

# **Information Prescription Pilots**

**January 2007**

**Proposal to participate from:**

**Heart of England NHS Foundation Trust  
Heartlands Hospital  
Room 2 New Main Entrance  
Bordesley Green East  
Birmingham  
B9 5SS**

## Information Prescriptions Pilot Application Form

### Proposed Pilot Site:

Heart of England NHS Foundation Trust was named as the top performing Foundation Trust in the UK in 2005/06 by the independent regulator, Monitor. The Trust has achieved the Healthcare Commission three-star status three years running, and in 2006 was awarded Acute Healthcare Organisation of the Year in the Health Service Journal Awards. Our vision is to create a centre of excellence in the provision of healthcare and education and to offer patients the best possible care.

The pilot would take place at Heartlands Hospital in the Respiratory Medicine Directorate, which hosts the regional speciality for Cystic Fibrosis. The West Midlands Adult Cystic Fibrosis Centre is based on Ward 26 and currently looks after approximately 295 adult patients from around the West Midlands Region, and some patients from other regions. The Centre has 20 single rooms for in-patients and 9 outpatient rooms, together with a clinical room.

The Centre also houses the Cystic Fibrosis multidisciplinary team including physiotherapists, specialist nurses, dieticians, an administrator and a social worker. Medical staff include a Specialist Registrar and a Clinical Fellow.

The multidisciplinary Cystic Fibrosis team are already working towards the CharterMark award, and have welcomed the opportunity to become involved in this pilot.

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## **Outline proposal for introducing information prescriptions**

### **Working with patients with Cystic Fibrosis**

Cystic Fibrosis (CF) is an inherited condition that currently affects approximately 7,500 people in the United Kingdom. Around one in five people with CF are diagnosed at birth and just over half of people with CF are diagnosed as babies. Neonatal screening has just been introduced nationally. There is no cure for CF; current treatments include care from a specialist team who aim to control the symptoms. By the time people with CF reach adulthood they have had extensive contact with the NHS and are often very well informed about their condition and treatment.

Reaching adulthood brings a new set of challenges to people with CF. Men can experience fertility problems and CF patients have a shorter life expectancy, the average being around the early thirties. Many of the patients using the adult treatment centre want to learn everything they can about their condition and how best to live with it. Some have joined the Expert Patient programme and share their experiences of coping with a long term chronic illness with others in a similar situation.

Many CF patients are computer literate and comfortable with developments in new technology. They are not afraid to explore new ideas, and to use and experiment with technology as a tool to assist them to find out more information.

### **Details of Proposal**

- An electronic information prescription pad will be developed. This will consist of a number of clearly defined template screens developed to reflect information needs at specific points identified in care pathways for patients with CF.
- These screens will be used by the health professional as part of their consultation with the patient to indicate what information is to be prescribed. Any additional information requested can be added in note form to the prescription.
- The Electronic Patient Record (EPR) would be updated with the information prescription request. Information stored in the EPR about the information prescription would include the identification of the health professional making the request, date and time of request, title of information prescription i.e. which template had been used and the version of information prescription issued. A “flag” will be generated by the system to remind clinicians each time they see the patient to check if they need a new information prescription.
- A copy of the information prescription will be printed for the patient, and an electronic version will be sent directly to one of a number of health information distribution points. The information requested would be put into information packs ready for the patient to pick up after their consultation with the health professional.

- Each information prescription template would have leaflets that are essential to patients accessing information at that point on the care pathway. To assist with information reaching people with language or literacy problems, where the content of the leaflet allows these leaflets would be made into audio versions using MP3 technology. These files could be burnt onto a CDROM and also made available as downloads from the CF website. The computer facilities within the Health Information Centre could also be utilised to assist people who wanted to use this format.
- The Patient Advice and Information Database (PAID) System already has the facility to provide information in large print format, and any new information leaflets produced by the CF Department would automatically be made available in a large print option
- GP surgeries currently accessing our systems would have access to these developments. Information packs could be made available at the surgery, or picked up from the hospital.
- A CF Website will be developed and a section will be dedicated to the Information Prescription project. There will also be the opportunity on the website to have a “blog” where information prescriptions can be discussed openly and honestly – and anonymously.
- A computer with Internet access and a printer would be installed in the Centre. CF patients, their relatives and carers would encourage to access and use their HealthSpace facility. We would welcome the chance to work with other agencies within the Department of Health to develop our system so that it could automatically upload information into an individual’s HealthSpace account.

