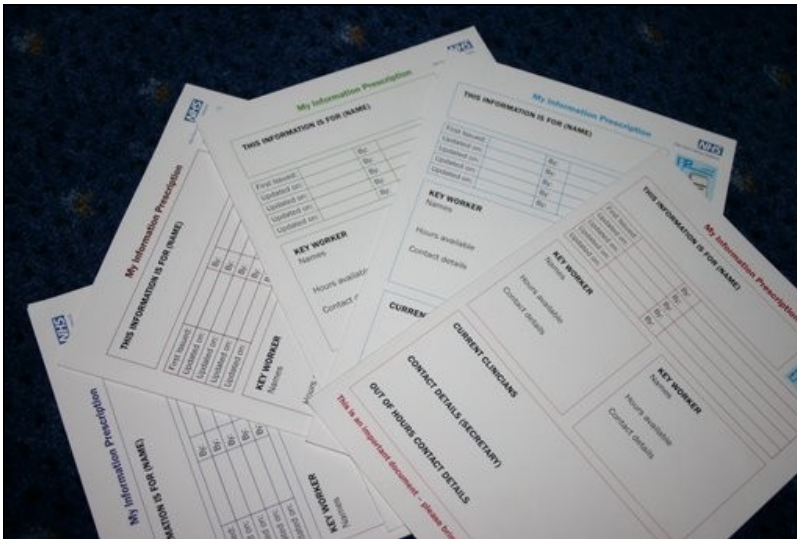




Mid Trent Cancer Network

# MID TRENT CANCER NETWORK INFORMATION PRESCRIPTIONS PILOT PROJECT

## END OF PROJECT REPORT AND SUSTAINABILITY PLAN



April 2008

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## FOREWORD

As a service user representative within the Mid Trent Cancer Network I felt honoured when asked to chair the Information Prescription Pilot Project Steering Group. This pilot project, funded by the Department of Health was one of 20 selected pilot project sites spread over the UK and this is the largest of this kind.

I have at the same time been privileged to be part of a highly motivated working team consisting of patients, family carers, and those involved in providing the health and social care services to people affected by cancer. Our academic abilities, knowledge and skills covered a wide and diverse range and included both Medical and Clinical Nurse Specialists with Elaine Wilson as Project Director and Sheila Williamson as Project Manager. They both kept the team focused ensuring total involvement from everyone so that the concept of the Patient Information Prescription became powerful, meaningful and helpful resource for people affected by cancer. Furthermore the design of this prescription could be readily adapted to suit a patient with any form of cancer or other long term health problem.

From a patient and family carers perspective I am very aware that patients are often expected to make choices about their treatments without having an adequate knowledge or understanding of their diagnosis or the treatments being offered. This creates great anxiety and uncertainty as it is so important for them to feel confident in the choice they make.

In August 2007 The Department of Health made the following promise: -

*"From 2008, information prescriptions will be given to everyone with a long-term condition or social care need, in consultation with a health or social care professional. Information prescriptions will guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence.*

*Information prescriptions will be nationally recognised as a resource of key information on services and care that is seamlessly and formally integrated into the care process."*

Here within the Mid Trent Cancer Network the patients and their family carers from across Nottinghamshire and Lincolnshire have worked alongside those who plan and deliver services to people affected by cancer to design, develop and introduce information prescriptions which are helpful and meaningful and provide a workable and sustainable resource in the NHS, supporting services and the private sector.

Freda Ingall  
Chair  
Information Prescription Pilot Steering Group

May 2008

## INTRODUCTION

This report is set out in four sections.

- **Section One** Outlines the context and ‘story so far’ in relation to the Mid Trent Cancer Network Information Prescriptions (IP) Pilot.
- **Section two** Focuses on making the case for information prescription roll out beyond the pilot.
- **Section three** Sets explore the issue of sustainability and sets out a process for implementation of integrated information support for people with cancer.
- **Section four** Provides conclusions.

## 1. SECTION ONE – BACKGROUND INFORMATION

### 1.1 THE NATIONAL CONTEXT

‘Our health, our care, our say’ (Department of Health, January 2006<sup>1</sup>) announced an intention to provide everyone with long-term health and social care needs, and their carers an ‘information Prescription’. The idea for these Information Prescriptions arose from the need for people with cancer to have access to information that is more directly relevant to their diagnosis and personal circumstances, so that they are better equipped to make decisions about their treatment and their future. Subsequently, the Department of Health established 20 pilot sites to develop and test Information Prescriptions. These pilots cover a range of geographic areas and clinical areas. The clinical areas include:

- Cancer
- Mental Health
- Long term conditions (asthma, diabetes, COPD)
- Arthritis
- Parkinson’s Disease
- Cystic Fibrosis
- Sight loss
- Deaf and hard of hearing

The aim of the Information Prescription Pilots is to develop a systematic approach to IPs that ensures that anyone with a long-term condition or social care need and/or their carer can access information that is relevant to their well being, health and care. Building on the results of the pilots, IPs will be rolled out across England.

The benefits of IP’s are anticipated as being:

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<sup>1</sup> Our Health, our care, our say – a new direction for community services (2006) Department of Health.  
<http://www.dh.gov.uk/en/Publicationsandstatistics>

- Patients having the right information at the right time to enable them to make informed choices.
- A process that will support and empower individuals to self-care/manage and to feel more in control of their care.

## 1.2 THE LOCAL CONTEXT

Historically the Mid Trent Cancer Network (MTCN) has focused on developing and delivering high quality patient and carer information. The MTCN has developed and implemented patient information pathways to support three clinical pathways within the areas of lung, head and neck and gynaecological cancers.

An evaluation by Nottingham University of the Cancerbackup/Mid Trent Cancer Network<sup>2</sup> Patient Information Project provided a rich data source highlighting the need for further work on information and how it is provided.

