

<b>INFORMATION PRESCRIPTIONS PILOT PROPOSAL</b>	
<b>PROPOSED PILOT SITE</b>	The Royal Marsden NHS Foundation Trust (RMH)
<b>Title and address</b>	The Royal Marsden NHS Foundation Trust, Fulham Road, London SW3 6JJ
<b>Contact name, telephone, e-mail and fax number</b>	Dr Jane latham Assistant Director, Quality Assurance, Tel: 020 7808 2315 e-mail: jane.latham@rmh.nhs.uk fax: 020 7808 2106
<b>Please outline proposals for introducing information prescriptions and areas that you are proposing to cover (see section 9 of criteria document)</b>	<p><i>See also brief description section for further details of areas the Trust proposes to cover</i></p> <p><b>1. Setting</b></p> <ul style="list-style-type: none"> <li>• Secondary and tertiary health care with integral pathways for social and pastoral care as part of rehabilitation.</li> </ul> <p><b>2. Content</b></p> <ul style="list-style-type: none"> <li>• To identify and assure Patient Information (PI) content, both general cancer and RMH specific, for all cancer patients seen at RMH.</li> <li>• To identify PI content which should be provided by RMH, other secondary care providers, and other providers who refer to RMH at various stages of the cancer patient pathway, including for second opinion.</li> <li>• To further develop and integrate current standards, and incorporate identified new standards into practice by adapting existing frameworks such as Department of Health, Healthcare Commission, Monitor and internal governance standards.</li> </ul> <p><b>3. Process</b></p> <ul style="list-style-type: none"> <li>• All components of the process required to implement Information Prescriptions as outlined in the pilot criteria will be included.</li> </ul> <p><b>4. Conditions</b></p> <ul style="list-style-type: none"> <li>• As a specialist cancer centre, RMH would address complex cancer care, which covers more than one point on a care pathway.</li> </ul> <p><b>5. Delivery .</b></p>

	<ul style="list-style-type: none"> <li>• Economic assessment of delivery options will be undertaken through methods such as comparisons with current economic status, value for money and patient/carer satisfaction.</li> </ul> <p><b>6. Impact</b></p> <ul style="list-style-type: none"> <li>• Utilising a whole systems approach, thorough evaluation of the pilot should evidence impact on the quality of PI for patients, health and social care users, carers and professionals.</li> </ul> <p><b>7. Support</b></p> <ul style="list-style-type: none"> <li>• During the pilot period, RMH would propose a further option of developing existing services for two specific hard to reach groups – those with visual impairment and Arabic speaking patients/carers.</li> <li>• A range of accessible formats for various client groups will be considered in the pilot.</li> </ul>
<p><b>Please provide a brief description of your proposals to:</b></p> <p><b>Work with stakeholders and partners</b></p> <p><b>Develop a system for delivering information prescriptions in your area</b></p>	<p>1. The PI Project Co-ordinator will be responsible description of your for co-ordinating, developing and evaluating the pilot with existing and new stakeholders and partners, both externally and internally, including:</p> <ul style="list-style-type: none"> <li>• Other members of the Quality Assurance Team and partners involved in a range of PI related services</li> <li>• Clinical Units across Chelsea and Sutton sites</li> <li>• Designated Information Prescription champions</li> <li>• RMH Patient and Carer Advisory Group</li> <li>• South West London Cancer Network</li> <li>• Other PI providers, e.g. Cancerbackup</li> <li>• If specific needs bid is successful; Royal National Institute for the Blind and/or accredited Arabic interpreters.</li> </ul> <p>2. a. The PI Project Co-ordinator will have agreed programme targets to meet during the pilot year through an agreed reporting structure.</p> <p>The Co-ordinator will meet on a regular basis with the Head of Service who will provide support and monitor progress against targets.</p>

