.nhs.uk">Lynne.dodson@uhb.nhs.uk</a></td>
</tr>
<tr>
<td>3. Mid Trent Cancer Network Nottingham University Hospitals NHS Trust</td>
<td>Information prescriptions were developed for people with cancer. Information prescriptions were delivered by clinical nurse specialists, and focused on palliative care, head and neck, lung and gynaecological cancers.</td>
<td>Elaine Wilson&lt;br&gt;0115 962 7988&lt;br&gt;<a href="mailto:elaine.wilson@nuh.nhs.uk">elaine.wilson@nuh.nhs.uk</a></td>
</tr>
<tr>
<td>4. Royal Marsden NHS Foundation Trust</td>
<td>This pilot is addressed complex cancer care, and was delivered by clinician nurse specialists within an acute setting and covered breast, urology, gynaecological and prostate cancers.</td>
<td>Beverly Van Der Molen&lt;br&gt;020 8661 3951&lt;br&gt;<a href="mailto:beverley.vandermolen@rmh.nhs.uk">beverley.vandermolen@rmh.nhs.uk</a></td>
</tr>
<tr>
<td>5. Doncaster Primary Care Trust</td>
<td>The pilot developed information prescriptions for people with common mental health problems, which was delivered by case managers in a community setting.</td>
<td>Terry Cawley&lt;br&gt;07909 935 431&lt;br&gt;<a href="mailto:terrycawley@nhs.net">terrycawley@nhs.net</a></td>
</tr>
<tr>
<td></td>
<td>Information prescriptions were delivered through a community based project providing support for young people with mental health problems.</td>
<td>Steve Gregory 01785 257 888 <a href="mailto:steve.gregory@ssh-tr.nhs.uk">steve.gregory@ssh-tr.nhs.uk</a></td>
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<td>6. South Staffordshire Healthcare NHS Foundation Trust</td>
<td>Delivered through a community focused mental health ward, this Pilot will developed information prescriptions on dementia, depression and Alzheimer’s for people over 65 with mental health problems.</td>
<td>Jill Hudson 01945 482 132/ 07884 313 286 <a href="mailto:Jill.Hudson@cambsmh.nhs.uk">Jill.Hudson@cambsmh.nhs.uk</a></td>
</tr>
<tr>
<td>7. Cambridgeshire and Peterborough Mental Health Partnership NHS Trust</td>
<td>This pilot delivered information prescriptions for older people with diabetes, dementia and memory loss through community care practitioners, social workers and district nurses, with dispensing at local authority libraries.</td>
<td>Alison Wheeler 01473 264 611 <a href="mailto:alison.wheeler@libher.suffolkcc.gov.uk">alison.wheeler@libher.suffolkcc.gov.uk</a></td>
</tr>
<tr>
<td>8. Suffolk County Council</td>
<td>This pilot developed information prescriptions through a whole systems approach for older people with mental health problems and was delivered through care managers, GPs and voluntary agencies</td>
<td>Sarah Mitchell 01983 821 000 <a href="mailto:sarah.mitchell@iow.gov.uk">sarah.mitchell@iow.gov.uk</a></td>
</tr>
<tr>
<td>9. Isle of Wight Council</td>
<td>The West Midlands Cystic fibrosis centre is based in Heartlands hospital, and contains both in and outpatient wards. This pilot site focused on developing information prescriptions for people with cystic fibrosis.</td>
<td>Susan Hyde 0121 424 0855/ 07887 507 829 <a href="mailto:susan.hyde@heartofengland.nhs.uk">susan.hyde@heartofengland.nhs.uk</a></td>
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<tr>
<td>10. Heart of England NHS Foundation Trust Birmingham Heartlands Hospital</td>
<td>Led by Diabetes UK, Asthma UK and Arthritis Care in conjunction with Hammersmith and Fulham PCT, this pilot developed information prescriptions for those with diabetes, asthma and arthritis. Information prescriptions</td>
<td>Nicola Kingston 0207 786 4900/ 07905 357 211 <a href="mailto:nkingston@asthma.org.uk">nkingston@asthma.org.uk</a></td>
</tr>
<tr>
<td>11. Hammersmith and Fulham PCT, Diabetes UK, Asthma UK and Arthritis Care</td>
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</table>
were delivered in primary care, through GP surgeries.