The key findings from the research are provided in Appendix One. The conclusions reached were that:

1. There is variability in patient preferences and responses to information. This can result in difficulties in developing appropriate and sensitive professional and service responses, which can adequately and appropriately address these.
2. Patients and carers prefer tailored information to be communicated directly to them by the health professionals involved in their care and treatment.
3. Administrative inefficiencies and bureaucratic unresponsiveness cause distress and frustration for patients and carers and this was the area in which respondents experienced the greatest information deficit.

The findings of the research provided an excellent baseline to develop further patient information, and the way it is given to patients and carers across the MTCN alongside the information pathways. These developments put the MTCN in a position of strength to successfully bid to become one of the four cancer IP pilot sites in December 2006.

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<sup>2</sup> Nottingham University Report (2006) Evaluating the 'Cancerbackup Network Patient Information Project 2004-2006': users' experiences of patient information delivery across a cancer network. Available from the MTCN

### 1.3 THE PURPOSE AND OBJECTIVES OF THE PROJECT

In reality the starting point for the IP pilot was a blank sheet of paper as very little previous work had been undertaken. The Cancerbackup definition of what an information prescription is has proved very helpful:

*A source of personalised information that lays out clearly and simply the salient points about an individual's consultation with a healthcare professional about their diagnosis, treatment and/or care plan and points the way to other relevant sources of high quality information and support. It is designed to improve the dialogue between patients and health professionals and enhance the valuable face-to-face time within consultations".*

With this in mind the purpose of the pilot was for IPs to empower people to:

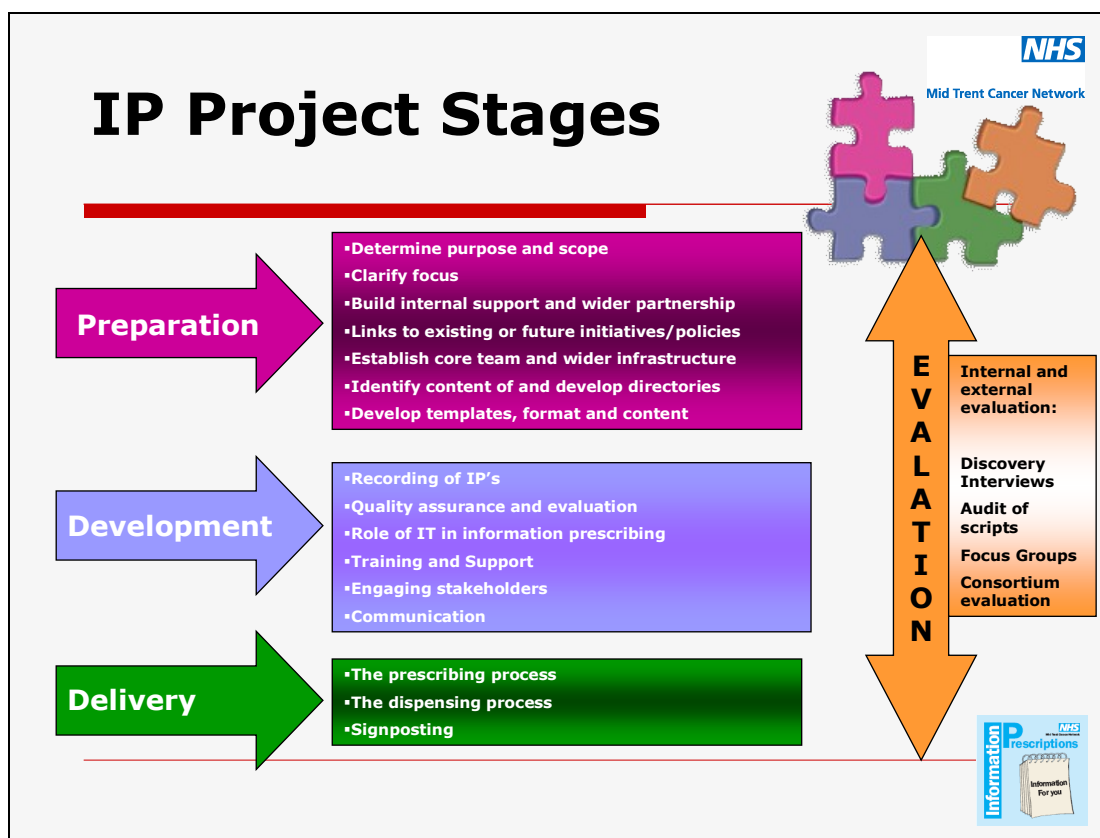
- Manage their care more effectively.
- Help them stay more independent.
- Feel more in control.

The overarching objectives for the Mid Trent Cancer Network Information Prescriptions Pilot Project were that by the end of March 2008 to have:

- Designed, developed and tested Information Prescriptions for patients with Lung, Gynaecology and Head and Neck Cancers, and their carers within the Mid Trent Cancer Network.
- Explored the opportunities of using Information Prescriptions in primary care.
- Developed a website for information prescriptions and patient information.

Figure 1 over the page, shows the different stages of the Information Prescriptions Pilot Project. Each of these stages will be discussed in turn throughout the remainder of this section.

Figure 1: The stages of the Information Prescriptions Pilot Project



#### 1.4 THE METHODOLOGY AND APPROACH – THE PREPARATION

Some principles that underpin the methodology and approach were agreed at the start. These included:

- The involvement and engagement of stakeholders, including patients and carers and the voluntary sector, would be continuous.
- A continuous improvement methodology would be used.
- That the work would always look beyond the end of the pilot and consider longer-term sustainability and roll-out.

A work stream with a Steering Group was established for the IP Pilot and is chaired by a carer and has patient representation. Several stakeholder events have been held with excellent clinical, patient and carer attendance as well as ongoing meetings and focus groups with the clinicians issuing the IPs.