<p><b>Identify the content for information prescriptions</b></p>	<p>With the Head of Service, the Co-ordinator will provide regular reports on progress to the PI Editorial Committee, Chaired by the Assistant Director, Quality Assurance.</p> <p>The PI Editorial Committee will report to the Clinical/Research Governance and Risk Management Executive Committee, Chaired by the Chief Nurse/Deputy Chief Executive.</p> <p>b. The pilot will build on an audit review of current RMH PI editorial resources completed in October 2006. The PI Project Co-ordinator will work with all identified stakeholders and partners to develop a comprehensive PI Resource Directory which will link with:</p> <ul style="list-style-type: none"> <li>• Primary cancer PI resources while treatment is being undertaken at RMH</li> <li>• Secondary cancer PI resources for other stages of the cancer pathway</li> <li>• Cross reference/glossary of PI resources from, e.g. other Directories</li> <li>• Other generic PI resources</li> </ul> <p>c. The PI Project Co-ordinator will work with all stakeholders, partners and specifically with IT to develop, pilot and evaluate:</p> <ul style="list-style-type: none"> <li>• the establishment of Information Prescription templates on the Electronic Patient Record system, including addressing issues such as level of staff access to the template. e.g. in terms of who is able to change details.</li> <li>• Develop operational logistics for patients and carers to have access to Information Prescription systems at agreed facilities/places of delivery and have access to relevant PI and individual Information Prescriptions.</li> </ul> <p>1. The PI Project Co-ordinator would:</p> <ul style="list-style-type: none"> <li>• Have a prime objective of building on findings of the recent PI editorial audit review to identify the current portfolio of general cancer, RMH specific, network and national resources.</li> <li>• Develop partnership working with PI organisations such as Cancerbackup on a range of PI cancer publications. This would include carer as well as patient information.</li> </ul>
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	<ul style="list-style-type: none"> <li>• Further develop the RMH-specific formats of information, such as the RMHPractice Series which gives specific information about treatments and care while at RMH, in order to complement the more generically developed range of cancer publications.</li> </ul>
<b>When do you anticipate that work will start?</b>	January 2007

**The Royal Marsden NHS Foundation Trust**

**Information Prescriptions Pilot Proposals  
Clarification Responses December 2006**

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

**Clarification**

1.1. The Trust sees approximately 1,047 new patients and 9,387 follow-up patients each month.

1.2. The pilot could not, therefore, include all patients seen in the Trust, and not every patient may require support from the Patient Information Service.

1.3. An evaluation and review of patients seen per month in the Trust will be undertaken to inform the roll out programme. This will inform whether the pilot will initially focus on a defined number of new patients, or whether it will focus on a group of new and old patients from one clinical division such as the breast unit.

1.4. A further component of this pilot will be to evaluate the number of patients who actually wish to receive information.

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

**Clarification**

2.1. The Trust has an established Electronic Patient Record system in place and this will form a major part of the information technology support required.

2.2. In addition to the above we will also provide a number of database terminals to ensure patients have direct access to local/national information systems at key points in their cancer journey. These terminals will be located at appropriate points around the two hospital sites at Chelsea and Sutton, e.g. patient waiting areas, and also across our partner organisations in the South West London Cancer Network.

2.3. The development of directories is outlined as a component of the pilot bid.

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.

**Clarification**

3.1. The prescription will be tailored to the individual and will include information needs which provide a holistic approach to their care, for example:

- coping with symptoms such as nausea or fatigue;
- financial/benefits advice;
- community support.

3.2. It is unlikely that one initial information prescription will be appropriate, as patients' information needs change throughout the cancer pathway of care. In addition to providing new information as indicated throughout the pathway, there may be elements of information signposting that require repeating.

3.3. Evaluation of the patients' needs will also consider the format in which the information is provided, for example, it may be appropriate to include a mixed-format prescription such as video, tapes etc.

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

**Clarification**

4.1. Due to the importance that the Trust place on the Information Prescriptions project and the potential time involved in engaging a project manager, consultation has been undertaken with the Patient Information Service staff and senior managers.