## **The Health Information Centre**

Located next to the Help Desk in the main entrance, the Health Information Centre (HIC) provides a completely free information service. The centre is a relaxed and informal space where you can take time to look for information on a wide range of subjects. We offer Internet searching facilities and have a range of services for people with additional needs. We provide information about healthy lifestyle choices, medical conditions and treatments, and can provide details of support and self help groups. We also have a wide range of information about benefits. Using the Health Events calendar we work with different groups within our organisation to help them to use the facilities within the Centre to highlight the services they provide.

If people are unable to visit the centre in person they can contact us with an information request by telephone or by e-mail. There are links to the Health Information Centre mailbox via the Trust’s Internet site. This link will also be available from the CF Website developed during the pilot.

The Centre works in partnership with our local PCT’s to provide information and drop in services around healthy lifestyle choices i.e. smoking cessation, healthy eating and blood pressure checks.

We also have strong links with our local Partners in Health Centre where chronic disease management takes place in a community setting.

At different times during each month we have regular slots where local community agencies and charities use the centre to hold drop in sessions. These include our local Disability Resource Centre, who offer a wide range of advice to people with any type of disability including benefit, training and back to work advice.

## **Overview of Project Governance and Project Management arrangements**

The pilot will be led by the Information Prescription Steering Group. This group would oversee the management of the project and would be responsible for the allocation and utilisation of the funding for the project. Membership would include:

- Executive Director
- Clinical Director for Respiratory Medicine
- Director of Clinical Governance
- Matron for Respiratory Medicine
- Directorate Manager for Respiratory Medicine
- Patient Representative
- IT Systems Architect
- Research & Development Manager
- Head of Quality/Patient and Public Involvement
- Project Manager/Health Information Manager

This group will meet monthly for the first 3 months of the project, then bi monthly. The membership of the group will ensure that the project receives ongoing support at the highest level within the organisation. The expertise that this membership will bring to the pilot will ensure that the project is kept on track and will deliver within the allocated time. The involvement of a patient representative will ensure that the tasks within the pilot continue to focus on the needs of the CF patients, relatives and carers.

Lead by the Head of Quality/PPI, focus groups will be set up to elicit the views of the various users of the CF services. The focus groups will be invited to select a number of patient representatives to work with the project manager and their team. These groups will be updated as to progress throughout the life of the pilot by the representatives, and their views will continue to be sought at each project milestone i.e. the draft information prescription templates.

Staff groups will meet with the Project Manager and IT Systems Architect. Each CF team will elect a champion who will represent the group at meetings and feedback decisions to the rest of the group. In addition to regular project team meetings, there will be a regular quarterly slot at the Respiratory Directorate meetings where a project update will be delivered to the whole directorate.

The Project Manager would liaise with the evaluation team and other pilot sites. This would include attending meetings to share experiences and presenting progress reports. Regular reports on this activity would be given to the Information Prescription Steering Group.

At the end of the pilot a final report will be presented to the Respiratory Directorate, evaluation team and Trust board. Please refer to the Project Plan at Appendix 1

A document showing how many of the questions asked in the project documentation would be answered is shown as Appendix 2.

## **Providing data to the national evaluation organisation (including ethical clearance)**

We would work with the evaluation organisation to ensure that any specific information requirements were met, and statistics will be gathered and disseminated throughout the pilot.

Information analysis is already taking place within the Health Information Centre via the use of a database. This system collects a wide variety of data, including the medium used to make an information request. This will enable us to ascertain the amount of requests coming in via the hand written information prescription. It also collects information about the type of resources people are accessing information from including leaflets, CDROMS, Internet access etc. and how many contacts are made during a day.

The PAID system also collects similar data and the enhancement written to include the information prescription will have its own reporting facility.

A Customer satisfaction survey will take place at month 9 in the project. This will be prepared in advance under the guidance of the Research and Development Manager and the Head of Quality/PPI to ensure compliance with ethics committee requirements. A staff satisfaction survey will also take place in month 9 to ascertain the view of staff about support they received during the pilot and their perception of the impact the pilot had on their practice.

## **How the project will include work with stakeholders and partners**

Cystic Fibrosis (CF) patients will be involved from the beginning of the project to ensure that the information prescriptions we are designing will be useful to them. Focus groups will help us to identify what CF patients, their relatives and carers are looking for and user "champions" will be invited to join in and support the project.

It is essential that professional health staff involved in the project approve of the quality and content of the information prescribed. This would be decided upon by the Health Professionals in consultation with the CF users. Links would be established and/or strengthened with approved suppliers i.e. Cystic Fibrosis Trust and we would invite them to participate in the project. The diversity of the membership on the Information Prescription Steering Group will ensure support from expert staff across the organisation.

