
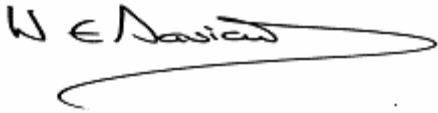


INFORMATION PRESCRIPTIONS PILOT PROPOSAL	
PROPOSED PILOT SITE	<b>Mid Trent Cancer Network</b>
Title and address  Contact name, telephone, e-mail and fax number	<p><b>Title and address:</b>  Mid Trent Cancer Network  C/O Department of Clinical Oncology  Nottingham University Hospitals NHS Trust  City Hospital Campus  Hucknall Road  Nottingham  NG5 1PB  <b>Telephone</b> 0115 9627988  <b>Fax:</b> 0115 8402652  <b>Contact person:</b> Elaine Wilson, Nurse Director  <b>Email address:</b> <a href="mailto:elaine.wilson@nuh.nhs.uk">elaine.wilson@nuh.nhs.uk</a></p>
	<p><b>Background Information on the Mid Trent Cancer Network:</b></p> <ul style="list-style-type: none"> <li>• The Mid Trent Cancer Network serves a population of approximately 1.564 million people, from which there are over 8,000 new cancers diagnosed and 4,500 deaths from cancer per year within Nottingham, Nottinghamshire and Lincolnshire. Within each of these health communities there are natural patient flows into secondary care. Patients are referred from the secondary care hospitals into tertiary care at Nottingham. There are also minor flows into and out of hospitals in neighbouring networks.</li> <li>• In total there are 3 Acute NHS Trusts (Sherwood Forest Hospital NHS Trust; United Lincoln Hospitals NHS Trust and Nottingham University Hospitals NHS Trust). There are now three Primary Care Trusts within the Network who have recently amalgamated from 10 PCT's. There are a number of specialist palliative care facilities within the Network that currently only deal with Cancer patients. There are excellent links with voluntary organisations and charities and well developed Patient &amp; Public Involvement arrangements</li> <li>• There are wide variations within the area covered by the Network with a mixture of urban, suburban and rural environments. There are areas of affluence beside areas of deprivation that are among some of the worst in the country. Nottingham City is in the top 10% most deprived Local Authorities in England, whereas Rushcliffe is in the 10% least deprived. 5 Local Authorities within the Network are in the top 25% of deprivation (Nottingham City, Mansfield, Ashfield, Lincoln and East Lindsey)<sup>1</sup>.</li> </ul>

<sup>1</sup> DETR Indices of Deprivation 2000

	<ul style="list-style-type: none"> <li>• The Network overall has markedly lower than expected numbers of people from Black and minority Ethnic backgrounds, with the exception of Nottingham City which has an above average Black and Minority Ethnic population.</li> <li>• In several areas of the network the rate of deaths from cancer is significantly higher than the national average, notably East Lindsey, Boston and South Holland in particular. Much of this can be accounted for by the age structure of these populations, with a higher than average elderly population.</li> <li>• <b>The purpose of the Mid Trent Cancer Network</b> is to provide leadership and direction to prevent people getting cancer, ensure early detection for those that do and secure optimum treatment. We do so by working in partnership with statutory and voluntary organisations, patients, carers and the general public. We always strive to remember the people we are here to serve and try, as much as possible, to see things from a patient perspective.</li> </ul>
<p>Please outline proposals for introducing information prescriptions and areas that you are proposing to cover (see section 9 of criteria document)</p>	<p><b>The Information Prescriptions Project (IPP)</b></p> <ul style="list-style-type: none"> <li>• <b>Settings:</b> The Information Prescriptions Project (IPP) would cover the whole of the Mid Trent Cancer Network as described above, covering primary and secondary care and the voluntary sector.</li> <li>• <b>Content:</b> The Project would seek to identify and assure the content of information prescriptions (For example, what do patients need, what do they want, and what is possible for professionals to deliver). The Project will examine these issues with a range of stakeholders (patients, carers and professionals), develop a range of prototypes and test them in the field to find out what works for patients). <b>Process:</b> The Project would focus on the process for issuing information prescriptions (How they are drawn up and who is responsible). It would also look at the integration of the information prescription into existing patient information pathways (Palliative Care, Head and Neck, Lung and Gynaecological Cancers) and see whether it needs to vary along the pathway, and how it gets updated and reviewed at different points along the pathway.</li> <li>• <b>Conditions:</b> The pathways identified above cover complex conditions with more than one point of care on the pathway. The Palliative Care Pathway includes non-cancer care pathways and is linked to information needs in the last stages of life (advanced care planning)</li> <li>• <b>Delivery:</b> The project would evaluate the economic implications of implementation and delivery of information prescriptions for the groups identified above.</li> <li>• <b>Impact:</b> The Network has strong links with Nottingham University, having just completed an evaluation of the implementation of the patient information pathways in patients with a diagnosis of Lung and Head and Neck Cancers. This research project evaluated the patients and</li> </ul>



