

Risk, safety and consent in blood services: information about focus groups

Invitation to participate

Thank you for expressing interest in our research study. This information sheet is designed to help you decide whether you would like to participate in this study. Please ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The study aims to find out more about people's experiences of and views about receiving blood transfusions. We are especially interested in the information that people receive about these treatments.

Who is eligible to take part?

We are recruiting about 20 people to attend four focus groups to talk about blood and blood services. People who have received blood in the past two years as part of their medical care in the NHS are invited to take part, as well as other people who are interested in blood transfusion and blood donation.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you are still free to change your mind at any time and you don't have to give a reason.

What will happen to the results of the study?

At the end of the project we shall send out a summary of our findings to everyone who has asked for one. Please tell Helen Busby if you are interested in receiving this summary. We shall also publish a summary report on our website. We also expect to publish papers about the research in academic journals.

What will happen if I am interested in taking part?

We will write to you to confirm the date and location of the focus group that we'd like to invite you to attend, after we've spoken with you about the research and answered any questions that you have. We will refund your expenses for parking and travel up to £15.

What will happen at the focus group?

The focus groups will be held at the Orange Rooms in Newarke Street in central Leicester. If you take part, we will invite you to discuss your experiences of and views about receiving blood and blood products. (The group will consist of 5-6 people plus Janet Willars who is running the groups, and Helen Busby who is the lead researcher).

We understand that people participating may not know very much about blood but we are still interested in your views and experiences. If there are questions that you would prefer not to discuss, you do not have to.

What are the possible risks and benefits of taking part?

There are no direct benefits to people who take part but we hope that the study will help to improve the experience of patients in the future. We do not think that there are any major risks but some people may get upset when talking about their experiences. We will do our best to make sure that the focus groups are carried out sensitively.

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential by the research team. We shall ask everyone to respect the privacy of others in the group.

We will only know what you tell us, and will not have access to any other information such as your medical notes. Personal information such as your name and address will be stored separately in a locked cabinet and will be deleted from our records at the end of the project. We shall use these details only to send you a summary at the end of the project, if you would like us to.

What will happen after the focus groups?

We would like to record what is said in the focus groups. After the group is finished we plan to make a transcript (a written record), so that we can study what has been said. Everybody's names will be removed from the transcript as well as any other details that might identify you or others (including the names of family members, doctors, hospitals). Because we think that people's views and experiences are very important, we would like to be able to quote directly from the discussion in academic papers in journals or reports that we write.

We are required to offer our transcripts to the UK Data Archive for storage so that other researchers can study them in the future, if you agree to this. Further information about this will be available at the focus group. It is completely up to you to decide whether or not you would like the transcript from your focus group to be included in the data archive.

Who is organising and funding the research?

This study is being organised and sponsored by the University of Leicester. It is funded by the Economic and Social Sciences Research Council, one of the government's research funding bodies.

Who has reviewed the study?

This study has been reviewed by an NHS Research Ethics Committee (REC), which considers the interests of people taking part in research. The Nottingham 2 REC have reviewed the study and agreed that it may go ahead.

What if there is a problem?

If you have any concerns about any part of this research project please contact Helen Busby or the head of the research group Professor Mary Dixon Woods. The contact details for Helen Busby are below. The contact details for Professor Dixon Woods are:

Mary Dixon-Woods, Professor of Medical Sociology, Department of Health Sciences, University of Leicester, 22-28 Princess Road West, Leicester, LE1 6TP. Telephone: 0116 229 7262 email: md11@le.ac.uk, website: www.le.ac.uk/people/md11

Taking part in this study involves attending a focus group only, and so it is unlikely that you will be harmed. In the unlikely event that anything did go wrong and you were harmed during the research due to someone's negligence then you may have grounds for a legal action for compensation against the University of Leicester but you may have to pay your legal costs.

Further Information

Thank you for taking the time to read this information sheet. If you have any further questions about this research please contact Helen Busby.

Contact details for participation in this study

Helen Busby, Department of Health Sciences, University of Leicester, 22-28 Princess Road West, Leicester, LE1 6TP. Telephone: (0116) 252 3648 Email: helen.busby@le.ac.uk