

INFORMATION PRESCRIPTIONS PILOT PROPOSAL	
PROPOSED PILOT SITE	Cancer Centre, Queen Elizabeth Hospital, University Hospitals Birmingham NHS Foundation Trust. Edgbaston, Birmingham
Title and address Contact name, telephone, e-mail and fax number	Nick James, Lynn Dodson, Paul Litchfield Patrick Room, Cancer Centre, Q. E. Hospital, Metchley Lane, Birmingham B152TH Lynne.dodson@uhb.nhs.uk paul.litchfield@uhb.nhs.uk Patrick Room: 01216978417 Lynne Dodson 01214721311 Ext 51516 Prof. James 0121472 1311 through switchboard Fax: 01216272902
Please outline proposals for introducing information prescriptions and areas that you are proposing to cover (see section 9 of criteria document)	<p>We have been using an information prescribing system for the Last 4 years, arising from a study of Internet use funded by the DOH (the project was entitled "A study of the accessibility and Usability of the internet as an information source for patients" (ACCIS) and covered 800 patients and 200 carers across 3 Birmingham hospitals).</p> <p>The system is currently used by the Urology team (both Surgical and non-surgical) and by the breast team. We now Plan to roll the system out across the whole of non-surgical Oncology by means of training sessions, seminars and mentoring. The system will thus cover chemotherapy, radiotherapy and palliative care as well as surgical urology clinics in the Cancer Centre.</p> <p>The present system in place starts with an initial consultation between consultants, patients, relatives/carers and the specialist team. Once the options and pathways have been discussed and noted the patient is signposted to the Information Service for further information and additional questions. In this way the patient will be able to have a frank consultation and be able to make an informed consent for treatment of their cancer. Also it means that all involved in the care of the patient in the cancer pathway can be fully aware of decisions made and the information received and available. It also means that as diagnosis changes the pathway can be adapted and prepared for by all involved.</p> <p>The current throughput of the Cancer Information service is approximately 6000 patients per year and there will be an increased workload when all the site specific cancer staff are utilising the service as the urology and breast teams presently do so.</p>

<p>Please provide a brief description of your proposals to:</p> <p>Work with stakeholders and partners</p> <p>Develop a system for delivering information prescriptions in your area</p>	<p>Work with stakeholders and partners</p> <p>Partners: We plan to establish a team to run the pilot including the Applicants Dr Inigo Tolosa (Psychology), Prof Harry Daniels (Education PI psychologist and co-investigator for ACCIS) as external consultation educational interventions, cancer network information team.</p> <p>Stakeholders: We already work with the Network Information Group to ensure consistency of information provision. We are connected to the local PCT's and as a supra-regional centre for oncology overlap with other cancer networks and SHA's. We will also continue to work with CancerBackcup and Macmillan to ensure high quality materials are sourced and used. In addition Prof James is Editor in Chief and founder of Cancer Help UK. We therefore plan to continue to work with CRUK/CancerHelp in the area of generation of materials.</p> <p>Develop a system for delivering information prescriptions In your area: We already have a well established system for prescriptions Outlined at the recent seminar at the ASPI. This is a paper Based prescription in triplicate, the top copy going to the patient, one in the notes and one with the radiotherapy or chemotherapy prescription as part of our Centre's consent validation process. We plan to pilot site specific forms, e.g. with diagrams of pelvic organs, or treatment package specific forms that would be partly pre-printed but with scope for personalisation.</p> <p>Identify the content for information prescriptions: As noted we have a well-established system, backed up by an excellent information room (the Patrick Room) staffed by a full time information Manager (who has a clinical background and supported by the lead Cancer Nurse) and a team of volunteers.</p> <p>The Information Managers role already includes sourcing and updating materials stocked as well as keeping a list of recommended web resources.</p>
---	--

<p>When do you anticipate that work will start?</p>	<p>January 2007(subject to making suitable appointment to cover the pilot scheme)</p>
--	---

Paul Litchfield,
Cancer Information and Support Services Manager,
The Patrick Room,
Cancer Centre,
Queen Elizabeth Hospital,
Birmingham
B15 2TH
Tel: 0121 697 8417
Email: paul.litchfield@uhb.nhs.uk

15 December 06

**Clare McDonald
Room G23b,
Richmond House,
79 Whitehall,
London
SW1A 2NF**

Dear Clare,

**Re: Information Prescriptions Pilot Proposal
University Hospital Birmingham NHS FT, Birmingham**

With reference to the above please accept this letter as clarification of the proposal sent to you on 4th December 2006. Below are the points you asked for clarification and I hope the answers will respond to some of the panel's questions.