<p>Identify the content for information prescriptions</p>	<p>inform the further rollout and implementation of information prescriptions to a much wider area, beyond the pilot sites in the longer term.</p> <ul style="list-style-type: none"> <li>• We would develop a sustainability plan to ensure that the work, started in the project, continues afterwards into the future</li> </ul> <p><b>Identify the content for information prescriptions</b></p> <ul style="list-style-type: none"> <li>• The Information Prescription Project Group would work with key stakeholders to develop and agree the content of the information prescriptions, which would then be tested and evaluated in more localised pilot sites.</li> </ul>
<p>When do you anticipate that work will start?</p>	<ul style="list-style-type: none"> <li>• Late December 2006, - Early January 2007</li> <li>• This depends on how soon the outcome of the bid is known. The Project Steering Group could be established with immediate effect, although it may take longer to recruit/second into the Project Manager post.</li> </ul>
<p>Signatures:</p> <div style="display: flex; flex-direction: column; align-items: flex-start;"> <div style="margin-bottom: 20px;">  <p>Peter Higgins Network Director Mid Trent Cancer Network</p> </div> <div>  <p>Wendy Saviour Chair Network Management Board Mid Trent Cancer Network</p> </div> </div>	

13<sup>th</sup> December 2006

Dear Maggie

**Re: Information prescriptions pilot proposal**

Thank you for your letter of the 4<sup>th</sup> December 2006 in response to our Mid Trent Cancer Network Information prescriptions pilot proposal. Thank you for your feedback and I am pleased to provide the following additional information to clarify the points raised in your letter:

**1. What are the estimated number of information prescriptions to dispensed per month?**

Based on the assumption that the information prescriptions will be dispensed to patients on the lung, gynaecological and head and neck cancer pathways (for which we already have patient information pathways developed) we would anticipate dispensing **approximately 150** information prescriptions per month.

**2. How will information technology be used to support information prescriptions (e.g. Electronic care record, internet use, database of directories etc)?**

The use of information technology is variable across the Mid Trent Cancer Network. Some areas have electronic records in place, while some do not. More widely, patients, carers and professionals have access to the Internet, and service directories (for example through the information centres, such as Cancerbackup at Nottingham University Hospitals NHS Trust, City Campus). We have developed patient information pathways for head and neck, gynaecology and lung cancer. The types and modes of information delivery are highlighted on these pathways, to promote access and also give patients and carers choice about how they access their information. Patients and healthcare professionals can access the information pathways and the information materials on the Network website - [www.mtcn.nhs.uk](http://www.mtcn.nhs.uk).

**3. Please clarify the type of information that the pilot proposes to give to patients at their consultation with professional. For example, will the information be based solely on the patients diagnosis or will it include additional links that may assist their condition i.e.; stop smoking advice, benefits advice.**

Appendix I shows the Lung, and Head and Neck Cancer Patient Information pathways, highlighting the types of information currently offered and given to patients and carers at different points along their cancer journey. This does include information on benefits and welfare rights, support and self help groups etc.

The network site-specific groups (NSSG's) who have developed these pathways are also looking in to extending the information offered to be more encompassing and more primary care focussed. We are also looking at more individually tailored information to patients and carers

about the timetable of their own cancer journey - which is based on the findings of a recent research evaluation project by Nottingham University.

We envisaged that the work undertaken in the information prescription pilot would facilitate the broadening of the information provided, so that it would become more holistic and incorporate these developments outlined above.

**4. What contingency plans are in place if you fail to engage a project manager in time to run the proposed pilot scheme?**

We already have someone in mind that has been working on a now completed 2-year joint project with Cancerbackup and the Cancer Network to develop the Head and Neck and Lung Cancer Patient Information pathways. Subject to that persons' availability and suitability to undertake the work on the information prescriptions pilot we should hope to appoint a project manager as soon as funding approval is given. In the event that this does not happen within the immediate timescale, then we already have plans to establish a project steering group, with key stakeholders, which will start the planning and preparation work. The Network Nurse Director, Elaine Wilson, with the support of the Network Patient Information Clinical Lead, Dr Peter Jones will lead this work until an alternative Project Manager is appointed. We fully appreciate the tight timescales of the project and the need to get it up and running with immediate effect. The Network Patient Information and Communication Group met on the 12<sup>th</sup> December 2006, where (without wishing to pre-empt the outcome of this proposal) we obtained formal sign up to the project from the Network perspective and the establishment of the Information Prescription Pilot Steering Group.

