

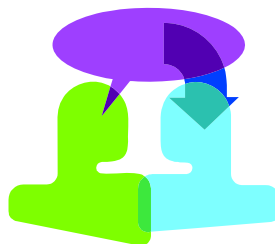
# Mid Trent Cancer Network Information Prescription Pilot Project: IP Briefing, Issue 1

Welcome to our first  
Information  
Prescription (IP)  
Briefing

These 'IP Briefings' will  
help keep you informed  
about the work that is  
going on in the Mid Trent  
Cancer Network

## Context

'Our Health, Our Care Our say' (Department of Health, 2006) says that everyone with long-term health and social care needs and their carers should have an 'information prescription' by 2008.



## Information Prescription Pilots

The Department of Health have launched 20 Pilot Sites to develop and test how information prescriptions might work. Mid Trent Cancer Network is one of the pilot sites.

## What is an information prescription?

Cancerbackup describe information prescriptions as:

*"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".*

## Mid Trent Cancer Network Pilot

The pilot is focusing on how information prescriptions (IP's) will be delivered along three clinical cancer pathways, lung, head and neck and gynaecology. The network already has information pathways in place and the IP project will explore how these can be enhanced and developed further to ensure patients and carers get information that is appropriate, personalised and given at the right time throughout their cancer journey.



The Information Prescription or IP has been designed to **provide** information to the patient or carer and **signpost** to other information that will help them through the journey. The prescription will not be a 'one off' but instead will travel with the patient and carer, helping them navigate, direct and manage their own care.

## What has happened so far?



Our pilot was launched in March 2007 with a stakeholder event that was attended by sixty-five participants who contributed to the development of what a Mid Trent Information Prescription would look like and contain. This involved patients and carers working alongside health and social care professionals and the voluntary sector.

## Who is issuing Information Prescriptions?

Clinical Nurse Specialists (CNS's) are the main people issuing information prescriptions at the moment. They are issuing them to patients who have been told that they have a diagnosis of cancer in lung, head and neck or gynaecological clinical pathways. On some of the clinical pathways Consultants are also getting involved and the information prescription is being used by both the Consultant and the CNS. The patient owns the information prescription and keeps it as a record of their discussion and as a tool to direct them to further personalised information.

The first information prescription was issued at the beginning of July to a patient on the lung cancer pathway. Since then nearly 20 Information Prescriptions have been issued, and are continuing to be offered on a daily basis.

## How are Information Prescriptions being evaluated?

Mid Trent are participating in both local and national evaluations.



The local evaluation is being undertaken by the Lead Cancer Nurses in the Network using a discovery interview methodology. The national evaluation is being undertaken by an external organisation (GfKNOP) on behalf of the Department of Health and patients are being asked for their consent at the time of issuing the information prescription as to whether or not they will participate in these evaluation processes.

## What happens next?



The project will run until January 2008. During this period we want to:

- Explore the possibility and process for issuing information prescriptions to carers as well as patients. ***“Do you think this is a good idea?”***
- Involve consultants much more widely in the issuing of Information Prescriptions. ***“Do you know a Consultant who might be interested?”***
- Explore how Information Prescription might work in primary care? ***“Do you know of a GP practice that might be interested?”***

## How to get in touch

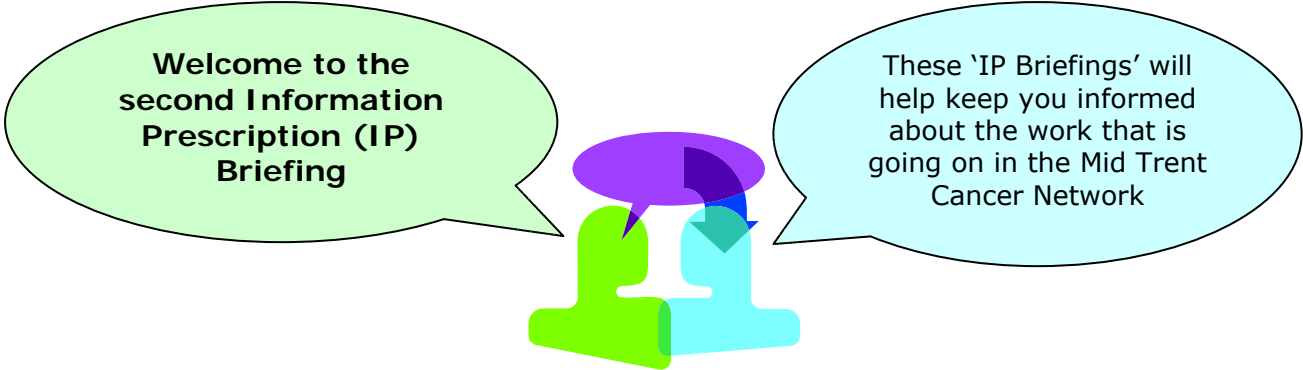
If you wish to talk to us about anything you have read in this briefing, or have any ideas and comments, then please contact either:

Elaine Wilson – Network Nurse Director – [elaine.wilson@nuh.nhs.co.uk](mailto:elaine.wilson@nuh.nhs.co.uk) or on 07887778354

Sheila Williamson – Project Manager – [Sheila.williamson@dearden.co.uk](mailto:Sheila.williamson@dearden.co.uk) or 07966330312



# Mid Trent Cancer Network Information Prescription Pilot Project: IP Briefing, Issue 2



## Designing the Mid Trent Cancer Network Information Prescription (IP)

*"We have issued over 100 IPs"*

One of the important features of this project has been that there has been a genuinely blank sheet of paper in terms of designing the IP. This has allowed the design to be determined and influenced by patients and carers and health care professionals. This has been achieved through work in the Stakeholder Workshop, regular meetings with the Steering Group (which includes patients and carers) and frequent meetings with the Clinical Nurse Specialists (CNS's) who are issuing the IP's.

A 'test and try' approach has been adopted where the CNS's have been able to make changes on a regular basis to the template. There are three cancer pathways participating in the IP process - head and neck, lung and gynaecology. The core content of the IP is the same for each pathway but all are in differing colours and have information checklists and diagrams that are specific to each cancer pathway. This is what the Information Prescription looks like. The example here is for Head and Neck cancers:

*"The pilot has built on previous work and not replicated or duplicated"*

*"There has been a lot of flexibility around the design of the IP"*

## National and local evaluation

**LOCAL EVALUATION** has included six discovery interviews with patients and carers and two focus groups with the CNS's issuing the IPs.



Some of the messages we have got back are:

### Messages from patients and carers

- Diagnosis may not be the right time to issue the IP
- The carer is often the key person looking after information needs at the diagnosis point in the pathway
- We need to explain to patients and carers about how important the Information Prescription is
- We need to encourage people to bring the IP back
- The IP has helped to keep all of the important information in one place

### Messages from the Clinical Nurse Specialists

- The process is helping to focus on patients and carers information needs but it takes time!!
- Some Consultants are getting involved with the process and like the diagrams
- How do we maintain this in the longer term and roll it out beyond the pilot?

***“IPs need to be a choice for everyone not just people on certain pathways”***

**NATIONAL EVALUATION** has included postal questionnaires to 41 patients and carers who had been issued with IPs as well as on-line questionnaires to the clinical nurse specialists issuing the IPs. A national interim report is expected in October and a second phase of evaluation will commence in November.

## What is happening in the coming months?



We are going to start developing an IP for carers and will be working closely with the CNSs, the Cancer Information Centres and carers to design an IP and a process for issuing IPs for carers. We believe this is both likely to look different and be issued differently.

**We would like to hear from any carers who would like to get involved with this.**

We have had one GP practice volunteer to work with us to look at the opportunities for using IPs in primary care. **We would like to hear from any other practices who would want to talk to us about getting involved.**

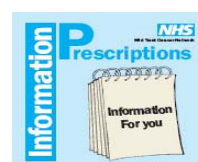
**We are starting work on developing an IP for carers**

## How to get in touch

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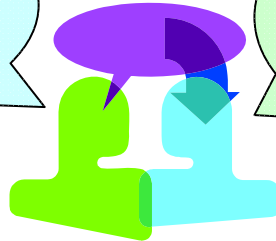
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## Mid Trent Cancer Network Information Prescription Pilot Project: IP Briefing, Issue 3

Welcome to the third  
Information  
Prescription (IP)  
Briefing



These 'IP Briefings'  
will help keep you  
informed about the  
work that is going on  
in the Mid Trent  
Cancer Network

**We are now developing an Information Prescription (IP) for carers!**

A workshop was held on the 14<sup>th</sup> of November 2007 with patients, carers and professionals to explore how an IP for carers (CIP) might look, what it might contain and how it might be issued. Judith Rookes, a local resident who cared for her husband during his prostate cancer journey shared a 'personal experience of how information could have made a difference to her'.

Thirty-four people attended the workshop and some clear messages to emerge were that:

- A carer IP would be an excellent development
- Carers feel they need a separate IP to that of the person they are caring for
- The current template is very helpful but would require some adjustment
- An information pathway for carers should be the starting point for developing a carer



**All participants received an IP mug, coaster and pencil**



**Some of the Clinical Nurse Specialists who issue the patient IPs facilitated the workshops**



## Headlines

- Both local and national evaluations have now been completed – CNSs are no longer asking patients for their consent to participate in either of the evaluation processes.
- The national interim evaluation report is available on the Information Prescriptions website <http://www.informationprescription.info/>.