We will work with the Expert Patient programme already operating within the area to provide more information and support about the benefits involvement with this programme can bring to people with long term illness.

Since 2003 HEFT has set up and worked with a Patient Information Advisory Group, made up of staff, patients and the public. The remit of the group is to read and give feedback on the clarity and “readability” of information designed for patients and their carers.

To ensure that feedback is received in a structured way the group fill out a checklist that asks relevant questions about the type of document they are reviewing (Appendix 3). This group would be asked to share their experience with the project team and user champions. A similar system would be adopted to review draft information prescriptions, and any new information leaflets generated within the CF Centre.

## **The system for delivering information prescriptions**

At Heart of England NHS Foundation Trust (HEFT) we believe that patients, relatives and carers want information to help them to understand and respond to the care they receive. Supplying timely, accurate information for patients, relatives and carers is an essential part of this process.

To address some of these demands, HEFT has developed the Patient Advice and Information Database (PAID). A multi award winning method of providing quality information to patients, the system is patient focused and provides an electronic means of controlling and distributing a library of over 650 patient information leaflets through the Trust’s Intranet.

Each time an information leaflet is printed a record is automatically entered into the electronic patient record for that patient, allowing staff to view a complete history of patient information leaflets issued to any patient. Each leaflet is personalised with the patient’s name, hospital number, date of birth, sex and NHS number. The system is accessible anywhere in the Trust and is available 24 hours a day, 7 days a week, giving healthcare staff access to the full range of patient information leaflets currently approved by the Trust.

Making the information database project part of the Trust’s Electronic Patient Record (EPR) development has raised the profile of providing information for patients. The database involves both the clinician and the patient in the information giving process. Patients feel that the information is worth reading and are able to trust it because it has been selected and given to them by a health professional.

The Patient Advice and Information Database has been designed and written in-house, and is still evolving, incorporating the requests for enhancements we received during the pilot phase and ongoing use of the system. Participation in the Information Prescriptions pilot scheme would form the logical next phase for the ongoing development of the PAID system, and supports “Working Together for Health” principles by encouraging people to seek health promotion advice.

Using the main points outlined in the project proposal, the Information Prescription would have all of the unique facilities offered by the PAID system, enhanced by the requests made by the service users and staff as the project developed.

## **Quality Information in the Right Format**

A version of an information prescription is already available to patients, relatives and carers at HEFT. Using a postcard format, people are invited to fill out details of the information they want us to provide. They can then select how they want to retrieve the information. We will send information via e-mail, post or they can collect it in person from the Centre. Using this method allows people privacy and anonymity when making an information request.

The Trust has already demonstrated its ongoing commitment to providing quality information for the local community by the provision of a Health Information Centre at Heartlands Hospital. The services this centre provides would enable us to enhance the information prescription service and allow us more flexibility to make contact with hard to reach groups.

The Health Information Centre would play a key part in the pilot as it would act as the main distribution point for information packs. The Health Information Centre uses carrier bags that have been coated with an antibacterial coating, making them safer for CF patients who run a high risk of infection.

The electronic notification that an information prescription has been requested can be picked up here, and packs made up ready for collection. These packs would not only be made up of written materials, as not everyone has the necessary literacy levels to read and understand information leaflets. They could include CDROMS with audio files of leaflets and any other electronic media made available through the project i.e. video clips.

Information Prescriptions are not just about leaflets; they are an opportunity to provide contact details for local support groups, community based facilities, benefit information and links to websites. The Health Information Centre staff can provide computer access and support to people who are unsure about using the using equipment.

Information should be available where it's needed, when it's needed and provided in a format that is appropriate for the recipient. We also need ways to provide information for people who may not be seen in the hospital, and for recording and fulfilling ad hoc information prescription requests. Information packs can be made up and taken out to patients in their homes, and we can use "Virtual" information packs which can be sent to people via e-mail

Access to Information Prescriptions will not only be through a health professional, people can make requests through the "postcard" service, by telephone, e-mail or in person in the Health Information Centre.

## **Content of information prescriptions**

The care pathway will usually decide the content of the information prescription as people will have different needs depending on where they are in relation to their treatment.

The CF Trust has drawn up a Patient's Charter for children and adults with CF detailing the essential health care they should expect to receive. It is based on guidelines drawn up by directors of Specialist CF Centres in the UK and reflects current best practice.

This document will be used as the basis when designing the various information prescription templates. Additions and refinements can be added after consultation with CF patients and clinical staff.

**Anticipated project start date:**

The project start date would be 20th<sup>th</sup> February 2007.

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**Proposal Endorsed by:**

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