**5. Please expand on your plans to ensure;**

- Robust governance arrangements
- Data protection
- Ethical clearance for access to patient information by the evaluation organisation

The Governance arrangements will be as follows - We aim to establish an Information Prescriptions Pilot Steering Group, with the Project Manager, Network Nurse Director, Network Patient Information Clinical Lead and key stakeholders (including patients and carers) from all the organisations that will be involved in the development and dispensing of the information prescriptions. This group will report to the Network Patient Information and Communication Group, who ultimately report to the Network Management Board. Individual members of these groups will also report back to their respective Trusts, through their own line management arrangements.

The Information Pilot Steering Group will be required to produce a project plan, highlighting outcomes and timescales and will produce bi-

monthly reports to the Network Patient Information and Communication Group, as well as reports to the Network Management Board.

**Data Protection** – all staff are employed by contract within their respective organisations, which includes compliance with the data protection act. Any patients and carers involved on the pilot steering group will need to sign a declaration of good practice, (if they have not already done so) which includes compliance with the data protection act. This form has been in use for all patient involvement activity within the Mid Trent Cancer Network for the last three years. These records are held confidentially within the Network Office

#### **Ethical clearance**

NHS Trust approval will need to be sought within those organisations taking part in the pilot project.

#### **6. What are the challenges posed by introducing information prescriptions across such a wide geographic area?**

There are some very obvious challenges in introducing information prescriptions across a large geographical area such as across the Mid Trent Cancer Network. As well as distance, each of the localities, namely Lincolnshire, Central Nottinghamshire and Greater Nottingham are all very different in characteristic. We have the challenges of large distances between services, rurality and an elderly population in Lincolnshire; to a primarily urban population with a high ethnic mix in Greater Nottingham and a traditional mining community in Central Nottinghamshire.

However, the Network Team are experience and familiar in working with these challenges and have developed positive ways in dealing with these. For example, we have well-established Network Site Specific Groups for each of the different types of cancers. These groups are made up of clinicians, healthcare professionals and patients across all of the areas. Clinical engagement and motivation is high within these groups, who work to common guidelines, specifications, strategies, but also implement them in a way, which is appropriate to their own locality.

We have good channels of communication through email, face-to-face, regular meetings and telephone contact.

Recently we have successfully developed and implemented patient information pathways for three different types of cancer across this same geographical area. We anticipate developing and dispensing information prescriptions with these same clinical teams, where the relationships have already been established.

We are optimistic that we have the infrastructure and resources to meet the challenges posed by introducing information prescriptions across Nottinghamshire and Lincolnshire.

7. In your costing you have identified funds for research evaluation, however we shall be appointing a national organisation to carry out this function on behalf of all pilots. Please clarify if this costing contains elements that are not part of the research evaluation.

Our thoughts behind including some costs for evaluation was to build on the project commissioned by Cancerbackup and undertaken by Nottingham University to evaluate users and carers experiences of patient information delivery across the Mid Trent Cancer Network. The team of researchers used a combination of interviews, questionnaires and patients diaries to collect data on patients and carers information needs, the nature, extent and quality of the information they received, how information was delivered and from what source, their satisfaction with the information and its impact on their experiences of cancer and how they coped with it. It was envisaged that this evaluation, as part of the Mid Trent Cancer Network Information Prescription Pilot, would provide a crucial patient experience element to the overall evaluation of the national pilot. It would also enable us to conduct some local research for local use. The costs would be minimal; as much of the baseline work has already been completed in the previous study, which concluded in September 2006.

However, we do realise, that if this work were already incorporated into the national evaluation, then this would not be required. To clarify the funds requested relates to the costs of the proposed evaluation with Nottingham University and does not cover any of the other elements in the proposal.

8. Please expand on your plans to deliver information prescriptions:
  - Who will deliver them
  - How will they be delivered
  - What will they include
  - What resources are required specifically for delivery

Some of the detail of this has not yet been finalised, as the Information Prescriptions Pilot Steering Group has not yet been established. However, our preliminary thoughts, based on previous experiences are as follows:

**Who will deliver them?** The Information Prescriptions will be delivered by the Clinical Nurse Specialists/Key Worker. There is a possibility that they could also be delivered in the information centres. This may be expanded,

once further development work, education and training has been completed.

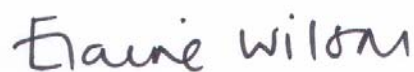
**How will they be delivered?** Alongside existing information delivery. Again this would need to be thought through in more detail and with the key stakeholders.

**What will they include?** – Information resources already identified on the Patient information pathways plus additional broader information about lifestyle, support and community resources and more individually tailored information.

**Resources required for delivery include education and training of healthcare professionals;** Resource costs of material, development and printing. Costs for providing education and training to staff.

I hope that this has provided some clarification for the issues raised. I look forward to hearing the outcome of this proposal.

Yours sincerely



**Elaine Wilson**  
Nurse Director  
Mid Trent Cancer Network