At the pilot launch event in March 2008 'Ten guiding messages' were developed. These have helped focus the project throughout, and are listed in Table 1:

**Table 1: The Ten Key Guiding Messages for the IP Pilot Project**

1. **Both patients and carers needs must be considered.**
2. **Written information should not replace verbal or face-to-face contact.**
3. **Information needs to be specific and personalised.**
4. **Information needs to be good quality and reliable.**
5. **Information Prescriptions should be a tool to help facilitate and navigate the journey.**
6. **Information Prescriptions should have content as well as sign post.**
7. **Information Prescriptions should compliment rather than duplicate what is already in place.**
8. **Information is a choice.**
9. **The information Prescription needs to cover the whole of the pathway of care including pre-diagnosis.**
10. **Keep it simple!**

## **1.5 THE DEVELOPMENT AND DELIVERY**

As described earlier the MTCN have previously developed three information pathways supporting the clinical pathways for lung, head and neck and gynaecological cancers. Because these pathways were already in place these were the clinical areas selected for the initial work on developing IPs in the pilot.

As a result of feedback from the launch event it was agreed that the clinicians best placed to issue the IPs in the early stages were the Clinical Nurse Specialists (CNS). Regular meetings and processes were put in place to engage widely with the CNS's to ensure their input into both the development of the IP documentation and of the issuing processes.

The initial development phase of the template and the operational policy were developed between April and mid July 2007 with the first IP being issued in July by a Lung Cancer CNS.

The development of both the IP and the operational policy has continued and is viewed as a dynamic process with each refinement bringing an improved IP and operational process.

## 1.6 NATIONAL EVALUATION

A national evaluation process has been undertaken by an evaluation consortium made up of OPM, GFKNoP and the University of York. The final evaluation report is available at <http://www.informationprescription.info/>

From the work of the pilots the interim report sets out the **success factors** believed to be needed for wider roll out of information prescribing. They state that IPs:

1. Need to be evidence-based and reliable providing high quality and timely information.
2. Must be cost-effective and affordable.
3. Must be accessible for all.
4. Need to be integrated and seamless.
5. Must be personalised.
6. Need to have user involvement – user-led design and development.
7. Need to contribute to the improved health of users and carers (especially those who are excluded).
8. Must be evolving and dynamic – responsive to the changing needs of patients and professionals and updated.
9. Must have professional and stakeholder support.

In addition they highlight the importance of well-trained professionals and information providers.

It is important to note that differing approaches to IPs were adopted across the pilot sites. In effect the approaches can be considered along a continuum ranging from:

- **Light touch** where pilot sites largely enabled users to access their own information through self dispensing, with limited information tailoring or the provision of additional support

To

- **In depth support** where pilot sites provided a significant amount of additional support to users and carers during the prescribing and dispensing process therefore 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.

The MTCN pilot adopted an ‘in depth support’ approach.

The final report outlines the impact of IPs on patients, carers and professionals. A short extract is provided below and full details of this can be found at <http://www.informationprescription.info/>

### Impact on users

Three quarters of users agreed that they felt more confident about asking questions about their condition following having an IP. 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 and people living in disadvantaged areas.

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, those in poorer general health, people who got an IP through primary care, those with light-touch information and for people living in less affluent areas. Higher figures were recorded for people living in more affluent areas and for those who received an IP through acute settings.

Two-thirds 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, mental health patients, those in poorer general health, people who had light-touch IPs and people living in relatively deprived areas.

### Impact on carers

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

## 1.7 LOCAL EVALUATION

In addition to the national evaluation there was a view that additional local evaluation was needed because:

- The national evaluation would not provide any specific local feedback.
- The timing of the national evaluation would not be early enough to make any changes or adjustments to local processes of development and implementation of IPS.

Two strands of work were undertaken for local evaluation:

- Focus groups with the Clinical Nurse Specialists issuing the IPS.
- Discovery interviews with a sample of patients who had received an IP.

### **Feedback from the CNS Focus Groups**

A full copy of the evaluation report from the focus groups can be obtained from the MTCN. A summary of the key messages is provided in Appendix Two. The key messages and thoughts shared for the future role out of IPs are outlined below.

#### **Sustainability**

- Additional time is required for whoever is issuing the IP which includes time for preparation, completion and copying.
- There are associated costs in terms of printing, copying and filing.
- Training and development – there will be a need for ongoing training and development if IPs are to be truly embedded in practice.

#### **Equity**

- It will be important that IPs are not just issued to patients and carers on certain pathways but need to be a choice that all patients and carers have.

#### **Quality**

- A fundamental aspect of the IP process will be ensuring up to date reliable information and sources of information. This will require ongoing commitment and input of health care professionals and network staff to ensure this is maintained.

### **Feedback from the discovery interviews undertaken with patients**

A copy of the report from the discovery interviews can be obtained from the MTCN.

Table 2 on page 12 outlines the key messages that emerged from the discovery interviews.

**Table 2**

<b>Theme</b>	<b>Key messages</b>
1. – Experience of receiving an IP	<ul style="list-style-type: none"> <li>• There was a general preference for people to receive the IP before or after the point of diagnosis although a judgement about this must be made by the CNS on an individual basis.</li> </ul>
2. – Time spent with the CNS	<ul style="list-style-type: none"> <li>• The time spent and discussion with the CNS is highly valued by patients and a key part of issuing an IP is this interaction and ongoing contact with the CNS.</li> </ul>
3. - The value of an IP	<ul style="list-style-type: none"> <li>• Having the contact details written down are very important</li> <li>• Having the diagnosis written down is very important</li> <li>• The IP provides a process for keeping all the information together</li> <li>• Not all people want written information and an IP should not replace verbal interaction</li> </ul>
4. - The format and layout of the IP	<ul style="list-style-type: none"> <li>• Generally the layout and design of the IP is good</li> <li>• There should be text on the IP telling patients that this is an important document and they should bring it to each appointment</li> <li>• The contact numbers and diagrams are particularly helpful</li> <li>• The principles, lay out and design of the IP may be applicable to people with diseases other than cancer</li> </ul>
5. - Could an IP help other family members or carer?	<ul style="list-style-type: none"> <li>• An IP specifically for carers would be helpful</li> <li>• The importance of the IP needs to be emphasised by health care professionals</li> </ul>
6. – Using the information and signposting from the IP	<ul style="list-style-type: none"> <li>• There is variation in how people use signposting within the IP – which may be dependant on how they prefer to access information – it is personal!</li> <li>• The contact numbers, the diagrams and the diagnosis written down were the key points that people remembered and used in the IP</li> <li>• The majority of people had looked at the leaflets and booklets they had been given at the time the IP was used</li> </ul>

As a result of the feedback both from the CNS focus groups and the discovery interviews changes were made to both the IP template and the operational process for issuing IPs.

