



Participant Information Sheet (4b) Dynamics of Virtual Health Communities (Online Interviews)

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. 4b, 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 will look at how virtual community members communicate with and influence each other. We also want to find out if membership of a virtual community has an effect on your healthcare experiences.

Why have I been chosen to take part?

You have been asked to take part because you are a member of a virtual health community of interest to us. We have contacted the gatekeeper of the community and asked their permission to contact members of the community.

Do I have to take part?

No, it is entirely up to you. This information sheet should help you to decide and we will be happy to answer any questions. We will normally ask you to decide whether to participate within five working days. The gatekeeper has signed a consent form to allow us access to the community. 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.

What will happen to me if I take part?

You will be asked to take part in an online interview.

What do I have to do?

You will be interviewed online, which will be recorded. 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?

We do not foresee any particular inconveniences. You will have to put time aside to take part in the interviews.

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 by the research team. 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 the information in part 1 has interested you and 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. 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 discussion logs and/or interview.
- 3) Code numbers will be used in place of names of people on all forms and transcripts so that all information collected for the study can be kept strictly confidential.
- 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 will be restricted to research staff and named team members. The research team will have access to the coded information for the purpose of analysis and writing reports and presentations. All have a duty of confidentiality to you as a research participant

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 and Open University, 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.