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

The Trust has 10 site specific cancer MDT's at present with a palliative care and young persons MDT. The present pilot will deal with those who are seen through the Cancer Centre with the plan being to roll out the process to the whole of the MDT system after the results of evaluation and audit.

Current prescription pilot as of 2006	~100/month
Surgical oncology new patients passing through clinics in the cancer centre per month	~120/month

Number of patients whose treatment regime changes and need new information prescriptions	~120/month
Number of patients passing through the Wellcome Trust.	~100/month
Estimated total number of new oncology patients passing through cancer centre outpatients. All will need information prescriptions	~550/month
Estimated total Number of new oncology patients passing through cancer centre outpatients at the end of the pilot.	~890/month

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

The Information Officer will compile a database of information sources. We currently do not have electronic care records, though all clinics etc are typed and stored in a common directory which is available on the Trust Intranet. Also with the new NHS computer system, Lorenzo there is the ability to cut and paste information into the electronic record. In this way there will always be a copy available at any point in time in the patient's treatment pathway. We also have the PICCS system in place which will correlate patient details from a drug and chemotherapy perspective. The intranet also has the ability to have links connected to it so that we can use it as a signposting tool which links with clarification point 8.

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.

The information on the Information Prescription will be based on the patient's specific diagnosis and treatment options for the patient's actual condition. Alongside this further information such as smoking cessation, dietetic advice, alcohol reduction programs, benefits, travel arrangements, support groups and counselling/psychology services can be highlighted and appropriate referrals made. Also information will be given relating to CNS services and contact numbers so that patients and their carers will have access to further help and advice as treatment progresses. In this way the patient information will link into the Trust wide 'Holistic Patient Assessment' policy.

A range of current information sources is in use e.g.
Cancerbackup

CancerHelp UK
Pan Birmingham Cancer Network Information sheets
University Hospital NHS FT Information sheets
National charities information sources
Benefits resources from DWP, local government etc

Please review the attachments for sample information prescriptions.

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 a Job Description/Personal Specification for this post. We would therefore look to immediately advertise the post if the pilot project is approved. The Trust has already made significant progress in developing this pilot and is issuing in the region of 100 prescriptions per month under the aegis of the Cancer Information & Support Services Manager. The current post holder is, however, unable to devote additional time to the pilot due to his existing job commitments. To manage the interim period the Trust will therefore use pilot funding to ensure the post holder's existing duties are covered to release his time to support the pilot.

5. Please expand on your plans to ensure;

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

In relation to the issues of governance the following is in place:

Regarding governance arrangements, the production of patient information in the Trust is governed by the Patient Information Policy which is supported by the Patient Information Group which meets on a monthly basis and is responsible for the approval of all patient information, to check it is in line with the policy. The policy reflects the requirements of the CNST standards and is currently being updated to reflect the new NHSLA Risk Management standards. The Trust has CNST Level 2 and received a full score on the patient information criterion of Standard 3 (Advice and Consent) at Level 2 of the CNST General Clinical Risk Management Standards when it was assessed in December 2005.

We will ask the Patient Information Group to formally approve the external information sources recommended and listed above as part of the implementation of the proposed project. As information on websites changes continuously, we will ask them to approve sites in principle, based on the editorial policies and provenance of the site rather than specific web pages. We will develop policies for flexible rapid approval of material, based on the principles of site approval summarised above.

Clinical Governance in Division 4 is of course monitored through the monthly Division 4 Clinical Governance Team which has multidisciplinary representation from all specialties in the Division and is chaired by the Divisional Director. Ongoing monitoring of any governance issues could be undertaken through this forum if necessary.

6. How would you plan to work with the independent evaluators to collect data and ensure contribution to national implementation?