| 12. Manchester City Council and Manchester Primary Care Trust | This site used a whole systems approach to long term conditions that was not focusing on a specific group or care setting and it covered four conditions, Parkinson's Disease, Osteoporosis, COPD, HIV and multiple sclerosis. The pilot worked with Manchester City Council and PCT, Manchester library services, advice services and voluntary agencies. It was mainly based in community settings. | Diane Eaton  
0161 273 2016  
diane.eaton@manchester.gov.uk |
|---|---|---|
| 13. North Tyneside General Hospital and Parkinson's Disease Society | This pilot developed information prescriptions for people with Parkinson's and their carers, which were delivered in secondary and tertiary care in the North Tyneside General Hospital. | Helen Kirrane  
0207 932 1325/ 07971 487 369  
hkirrane@parkinsons.org.uk |
| 14. RNIB and Yorkshire and the Humber Strategic Health Authority | The pilot site developed information prescriptions for people with sight loss, delivered in conjunction with PCTs in the Leeds area working with RNIB. Information prescriptions were delivered in a variety of health and social care settings. | Rebecca Sheehy  
0117 934 1719/ 07918 085 571  
rebecca.sheehy@rnib.org.uk |
| 15. Oxfordshire County Council | This pilot site developed information prescriptions for the deaf and hard of hearing through the Oxford Centre for the Deaf. The pilot delivered information prescriptions through audiologists and the hearing impairment team in secondary care, in collaboration with primary care and voluntary organisations. | Varsha Raja  
01865 854 437/ 01865 854 508  
varsha.raja@oxfordshire.gov.uk |
<p>| 16. Leeds Mental Health Trust | The pilot developed information prescriptions for older people with | Dr Tim Branton |</p>
<table>
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<tr>
<th>17. Evelina Children’s Hospital, Guys and St Thomas NHS foundation Trust</th>
<th>Mental health problems, including depression, dementia and memory loss, from three community care settings. Information prescriptions were delivered through the trust’s ‘care programme approach.’</th>
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<td><strong>Steve Tomlin</strong>&lt;br&gt;0207 188 9202&lt;br&gt;<a href="mailto:Stephen.Tomlin@gstt.nhs.uk">Stephen.Tomlin@gstt.nhs.uk</a></td>
<td>This site developed information prescriptions for children with a particular focus on the appropriate use of medicines. Information prescriptions were delivered in secondary care through the hospital and in primary care through community pharmacy practices. The long term conditions covered included epilepsy, renal transplants, asthma and cardiac problems.</td>
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<th>18. Oxleas NHS foundation trust</th>
<th>This pilot site developed information prescriptions for people with long-term complex conditions including long term psychosis and bi polar disorder. Information prescriptions were delivered in the Bromley complex needs services through care co-ordinators.</th>
</tr>
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<tr>
<td><strong>Dr Geraldine Strathdee</strong>&lt;br&gt;0208 676 8250/ 07771 982 946&lt;br&gt;<a href="mailto:geraldine.strathdee@oxleas.nhs.uk">geraldine.strathdee@oxleas.nhs.uk</a></td>
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<tr>
<th>19. Darlington Primary Care Trust</th>
<th>This site, led by PALs, developed the role of GPs and practice nurses in referring users to dedicated website from which users can dispense information prescriptions. This pilot focused on diabetes, COPD, depression and long term neurological conditions.</th>
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<tr>
<td><strong>Clare Hinton</strong>&lt;br&gt;01325 746 175&lt;br&gt;<a href="mailto:clare.hinton@darlingtonpct.nhs.uk">clare.hinton@darlingtonpct.nhs.uk</a></td>
<td></td>
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</tbody>
</table>
| 20. South Essex Partnership NHS Foundation Trust | Information prescriptions were developed for complex mental health conditions including Huntingdon’s disease, Asperger’s syndrome, Obsessive compulsive disorder and manic depression through the Adult Mental Health Assertive Outreach Service in a range of settings | Mike Waddington  
01375 364 650  
mike.waddington@southessex-trust.nhs.uk |
Appendix Two: Glossary of terms