## 1.8 PROJECT OUTCOMES

The end of the official information prescriptions national project was in January 2008, however, the MTCN has continued with the local pilot until March 2008. The key deliverables achieved by the project have been:

- Engagement of a range of stakeholders including patients and carers in the development of both the IP template and operational process.
- Development of an IP template for head and neck, lung and gynaecological cancer clinical pathways.
- Development of an operational process and policy for the prescribing of IPs and for issuing information.
- Design, development and launch of a website specifically dedicated to patient and carer information.
- Initial development of an information pathway, IP template and operational policy for the colorectal cancer pathway.
- Initial development of an information pathway and IP template for a carers IP.
- Development of an information pathway and template for an IP for end of life care to be issued in primary/community care.
- Review and further development of the information within the information pathways for head and neck. Lung and gynaecology.
- Delivery of all targets set by the national team for the IP project.

Over 454 IPs were issued across the network to the end of March 2008.

- The bar chart in Figure 2 shows the number of Information Prescriptions issued each month from July to the end of March 2008
- The Pie chart in Figure 3 illustrates the number of IP's issued for each of the tumour sites.
- Figure 4 shows the number of IPs issued by gender

Figure 2

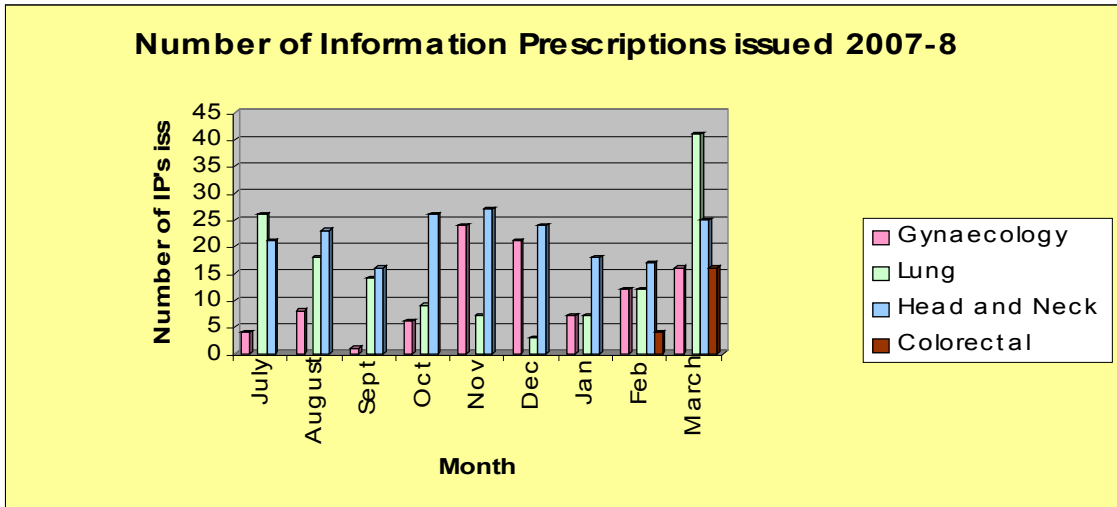


Figure 3

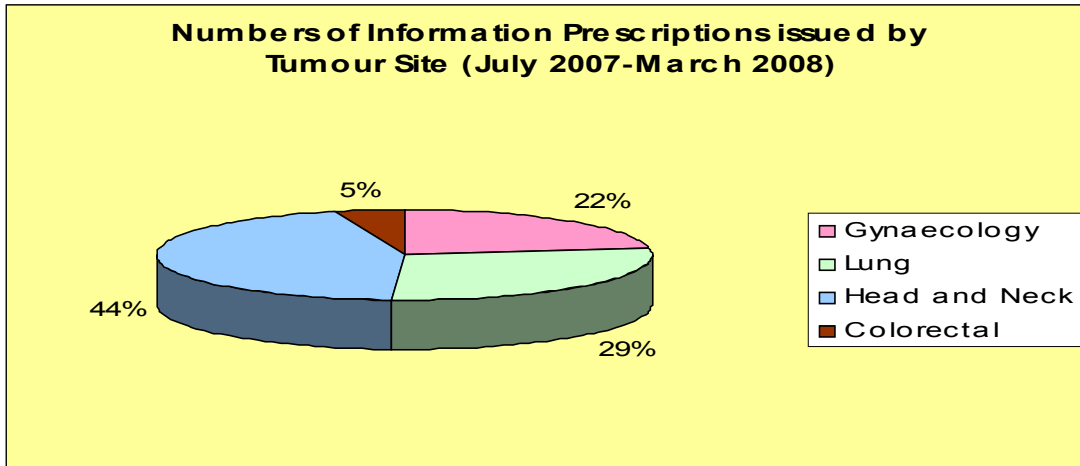
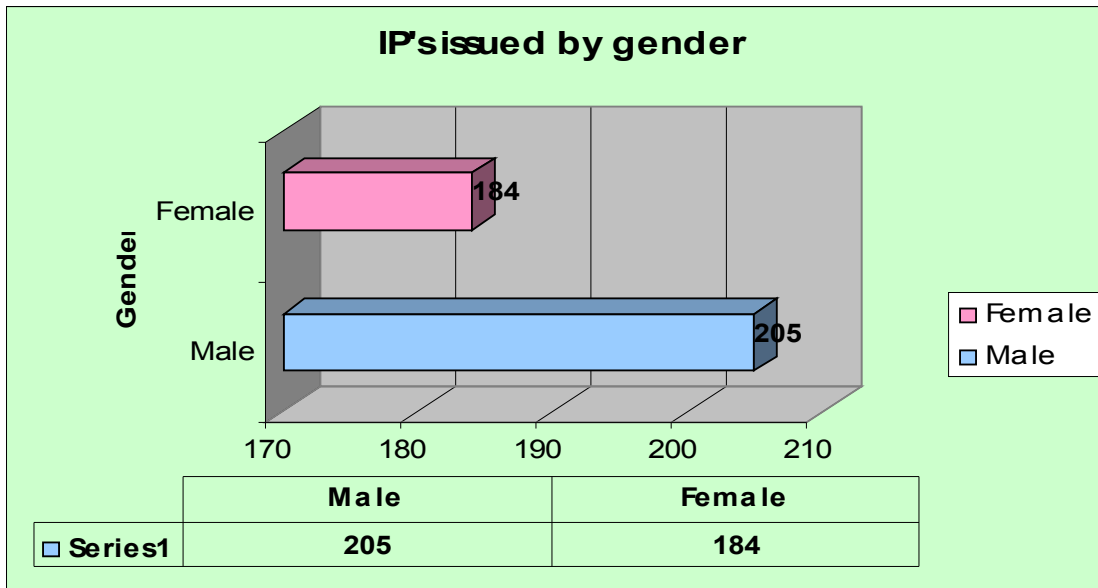