Once the pilot is set up and the evaluators have decided the statistics, criteria and evidence they require, then we can work alongside them so as to provide a seamless service. This will be the primary role of the project manager to manage this side of the project. Please refer to clarification point 4 also. The implementation process is not available to us at this point in time so we await the guidance of independent evaluators as to expectations. Once we have the guidance we can put a solid process in place.

7. Could your model of information prescriptions be extended in principle to other hospitals during national implementation?

We propose to have a band 7 project manager to roll out the pilot at the University Hospital Birmingham NHS FT. The post holder will be responsible for the facilitation of the roll out of information prescriptions across the Trust with respect to patient care and service development. The post holder will engage and influence all levels of staff in the rolling out of the information prescription. The post holder will support all the CNS' and clinical leads in this process and will link with the Pan Birmingham Cancer Network Information Manager in the developing of awareness of the information prescription among other Trusts and the community. The post holder will participate in the evaluation research process by collecting the data necessary for the evaluation of the information prescription and undertake audit as required.

This project will also support the cancer measures particularly relating to providing patient centred care such as

- Provision of a permanent record of treatment options
- Key worker role – ensuring patients and carers know who to access to receive information and advice.
- Information specific to the MDT relating to disease and treatment options
- Information about psychological , spiritual and cultural support
- Local provision of service – support groups, self help groups etc.

There is no reason why the information prescription could not be used anywhere else or adapted for others to utilise simply. It maybe that modification will be made to the format to ensure suitability for all the consultants using the system and these could be passed on as required.

Also it must be pointed out that as the University Hospital Birmingham NHS FT is a supra-regional Cancer Centre, the Medical and Clinical Oncologists work within peripheral clinics at local district hospitals throughout the West Midlands region. The areas we cover are as follows:

Queens Hospital, Burton-on-Trent
Good Hope Hospital, Sutton Coldfield
City Hospital, Birmingham
Heart of England Hospital, North Birmingham
Children's Hospital, Birmingham
Women's Hospital, Birmingham
University Hospital Birmingham
Sandwell District General Hospital, West Bromwich
Walsall Manor Hospital, Walsall
Royal Orthopaedic Hospital, Birmingham
Local Private Hospitals in Solihull, Sutton Coldfield, Birmingham and Walsall

In relation to peripheral clinics, as the consultants utilise the system we will then need to look at the service level agreements relating to the information being utilised and provided.

8. Could your model of information prescriptions be extended in principle to explore information in their own way and time without going through a referral point? Could patients be signposted to sources of information other than the information centre?

We are presently finding that patients are exploring information in their own time. Patients who are comfortable with the internet are already referred directly to our preferred web sources to study them in their own time. Our previous research indicates that web-savvy patients want their doctors and health professionals to do this on their behalf. Some patients or their relatives (at least 50% based on our previous research) will have done a lot of research before attending and with this being the case we can guide people to sources that are useful to them. Also it is important to note, cross referencing to clarification point 7 that some of the peripheral hospitals do not have a cancer information service in place. Therefore in order to inform patients, they will need to be signposted where possible to the information service at the Q.E. Hospital or to set web sites. One of the advances in relation to peripheral hospitals will be further development of the hospital website with links to the recognised charitable sites used, Cancerbackup, CancerHelp UK, Pan Birmingham Cancer Network, University Hospital NHS FT and Benefits resources from DWP, local government etc

9. Please provide more information on the governance arrangements for the project.

Clarification point 11 – please see point 5 above.

10. How will data collection from patients, carers and staff be handled?

Data collection will be through the post holder in project management and will be in line with Trust policy, Caldicott requirements, clinical governance and also the independent evaluators. We will use simple database software to collect information systematically. For analysis we will use standard packages such as SPSS. Initial statistical analysis will be largely descriptive – frequencies, demographics etc. It is not possible to state specific statistical hypotheses in advance and further statistical advice will be sought on this if funded. We will use the instruments developed by the DOH funded ACCIS project for assessing patient satisfaction with the information provided (NJ to provide). These are in machine readable format, aiding data transcription.

I hope this gives an explanation of the questions you sought clarification on. Please do not hesitate to contact us further should you require further information.

Yours sincerely,

Paul Litchfield