

Cystic Fibrosis Patient Information Audit – May 2007

1. Introduction

As part of the Information Prescription Pilot Delivery plan a baseline audit of information provision within the Cystic Fibrosis (CF) Unit took place. Involving staff and patient representatives the audit seeks to establish what information is currently given to patients, and what the gaps are in this service.

2. How is information currently given to CF Patients, relatives and carers?

Interviews were set up with representatives from each clinical specialty within the CF Unit to discuss how information is currently given to patients. These groups are:

- Clinicians
- Nurses
- Dietetics
- Physiotherapists
- Pharmacy
- Social Worker

Verbal information was given to all patients by all groups of staff. This was enhanced where necessary with written Information using photocopies of leaflets. Some of these leaflets were fact sheets which came from the CF Trust website, others had been written in-house by each specialty in response to a need or request for information from their patients. Several staff raised the issue of the time it takes to write, format and produce a patient information leaflet, especially as some staff did not have secretarial help. Time is also a factor in finding new information sources relevant to their patients.

The written information contained in these leaflets was considered sound, but the presentation and quality of the photocopies left a lot to be desired. Some groups put their leaflets into electronic format, but then cited the fact that printers were not available in the various consulting rooms where they had patient contact – hence the photocopied versions. Some staff also highlighted training issues if they were asked to use a computer to issue leaflets and were concerned about the time it might take to use an electronic system.

The overall consensus was that although most people in these groups had “heard of” the Patient Information Database, they had not actually used it. The introduction of an electronic system to issue information and information prescriptions was welcomed by all staff groups.

Information was also given to patients via letters. The doctors and consultants are participating in the “Letters to Patients” initiative. After a consultation doctors write to the patients, in a language that patients can understand, and the GP is sent a copy of this correspondence.

3. What sources are used to provide information for patients?

Much of the information provided for patients comes from the Cystic Fibrosis Trust, and is a source of information that appears to be trusted by both staff and patients. Staff have also written their own information leaflets to cover more local information issues. Other information sources are accessed i.e. the Department of Work and Pensions by the Social Worker, but there is not currently a wide selection of information sources readily available to the patients.

4. What do the patients think?

A total of 18 CF patients were interviewed on a one to one basis and asked for their views on a variety of topics including information. Some of the comments made by patients are shown on the spreadsheet at Appendix 1. Contributions were also made by the information prescription pilot patient representative and a colleague who has CF.

Themes emerging from looking at information and communication reveal that this is an area where improvements can be made. A common theme suggested patients are dissatisfied with the level of information given to them. In addition to this patients did not always understand verbal communication from doctors and nurses, and would like it if doctors and nurses checked their understanding more often.

We received feedback from a patient who wanted more information about the other possible conditions that may develop during their lifetime, and also more information about organ transplantation.

Several patients highlighted the isolation they felt when they were inpatients, as they have to stay in solitary rooms sometimes for weeks at a time. It was felt by some patients that access to the Internet while in hospital would help them to research more about their condition and treatment, and allow them access to the outside world. This was felt so strongly by one patient that they stated they would be prepared to pay for this facility.

One response was that they were too embarrassed to ask staff for information; this may be a quite common occurrence with patients having a long term condition as they can build up a rapport with staff.

The response to the question "have you looked elsewhere for information" was very comprehensive. Patients have tried a wide variety of different sources to find out more information about their care and treatment. The Internet again features high up on people's lists of information sources.

Patients were also very interested in having their own local hospital website. It was seen as a major communication tool where patients could get the latest news and give their views on local issues.

5. How can the pilot address these issues?

Writing and Producing leaflets

All of the leaflets currently in use across all of the CF teams have been sent to the project manager. These leaflets are now being retyped and reformatted into the database format. Once this has been done the leaflets will be sent back to the originating team and they will be asked to check them. When satisfied with the content they will be passed to the clinical director, who will sign them off as ready for the database. This alleviates the need for staff to have to worry about typing and presenting the information, as this will be taken care of for them.

Printing leaflets and Information Prescriptions

Issues around the time it takes to access the system will be dealt with by providing comprehensive training sessions on site for the staff, using their own information leaflets. The problems around printing the leaflets will be addressed by installing a printer in each consulting room (these rooms already have PC's). This will make it easy and accessible for staff to print out information for their patients as part of the consultation process, and the leaflets and information prescriptions will be personalised for the patient.

Sourcing reputable information

The Cystic Fibrosis Trust has agreed to become our partner in the development of information prescriptions, including access to all of their fact sheets and patient information. This allows us to reproduce this information on our database so that we can record against each patient's electronic patient record each time a leaflet and/or information prescription is issued to a patient. In turn we will acknowledge them as the information source, and share any relevant information we have with them.

Staff involved in the pilot will produce information directories of information that people with CF, and/or their relatives and carers may find useful. The CF teams will be asked to evaluate these sources as to suitability. However the final say should lie with the patients, and if they believe a source to hold useful information their wishes should be respected.

Set up a Hospital Based CF Website

Produce a local website for users of the West Midlands Regional CF Unit. Keep this updated with local news, views and articles relevant to the Unit, but also providing links to the "outside world". See Appendix 2.

Provide a forum for patients to exchange news and views. Although this may have to be monitored it is the aim of the Unit not to censor this area unless it is necessary. We would also like to involve patients in the upkeep of this area.

Use the website as a vehicle to publicise the latest developments and gain feedback about the information prescription pilot.

Provide “Touch Screen” kiosk in the CF clinic waiting area

Patients sometimes have to wait for a while before they can see a member of the CF team. By providing an information kiosk we can give patient’s relatives and carers the opportunity to use this time to access and print information, without the involvement of clinicians.

Information Prescription Cards

These cards will be left on view all around the Unit. They can be used by patients to write out a manual information request, and dropped into the Health Information Centre anonymously. The information can then be either sent out to the patient by post or e-mail (if they are prepared to give us their details) or picked up later on in person.

Provide Internet access for inpatients

The pilot will contribute to the provision of Internet access for CF inpatients on Ward 26. This will allow patients who otherwise have to stay in separate accommodation to access information via the Internet, and communicate with other patients via the local website.

Keep patients involved in the development of the Information Prescription

We need to listen to the views of our patients as we develop and deliver the information prescription, but we don’t want to pester people who are too ill to participate. To this end we have sent each CF patient a letter informing patients about the project and asking if they are willing to participate in giving us feedback. We have had approximately 50 responses to date and will be sending out reminders via post and the website. See Appendix 3.

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