- **Users** - patients or social care clients who could receive information prescriptions
- **Carers** – those who provide unpaid care for users
- **Professionals** – paid staff from either the statutory or voluntary sector involved in delivering IPs
- **Volunteers** – unpaid staff who support IP processes
- **Personalised** - refers to the process through which information is customised to ensure that it meets the user’s needs at each stage in the care pathway. The aim is for an IP to facilitate self-management, by offering synthesised information on a range of topics, agreed between the user and the professional, in a format accessible to, and appropriate for, the user.
- **In depth support** – refers to pilot sites which were able to provide a significant amount of additional support to users and carers during the prescribing and dispensing process, such ensuring that information is tailored around the needs of the user so that they can receive a range of information sources depending on where they are in their care pathway and providing additional explanations and advice on the information sources.
- **Light touch** – refers to pilot sites that largely enabled users to access their own information through self dispensing, with limited information tailoring or the provision of additional support.
- **High risk** – this describes a user who is likely to have one or two conditions but can become unstable and may need a significant amount of acute care.
- **Highly complex** – this describes a user who is likely to have a number of conditions and complex problems and requires a significant amount of treatment in acute settings.
- **LSP** - Local Strategic Partnerships are non-statutory, multi-agency partnerships, which matches local authority boundaries. LSPs bring together at a local level the different parts of the public, private, community and voluntary sectors; allowing different initiatives and services to support one another so that they can work together more effectively.
- **Signposting** – signposting refers to when a user is directed by a care professional to a place where information can be accessed
- **Tailoring** – is part of the personalisation process, and involves the professional identifying and selecting the user or carers information needs from a range of options depending on which point in care or stage on the care pathway the user is.
- **IP systems** - the whole approach to delivering IPs adopted in a pilot site; to include, the processes for developing and maintaining directories, completing templates, prescribing and dispensing IPs
- **IP directories** - categorised databases or lists of resources which contain the information provided to the user or carer. These may take the form of websites, electronic databases or hard copy lists.
- **Integrated care pathway** - a multidisciplinary outline of anticipated care (i.e. one that involves different groups of professionals), supported by a detailed timeframe, that
enables a user to move progressively through a particular section of the health and social care system.

- **The IP template** - electronic, audio or hard copy format in which the information needs of a user or carer are summarised and issued to them in order that they can access them. IPs aim to cover the health, social care, practical and local information that can support users and carers in managing their condition and improving their quality of life.

- **Information prescribing** - the process of assessing and recording the information needs of a user or carer on an IP template, through a supported and structured conversation between professional and IP recipient.

- **Information dispensing** - the process of compiling and issuing the information which responds to the stated needs of the user. This may be done in person or remotely, e.g. by post, electronically or via a website.

- **Information Prescription Generator (IPG)** - a tool which provides an interface between a directory and a template, and produces, or generates, an IP electronically.
Appendix Three: Examples of IP templates

Northumbria Healthcare NHS Trust

Evaluation of Information Prescriptions

Hammersmith and Fulham

Health Professional’s Name

Diabetes (Type 2)

Working together to improve care for people with long-term conditions
Doncaster PCT

Special Requirements
Language ________________ Braille ☐ Audio ☐ Large Print ☐

ID Number

Useful Information & Resources (Websites, organisations etc)
1
2
3
4

Additional Information (Employment, education, benefits etc)
1
2
3
4

Useful Contacts
IAPT: 01302 640162 Samaritans: 08457 90 90 90
NHS Direct: 0845 46 47 Saneline: 08457 767 8000

Case Manager ________________ Date __________
Consent to survey ☐