## Information4u website



As this project has progressed a key area requiring further work has been the development of an 'eInformation Prescription' and electronic access to the information being issued and signposted to within the IPs. Work is underway to develop a Mid Trent

*"CNS's have issued over 180 IP's since July"*

Cancer Network Information4U website.

[www.information4u](http://www.information4u)  
will be launched in  
Jan 2008

The vision is that the website will become a resource for patients, carers and professionals with domains for each of these groups as well as many public spaces. We are currently working both on design and population of the website which will be launched in January 2008. If you wish to be involved or contribute to this development in anyway please contact Elaine or Sheila – contact details at the bottom of the page.

## Other developments

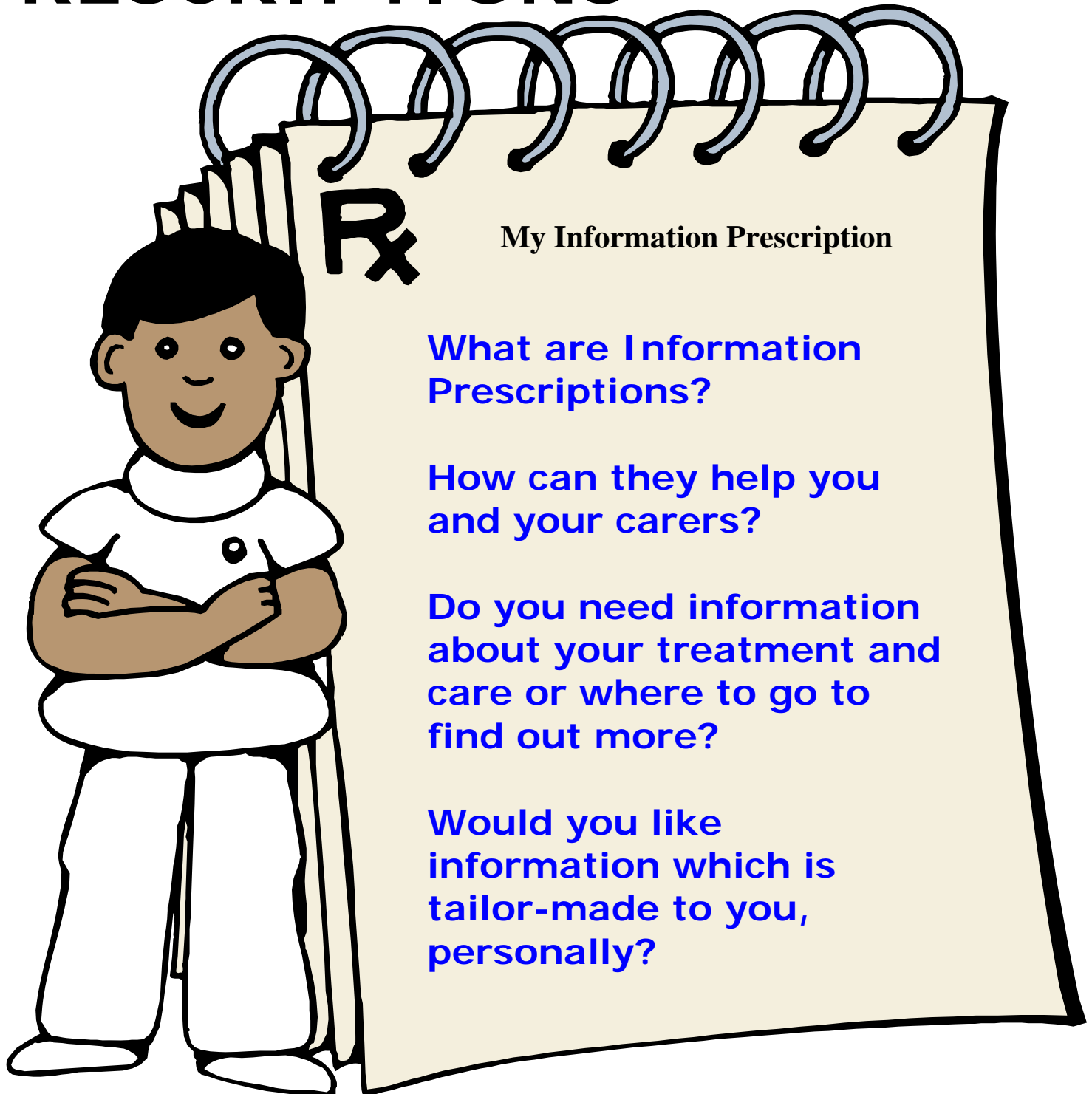
We are establishing a work stream to develop **an IP that will support the End of Life** work that has been happening across the Network. A workshop will be held on the **23<sup>rd</sup> January 2008** at the **Newark Showground.** Please get in touch if you would like to participate in this event.

## How to get in touch

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# INFORMATION PRESCRIPTIONS



For more details on the Information Prescriptions Pilot Project in Mid Trent Cancer Network, please contact:

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