4.2. A senior member of the Patient Information Service, with comprehensive experience in the provision of all aspects of the service, has been identified as being suitably qualified to take the project forward from February 2007. This individual has agreed to continue as Project Co-ordinator for the one-year duration of the pilot.

5a) Please expand on your plans to ensure robust governance arrangements:-

**Clarification**

5.1. Regular review of, and reports on the progress of the pilot against agreed action plans will be scheduled through the following:

- Regular monthly and specific ad hoc progress meetings between the Project Co-ordinator and Head of Service for Patient Information;
- Progress meeting every two months with the Project Co-ordinator, Head of Service and Assistant Director of Quality Assurance;
- Standing agenda item at the Patient Information Editorial Board (Chair, Assistant Director of Quality Assurance);
- Pilot update included in Patient Information Editorial Board reports to Clinical/Research Governance and Risk Management Executive Committee (CGE) (Joint Chairs, Chief Nurse/Deputy Chief Executive and Associate Medical Director/Clinical Governance Lead).

5.2. The Information Prescriptions pilot will be a component of an active Cancer Peer Review programme, which will further ensure robust governance arrangements.

5.3. The Project Co-ordinator would be responsible for ensuring that all Information Prescription developments within the Clinical Units, across the Trust, and throughout the Network complied with relevant local and national governance guidelines.

5b) Please expand on your plans to ensure data protection:-

**Clarification**

5.4. The Trust scored 77 for the Information Governance Toolkit score for 2005/06, which placed in the top group nationally. This was an increase of 10% on the previous year and it is expected to increase again this year.

5.5. Well established Caldicott arrangements are in place within the Trust, with the Chief Nurse/Deputy Chief Executive being the Caldicott Guardian.

5.6. The Trust is currently co-ordinating the sign off of a Network Caldicott agreement for all partner organisations who are involved in the various stages of the cancer patient pathway. This is due to be finalised by March 2007.

5c) Please expand on your plans to ensure ethical clearance for access to patient information by the evaluation organisation:-

**Clarification**

5.7. The Trust would confirm with the Department of Health that the appointed evaluation organisation had agreed the appropriate clauses of confidentiality and best practice within their contract.

5.8. The Trust would ensure, through the relevant Human Resources processes, that all members of the evaluation organisation involved in the project were provided with the relevant status and levels of access to patient information within the Trust.

5.9. Pending further details on the detailed methodology, it is not currently envisaged that the evaluation would require full research ethics approval for ethics clearance. The pilot evaluation would therefore be presented at the Trust Audit Liaison Group for approval. This would be confirmed following review of further details of the methodology.

5.10 As previously indicated, the Trust has very proactive governance arrangements, which could be utilised as appropriate for the pilot. For example, the Consent Working Group may be engaged in the project to ensure ethical issues are addressed appropriately in relation to consent issues.

6. Please describe more fully how the interface you suggest with the electronic patient record (EPR) system will work.

**Clarification**

6.1. The Information Prescription entries will be operationalised in line with established Trust protocols. Systems are in place to ensure agreed levels of access and appropriate use of format.

6.2. The Information Prescription form would be electronic with a list of various headings and subheadings such as:

*Types of cancer*

Breast  
Prostate  
Lung etc.

*Treatments*

Chemotherapy  
Radiotherapy  
Surgery etc.

*Symptom control*

Fatigue  
N&V etc.

*Living with cancer*

Benefits  
Support groups etc.

6.2. Access would be given to relevant clinicians (doctors, nurses etc.) who put in the general headings e.g. breast cancer, chemotherapy, hair care, rehabilitation services.

6.3. A copy will be given to the patient and a copy scanned on the EPR (as per established protocol for consent forms).

6.4. The Information Prescription would also inform the patient where to get the information from e.g. Help Centre, Clinical Nurse Specialist, and/or ward.

7. Please clearly describe the additional work you propose to undertake for the information prescription pilot and distinguish this from the existing patient information work. It was difficult to distinguish the difference between the two.

