

## Participant Information Sheet

### (3) Patient Information Searching and Evaluation

Funded by NHS Service Delivery and Organisation

Thank you for considering participation in this NHS-funded research. Before you commit it is important for you to understand why the research is being done and what it will involve. This information sheet (no. 3, version 6, 28/3/07) tells you about the project. Please read this sheet carefully and ask us if there is anything that is not clear or if you would like more information. This research is confidential and your anonymity will be protected at all times.

#### Part One

##### What is the purpose of this study?

The aim of this study is to understand how patients (and carers) use the Internet to get health information and how this changes their experiences with doctors, consultants or other healthcare professionals. The part of the study you have been asked to participate in looks at day-to-day usage of the Internet for obtaining health information. We would like to build a picture of your experiences with and expectations of using health information websites.

##### Why have I been chosen to take part?

You have been asked to take part because you are in one of the following patient groups: cancer (breast or prostate), diabetes and depression, and have agreed to have your contact details given to us. We are asking approximately 40 patients to take part in this study.

##### Do I have to take part?

No, it is entirely up to you. This information sheet should help you to decide and we are happy to answer any questions. We will normally ask you to decide whether to participate within five working days. If you do decide to take part you will be asked to sign a consent form. You can leave the study at any time without having to give a reason. A decision to leave the study or a decision not to take part will not affect your standard of care.

##### What will happen to me if I take part?

You will be observed using the Internet to search for health information. These sessions will be audio-video recorded. You will also be interviewed after your Internet session.

##### What do I have to do?

You will be asked to search the Internet for health information relating to your condition (for one session only). A researcher will observe you and video record the screen showing the websites that you visit during the session. You will not appear in the video recording. They will ask you to think-aloud, describe your thoughts and talk about your

experience of using the Internet (this will be audio recorded). You will be asked to take part in an interview after the session talking about any stories or incidents that were particularly important to you. You will be invited to take part in further parts of the study. If you do not wish to take part in further research please let us know.

##### What are the possible benefits of taking part?

The information will be used to help improve future health services by understanding the ways in which Internet sources of health information can be used and improved to help patients and carers. The study may not have any immediate direct benefits for you.

##### What are the possible inconveniences or disadvantages of taking part?

You will need to set time aside for taking part in the audio-video recorded session and for the interview following that session.

##### What happens when the study ends?

The findings from this study will show how health information from the Internet can help to improve patient care, and will be used by the NHS to improve health service delivery. Findings will be made available for participants.

##### What if I have a concern?

Any concerns about any aspect of the research or any possible difficulties you may have will be addressed (details in Part 2).

##### Will my taking part in the study be kept confidential?

Yes. All information about your participation in this study will be kept confidential. In the unlikely event that there is a need to disclose information, this will be done with your consent (details in Part 2).

##### Contact details:

Dr. Diane Speier, Tel: 0161 2756327  
Dr. Debbie Keeling, Tel: 0161 2756569

Manchester Business School, The University of Manchester, Booth Street West, Manchester M15 6PB

**This completes part 1 of the information sheet. If you are considering taking part in the study, please continue to read the additional information in part 2 before making any decision.**

## Part Two

### What will happen if I don't carry on with the study?

You can withdraw from the study at any time without your standard of care being affected. Information collected during the time that you took part in the study will still be used, but your anonymity and confidentiality will be protected. However, you can request that we delete all or part of the data that we hold about you. You can attend the end of study conference if you wish to do so.

### What if I have a concern?

If you have a concern about any aspect of the study, you should ask to speak with the researchers who will do their best to answer your questions (Dr. Diane Speier 0161 2756327 or Dr. Debbie Keeling 0161 2756569). If you remain unhappy and wish to complain formally, you can do this through the University of Manchester Complaints Procedure. Details can be obtained from the University.

In the event that something does go wrong during the research study that affects you there are no special compensation arrangements. If you are affected and this is due to someone's negligence then you may have grounds for a legal action for compensation against The University of Manchester but you may have to pay legal costs. The normal University of Manchester complaints mechanisms will still be available to you.

### Will my taking part in this study be kept confidential?

Yes, all information that is collected about you during the course of the research will be kept strictly confidential. You should be aware of the following:

- 1) We are required to comply with the Data Protection Act 1998 in terms of handling, processing, storage and destruction of the information that we collect from you.
- 2) We will collect data from you by interview, observation, and audio-video recordings. We will also ask you to sign a consent form on which your name will appear.
- 3) Code numbers will be used in place of names of people who have given us information on all forms and transcripts so that all information collected for the study can be kept strictly confidential. Consent forms will be kept separately from other data collected.
- 4) All patient-identifiable data will be kept by the research team in the research office at the University of Manchester. It will be stored securely in locked cabinets. Anonymised data will be kept on secure servers/computers and DVDs (all will be password-protected).

5) Access to data is restricted to research staff and named team members. The research team have access to the coded information for the purpose of analysis, writing reports and presentations. All have a duty of confidentiality to you and nothing that could reveal your identity will be disclosed outside the research site (see point 8 below).

6) Anonymised data will be kept for a period of 5 years from data collection. All paper forms of data (e.g. signed consent forms and transcripts) will be destroyed at the end of the funded period for this project.

7) You can request a review of the data that the research team hold in relation to your case only.

8) The only reason that we might have to break confidentiality is if anything you told us suggested that you or another person was at risk of harm. Depending on the circumstance, health researchers are required by law to co-operate with designated authorities to prevent or minimise harm in line with legislation or guidance (especially to children – Children Act 1989). This might mean informing someone else about our concerns, AFTER DISCUSSING THIS WITH YOU FIRST.

### What will happen to the results of this study?

The results of this study will be used to guide NHS policy and practice for future health services. In particular, how the Internet can be used and improved to help patients, carers and healthcare professionals. To do this, guidelines and workshops will be developed for healthcare professionals and website designers to let them know how the Internet is used for health information and how it could be improved in the future. We will also make our suggestions for using and improving the Internet for health information available to healthcare academics, healthcare professionals, patient groups and the public through published reports. A project conference will be organised to which participants will be invited. The results of this study may be used as a basis for further research projects.

### Who is organising and funding the research?

The research is funded by NHS Service Delivery and Organisation (SDO) and organised through the University of Manchester and the University of Glasgow. The Research Team consists of researchers from the University of Manchester, University of Glasgow, Open University and University of Strathclyde.

### Who has reviewed the study?

This study has been reviewed through the NHS SDO, Central Office for Research Ethics Committees and the University of Manchester Ethics Committee.