Figure 4



## 2 SECTION TWO – THE CASE FOR INFORMATION PRESCRIPTIONS BEYOND THE PILOT

### 2.1 BACKGROUND

The giving and receiving of information is widely regarded as essential in helping individuals understand what is happening to them and enabling them to make informed decisions. This need for information and support when people are facing serious health problems is well documented and is seen as a primary mode of coping with the stress of illness<sup>3</sup>. In the cancer setting, information has been found to aid coping<sup>4,5</sup> to lower anxiety and distress<sup>6</sup>, and to be a necessary pre-requisite to informed decision making<sup>7</sup>.

Providing cancer patients and their carers with high quality tailored information to meet their needs at appropriate stages in their care pathway is now a policy priority, backed by a range of policy documents<sup>8,9,10</sup> the most recent being the Cancer Reform Strategy (CRS)<sup>11</sup>.

The CRS<sup>11</sup> clearly sets out the importance of information and places importance on developing:

- National information pathways and tailored Information Prescriptions that will help to ensure that patients receive high quality information at each step in the care pathway.

The CRS recommends that the issues of information, better face-to-face communication and support for decision making should be given the highest priority with regard to actions to improve patient experience. It is recommended that action be taken at both national and local levels.

The work currently happening across all health communities following Lord Darzi's interim report<sup>12</sup> has 'end of life care' as one of the eight work streams where information is recognised as a key feature in ensuring a positive experience for both patient and carer at this highly sensitive and personal point in the cancer journey. This is reflected in the NHS East Midlands Strategic Plan<sup>13</sup> where there is commitment to the 'end of life' point in disease trajectory to ensuring that carers and their families are central to decision making.

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<sup>3</sup> The University of Nottingham (October 2006) evaluating the 'Cancerbackup Network Patient Information Project 2004-2006': users' experiences of patient information delivery across a cancer network.

<sup>4</sup> Weisman, A.D. (1979) Coping with cancer, London, McGraw Hill.

<sup>5</sup> Harrison-Woermke D.E. & Graydon J.E. (1993) Perceived informational needs of breast individuals with cancer receiving radiation therapy after excisional biopsy and axillary node dissection. *Cancer Nursing* 16 (6) , 449-455

<sup>6</sup> Ridgeway, V. and Mathews, A. (1982) Psychological preparation for surgery: a comparison of methods. *British Journal of Clinical Psychology*

<sup>7</sup> Luker K.A., Beaver K., Leinster S.J et al ( 1995) the information needs of women newly diagnosed with breast cancer. *Journal of advanced Nursing*.

<sup>8</sup> Department of Health (2000) The National Cancer Plan Department of Health

<sup>9</sup> Department of Health (2000) Towards a cancer information strategy Department of Health

<sup>10</sup> Department of Health (2004) Better information, better choices, better health, Putting information at the centre of health Department of Health

<sup>11</sup> Department of Health (2007) The Cancer Reform Strategy Department of Health

<sup>12</sup> Our NHS Our Future Interim report (October 2007) Department of Health

<sup>13</sup> Better Health, Better Care Preparing for the next stages (October 2007) NHS East Midlands Strategic Plan

These are all clear drivers grounded in research and policy, to provide high quality, personalised information, which is delivered using co-ordinated and planned approaches. One option for achieving this is to develop further IPs supported by information pathways.

## 2.2 HOW IP's SUPPORT AND ENHANCE OTHER NHS PRIORITY WORK STRANDS

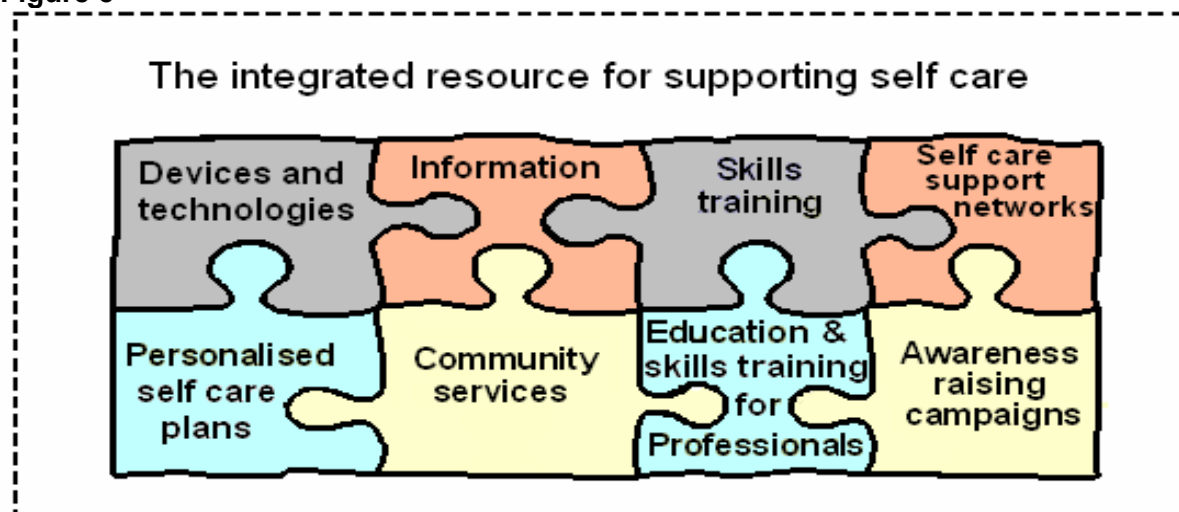
There are clear policy messages regarding designing and delivering services that empower and support individuals and their families and carers to 'self care' of which a key feature is information. A recent DH publication reviewing large number of systematic reviews and primary research relating to self care interventions reported that<sup>14</sup>