**Clarification**

7.1. Three specific areas of work, which are additional to the existing patient Information work, have been identified as essential in order to establish the required infrastructure for an effective Information Prescription Service (see 7.2 – 7.4).

7.2. Pre-operational pilot work, led by the Information Prescriptions Project Co-ordinator to include:

- Establishment of an Information Prescriptions Pilot Group (IPPG);
- Full consultation with staff and patients including involvement of the Trust's Patient & Carer Advisory Group (PCAG);
- Representatives identified to work on the pilot scheme;
- Relevant training needs identified for representatives;
- Mapping of Patient Information pathways with established Multi-disciplinary teams (MDTs) and PCAG;
- Liaison with the Computing/IT Departments to ensure Information Prescriptions are identified on EPR system and linked with operational management processes.

7.3. Pilot operational plans, led by the Information Prescriptions Project Co-ordinator to include:

- Design of the Information Prescription form;
- Agreement on who will write prescriptions;
- Protocols for ; dispensing prescriptions;
- Agreement on when during their pathway of care, identified groups of patients will be given their Information Prescription;
- Liaison with the Training & Development Department to design and implement staff training sessions;
- Identification and review of the impact of new ways of working for the Patient Information Service internally and externally with Network Partners.

7.4. Pilot role out period, led by the Information Prescriptions Project Co-ordinator, to include:

- Plan role out across clinical units with the relevant teams;
- In liaison with the Trust Quality Assurance Department, audit and review pilot on agreed areas, including the impact across the Trust and the Network.

8. How can work on information pathways be integrated into your proposal?

**Clarification**

8.1. There are established MDT and shared care cancer pathways both internally in the Trust, and across the Cancer Network (see also 7.2). These processes will ideally lend themselves to integration of information pathways within the pilot.

9. What was the reasoning behind selecting Arabic speakers and the visually impaired as pilot groups? What are the expected special needs costs?

**Clarification**

9.1. The Trust currently has two Arabic advocates in post, with Arabic being in the top five requests for interpreting services. The advocates' in-depth knowledge and support would be invaluable in ensuring we provide appropriate information to Arabic speaking patients/relatives.

9.2. The Patient Information Service has planned to approach the RNIB to propose working jointly on creating accessible websites for those with sight impairment as the RNIB have produced guidelines on meeting information needs and providing accessible information for this special needs group.

10. How would you work with independent evaluators to inform national implementation of information prescriptions?

**Clarification**

10.1. The Information Prescriptions Group, compiled of key staff from the Trust, PCAG and the Network, would work with the evaluators to agree roles, responsibilities and action plans for the evaluation.

10.2. Recognition of the need for a Project Co-ordinator reflects the importance the Trust places on a focused approach to working with the independent evaluators.

10.3. The Trust is also committed to senior management support for the pilot through the structures and functions previously outlined. All identified senior staff are well placed to work at the agreed levels and agendas with the evaluators, and are experienced in participating in dissemination of such work both nationally and internationally.

10.4. The Trust has a proven track record of disseminating the development of best practice both nationally and internationally. Such dissemination is often based on effective partnership working on collaborative projects.

11. How will information prescriptions be delivered and embedded in care pathways?

**Clarification**

11.1. The Trust has very well established MDT's and out reach clinics and intends to use a proactive approach to embedding care pathways and ensure this reflects current management systems.

12. How will stakeholders be engaged in the information prescriptions pilot?

**Clarification**

12.1. Stakeholders will be actively engaged in the pilot through input from PCAG, regular news updates in the Trust's internal newsletters – 'Lifestyle' produced specifically for patients and 'In Touch' which targets staff members.

12.2. The Trust have had discussion with the Nurse Director for the South west London Cancer Network, who is the Lead for Patient information. She has confirmed that the Network will enthusiastically support the Information Prescriptions project, and engage in the development of the various developments across the Network (see attached e-mail of support).