*“Overall the evidence suggests that self care support can result in beneficial health outcomes for people and more appropriate use of health and social care services. It should help ensure that self care support becomes an integral part of an effective and efficient healthcare system throughout the country.”*

The report states that the beneficial impact of different types of self care support will be best achieved if the self care support resource is integrated, and also includes self care skills training health and social care professionals. Figure 5 illustrates this.

IPs, the Information4u website developed by the IP pilot and the MTCN 'My little blue book' initiative together provide many of the aspects of this model of integrated support for self care.

Figure 5



The integrated information4u website and my little blue book provide a process for delivering features 2, 4, and 5 with further potential for 3 and 7. This is outlined in more detail below.

## 2.3 PATIENT INFORMATION

As highlighted in Section 1, the starting point for developing an IP is ideally to develop an underpinning patient information pathway which provides information that has been quality assured. This ensures that there is a readily available cohort of information that is deemed appropriate by both patients and carers for key delivery points on the pathway. In addition there is additional, more generic information, that again is quality assured, and can be

<sup>14</sup> Department of Health (2007) Research evidence on the effectiveness of self care support

selected as felt appropriate. A key feature of the IP is the contact numbers that are regularly updated by health care professionals to ensure all patients and carers know how to contact the right service at the right time.

There is evidence from recent work in Lincolnshire of the importance of people being able to contact services out of hours and of this preventing inappropriate hospital admissions.

The IP process could be easily further developed to provide the 'front end' of a process that directs people 'out of hours' to appropriate services.

It is important to be clear that when developing a new pathway not all the information has to be newly written - there are excellent sources of information available from charities and other sources. However it does have to be agreed and a process established to ensure it is maintained, up to date and relevant. The Cancer Action Team is currently developing a number of national information pathways that will be available for local use and will support the IP process.

As well as prescribing information the IP is a tool for signposting and for each pathway or process agreement must be reached on the appropriate websites or contact numbers to signpost.

The information4U website contains all the leaflets and sources of information that can be downloaded and printed. In addition it provides links and signpost to other high quality information including many of the charity websites.

### **2.4 SELF CARE SUPPORT NETWORKS**

The IP and the information4U website both provide details of local support networks. The information4u website is developing a discussion forum that allows patients and carers to share concerns or worries within an online forum. This is an area that carers reported they were keen to see developed.

A process is being established to get consent and record details of individuals who have accessed the website. There is the potential to then use this information for social marketing. In the longer term it is anticipated that there will be a question and answer facility that will allow people to post questions and a forum moderator will pass the questions to appropriate health care professionals for a response.

### **2.5 PERSONALISED CARE PLANNING**

The IP provides a process that encourages a discussion between the health care professional and the patient and family or carer about 'what happens next'. This can be recorded in the IP and updated at subsequent visits. In addition to the IP is 'My little Blue Book' which acts as a personal record for the patient to record and share both their process or plan and experience of care.

Work is currently underway to develop and pilot an 'end of life' IP which incorporates aspects of care planning where patients and carers can indicate and document their:

- Wishes and preferences for how and where they want to be cared for
- Action plan
- Worries and concerns

- Information needs.

The development work for the 'end of life' IP has included representation from patients, carers and professionals beyond cancer. It is reported that the IP template that has been developed could be easily used for the 'end of life' stage for any condition.

## **2.6 SELF CARE SKILLS TRAINING**

The MTCN have plans to develop a self care skills training module that will be accessed via the information4u website. This will be tailored to support patients, carers or/and health care professionals. A similar approach has been adopted for Advanced Decision Making training.

### 3 SECTION THREE – IMPLEMENTATION OF IP'S BEYOND THE PILOT

#### 3.1 SUSTAINING THE WORK OF THE IP PILOT

It is clear that IPs and the supporting processes can make a contribution to both the cancer agenda on supporting and empowering individuals, their families and carers and also the wider long term condition agenda where these tools and processes could be easily adapted to any long term condition.

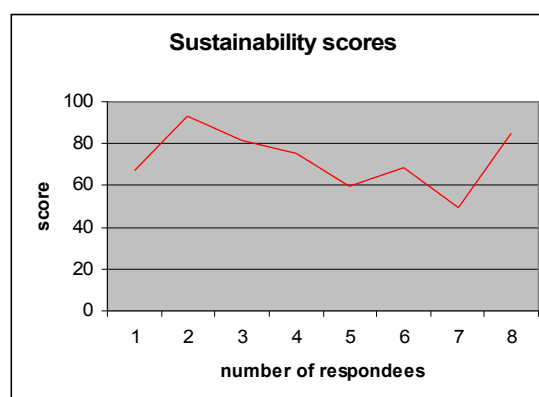
This paper only considers how the integrated information support model can be rolled out within the MTCN.

As previously described, IPs have been developed across 3 cancer clinical pathways with work underway for 3 others. As well as identifying opportunities to develop the project further it is important to establish if what has already been developed is sustainable.

The NHS Institute for Innovation and Improvement (NHS III) identifies that one of the primary reasons why quality improvement is difficult to integrate into an organisation is that many of the changes that are put into place fail to survive<sup>15</sup>. Within the literature there is evidence of a high failure rate, up to 70%, of organisational change<sup>15</sup>. In an attempt to substantially increase the sustainability of improvements for patients and healthcare services, the NHS III have developed a Sustainability Model and Guide for use by individuals and teams who are involved in local improvement initiatives. The Sustainability Model is a diagnostic tool that is used to predict the likelihood of sustainability of an improvement project.

The Model consists of ten factors relating to process, staff and organisational issues that play a very important role in sustaining change in healthcare. The NHS III report that preliminary evidence suggests an overall score of 55 or higher offers reason for optimism. Scores lower than this suggests that action needs to be taken to increase the likelihood that the improvement initiative will be sustainable.

Members of the Network Information Steering Group were asked to complete the tool in terms of their perspective on whether or not the project was sustainable. The scores are illustrated in the graph opposite illustrates the scores.



Overall the scores showed that members of the Steering Group and the CNS's issuing the IPs believe that the current IPs for the three clinical pathways could be sustained assuming there is ongoing training and support in the form of focus groups. However there was clear feedback that additional resource would be required in order to progress the further roll out of the IPs beyond the current three pathways. The feedback relating to the support that would be required in terms of rollout is outlined under the model headings process, staff and organisation.

<sup>15</sup> NHS Institute for Innovation and Improvement (2007) Sustainability Model and Guide [www.institute.nhs.uk/sustainability](http://www.institute.nhs.uk/sustainability)

### 3.2 PROCESS

There was clear feedback from the evaluation work undertaken locally that there are benefits in the process. This includes:

- Reducing duplication of information.
- Focusing on the quality of information.
- Providing a clear process for how individuals contact services out of hours thus potentially preventing inappropriate hospital admissions.

Staff involved in the process can see the benefits and are committed to continuing.

In order to roll this out beyond the current pathways then resources would be required in process terms to:

- Develop the supporting information pathways for the additional clinical pathways – ensuring involvement and engagement of clinical staff.
- Sell the concept of the IPs to a wider range of professionals to become involved in issuing.
- Refine the operational policy.
- Amend the templates to reflect the information pathways of each clinical pathway.
- Ongoing updating and development of the Information4U website.
- Dedicated session to moderate the online discussion forums and question and answer sessions.
- Support to evaluate the integrated model at the 6 and 12 month points.
- Dedicated time to develop further the work on how IPs could be rolled out wider in primary care.

### 3.3 STAFF

The Sustainability model identifies four areas under the heading of staff that require attention for successful sustainability these are:

- Staff involvement and training to sustain the process.
- Staff behaviours toward sustaining the change.
- Senior leadership engagement.
- Clinical leadership engagement.

All four of these areas would require additional input beyond the current network infrastructure for further roll out of this model. Staff involvement and training would be a key aspect of ensuring further roll out and sustainability. Additional resources would be needed to engage key staff, including clinicians, in the concept of the model and in gaining 'buy in' to both the principle but also to implementation. There would also be a need for ongoing training and support to new staff issuing IPs similar to the support provided in the pilot. This comprised of regular 3-4 weekly meetings with staff issuing the IPs for the first 3-4 months using an Action Learning type approach.

Regular and ongoing clinical engagement would be necessary in the form of regular updates provided to NSSGs and clinical education forums.

Senior leadership sponsorship would be sought through the MTCN board.

### 3.4 ORGANISATIONS

In order to embed IPs, within day to day practice, health and social care organisations need to be engaged and committed to the process as an integrated aspect of the wider self care agenda.

Historically self care and empowerment has often been seen as an 'add on' and not featured highly in strategic plans. If IPs are to be sustained and developed further to be one of the vehicles for delivering an integrated self care product, then health and social care organisations will; need to invest resource.

The MTCN will be the infrastructure that supports the further development of IPs in a way that is equitable and integrated across the PCTs. Appendix Three illustrates how the work stream for the IP pilot will be integrated within the other Network work streams.

### 3.5 WHAT RESOURCE IS REQUIRED TO ROLL OUT IP'S BEYOND THE PILOT TO THE OTHER CANCER CLINICAL PATHWAYS?

Based on the experience of the pilot project the cost to sustain and develop this further as described above will be **£100,000** for the financial year 08/09. This funding will be used to:

- Provide expert facilitation in the development of the IPs and in stakeholder engagement.
- Fund all the necessary materials.
- Fund all meeting expenses – including patient and carer expenses.
- Resource the ongoing maintenance and development of the Information4U website.
- Provide support to clinical teams in developing the information pathways.
- Develop and deliver a training package.
- Fund an evaluation process.

If funding was provided beyond the end of the pilot for 08/09 then it is expected:

- That IPs will be being issued across all cancer pathways across Nottinghamshire and Lincolnshire (the Mid Trent Cancer Network).

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- To be some way towards meeting the target in 'Our health, our care, our say' (DH, 2006) that all patients and their carers by end of 2008 with a long term condition will be offered an IP.
- Support the delivery of outcomes highlighted in the locality Cancer Commissioning Action Plans.
- To implement some important aspects of the Cancer Reform Strategy (2007) in the development and delivery of patient information.

### **3.6 IP'S BEYOND CANCER**

Two PCTs have expressed interest in developing further a generic IP for 'end of life care. Both have included £35k in their proposed LDP process to fund the skills and expertise and the supporting infrastructure as described above to develop and pilot an IP for 'end of life care' for a broad range of long term conditions. One PCT to date has confirmed funding.

## **4 SECTION FOUR - CONCLUSIONS**

This report has provided detail of the MTCN Information Prescriptions Pilot. The outcomes from the pilot have been the development and implementation of an Information Prescription for three cancer pathways. In addition the pilot has:

- Commenced development work on three further IPs for colorectal cancer, carers and end of life care.
- Reviewed and updated the information pathways for head and neck, lung and gynaecological cancers.
- Develop the Information4u website as a Network wide resource.

A total of 454 IPs have been issued during the pilot phase.

National and local evaluations, including a sustainability evaluation have been undertaken - all evaluations have included patients and carers. Findings from these are that the current IPs being issued across three cancer pathways will be sustained beyond the pilot if the current support infrastructure continues in the form of training and Action Learning Set meetings. Further roll out of IPs beyond these three pathways will require investment in the financial year 08/09.

Although locally IPs have been only developed and tested for people with cancer, there is a view that the template and process that has been designed can easily be adapted to meet the needs of any person with a long term condition.

Nottingham City PCT has committed financial resource for 08/09 to develop further the end of life IP for all people with a long term condition. Bids via the LDP process have been submitted via the cancer commissioning group for additional monies to roll out the IPs to the other tumour sites across the MTCN.

### **AND FINALLY**

Thank you to everyone who has been involved with the IP pilot across the Network. Many people, including patients, carers and professionals have given freely of their time, thoughts and ideas to develop a tool and process that we believe can positively impact on both patient and carer experiences.

## APPENDIX ONE

### FINDINGS FROM THE NOTTINGHAM UNIVERSITY RESEARCH

A total of 50 interviews, 40 completed questionnaires and 4 diaries were analysed. The interviews raised a multitude of complex issues and interesting aspects of information delivery and presentation. The points that were highlighted in the report were:

- That there was a wide variation in information needs of different individuals, with some individuals stating that they would like a great deal more information than others. Advance information about tests and procedures, the nature of side effects of treatment and how to manage subsequent care were appreciated. However a marked ambivalence and even resistance towards information was also commonly expressed. Trust in professional expertise, and a preference for maintaining uncertainty, appeared to be being pursued as alternative strategies to seeking information as a means of coping with serious illness.
- As part of the evaluation it was discovered that the protocol for delivering information to patients and carers in the lung group was not being implemented in the way it had originally been envisaged. A composite pack of information was handed to patients at the start of the treatment, rather than individual items being provided selectively at appropriate points throughout the process of care. As soon as this was identified by the Project Steering Group appropriate training and intervention was implemented.
- Many respondents from the lung group expressed concerns about:
  - The volume of information received
  - The repetitiveness of information received
  - The appropriateness or relevance of the information to their particular medical condition; and
  - The appropriateness of the information to the particular stage they had reached in their illness.
- Respondents in the head and neck group rarely commented on the volume of information they received, despite the fact that they received much less than was available to most lung cancer patients, and they did not identify any repetition. They did express concern that information was too general and not specific enough to their own medical conditions. There was less concern about information being provided at an inappropriate stage.
- Respondents in both groups had a clear preference for verbal rather than written sources of information. Written information was valued as a supplement, but not viewed as a substitute, for fact-to-face discussions with health professionals.
- Respondents in both groups expressed a preference for selective, personalised and tailored information provided at appropriate stages in their illness trajectory. They were not interested in general information which had no personal application.
- Patients' and relatives' information needs differed. Relatives valued information which helped them form their own understanding of the illness. They noted that they did not always receive this kind of information.
- Most respondents reported high levels of overall satisfaction with the information they had received. However a number expressed uncertainty in not knowing what to expect or demand from information delivery. For some there was awareness of having no comparison against which to gauge their level of satisfactions, which was assessed within a context of generally low expectations.

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- Much of the pack of information was directed at patients' medical or clinical needs. Respondents would have liked more practical and lifestyle information (e.g. about travel to the hospital, or diet). The pack contained several publications providing advice concerning patients and carer adjustment to cancer and its impact on psychological wellbeing and interpersonal relationships. However these did not relate to any concerns expressed by respondents in the interviews, and do not appear to have been useful to them.
- Patients often reported frustration over the consequences of inefficient administrative routines and poor inter-professional and inter-agency communication. This translated into the experience of cancelled and missed appointments, delay in learning results of tests and in administration of treatment and difficulties in making effective contact with professional support. Lung cancer patients in particular felt uninformed about the post treatment plans for follow up and monitoring.

## APPENDIX TWO

### A SUMMARY OF THE KEY FINDINGS FROM THE CNS FOCUS GROUPS HELD AS PART OF THE LOCAL EVALUATION OF THE IP PROJECT

- Early involvement of patients and carers has been good both at the stakeholder event and as part of the steering group. This has resulted in the IP being patient focused rather than treatment focused.
- Early and ongoing involvement has resulted in passion and enthusiasm from everyone.
- The IP pilot has enabled thinking around addressing issues of equity of information. In addition the process has meant that there has been a more formalised focus to information provision.
- The process has stimulated involvement of Consultants in considering patients and carers information needs.
- The pilot has been good because it has built on previous work and has not replicated or duplicated.
- The work that had already been done on the information pathway has been invaluable in supporting the process.
- Participants felt that meeting regularly with peers has offered invaluable support both in developing the IP and supporting operational policy but also in implementation and learning 'how others were doing it'.
- Participants reported that they felt that they have been able to 'set their own boundaries' and that this has allowed them to define how the IP will look and work.
- It was reported that it has been helpful having a Project Manager and that this has resulted in there being lots of flexibility and support for making changes to the template and the information checklist.
- Participants felt that the meetings they had attended have produced outcomes and that this has helped to maintain their engagement.
- CNSs thought that issuing IPs just at the point of diagnosis was too restrictive and would like to be able to issue IPs at any point in the pathway that they think is appropriate.
- This was considered a major stumbling block for the CNSs and particularly to have to ask for it at the point of diagnosis.
- Issues were raised in terms of the additional time that is required to issue the IPs. This included the extra time required in busy clinics but also the time required in particular for CNSs who work alone, or who work part time.
- A clear message to emerge from participants was that there should be four aspects to training:
  - A robust operational policy
  - Half day training sessions
  - Learning in practice
  - Peer support
- Participants reported that the process and use of the IP tool is encouraging a focus of standardising and formalising the issuing of patient information

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