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Bathing Adaptations Research The BATH-OUT Study Interview Participant Information Pack

You are already taking part in our research involving people having level access showers installed. We would like to invite you to take part in this additional interview study. To help you decide whether to take part, this sheet explains why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Please ask us if there is anything you are unclear about or would like more information on.

What is the purpose of the study?

We are carrying out some research looking at the impact of level access showers on people and their carers. We want to find out about the experiences which led to them needing the level access shower and also how they have experienced it since it has been provided. We also want to find out whether there are aspects of our study which could be improved upon. This project is a small 'feasibility study' which should help us to plan a bigger study.

Why have I been invited?

You have been invited because you are already taking part in the main BATH-OUT study and the level access shower has now been installed. We would now like to invite you to take part in this additional interview study. We are inviting up to 30 participants like you to take part

What will happen to me if I take part?

We would like to carry out an interview with you where we talk to you about the adaptations service and how the level access shower has affected you. We are also interested in hearing your views about taking part in the BATH-OUT study, what has worked well and what has worked less well. The interview will take place in your own home and will be conducted by a researcher from the University of Nottingham and will take about 30 to 45

minutes. It will be audio recorded, with your consent. All your normal health and social care services will continue.

Do I have to take part?

It is up to you to decide whether to take part in the study. You have some time to think about it. The study researcher, Phillip Whitehead, will contact you within two days of receiving this information sheet, to ask if you would like to participate in the study. He will also be able to answer any further questions that you have. If you decide to take part, you will be asked to sign a consent form. Even if you give your consent, you can withdraw from the study at any time, without giving a reason. This will not affect the care you receive or your participant in the main study.

What will I have to do if I want to take part?

If you decide to take part in the interview study you do not have to do anything - a member of the research team will contact you to ask whether you want to take part.

What are the potential benefits of taking part?

There may be no direct benefit to you. However, the information we get from the study may help us to plan a bigger study. The aim of the bigger study would be to determine how to organise adaptations services in the future.

What are the potential disadvantages and risks of taking part?

We do not anticipate there are any serious risks involved in taking part. Some of the questions in the interview will focus on the activities you are having difficulty with, as well as those you are able to do, and there is a possibility that some people may find these questions upsetting. However, the interview will be completed by a qualified healthcare professional who is used to dealing sensitively with these issues. You are free to refuse to answer any question which you do not wish to answer.

What if I become distressed during a visit?

If you are upset or distressed by any questions we will stop asking the questions immediately and discuss this with you. You will be given the option of not continuing with certain questions or with the study. We will only continue if you tell us that you agree.

Expenses and payments

Participants will not be paid to participate in this study.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, some parts of your data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research.

They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Your name and address will be removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, telephone number) will be kept for 6 months after the end of the study so that we are able to contact you about the findings of the study. We may also wish to contact you about *possible follow-up studies* and will ask you to indicate whether you are willing for us to do this. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although what you say in the interview is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. We would discuss this with you before telling anyone else.

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

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw after the interview has been completed, then the information collected cannot be erased and may still be used in the project analysis. You will continue to receive treatment as normal from health and social care services.

What if there is a problem?

If you have any concerns about the study you are encouraged to speak to a member of the research team and they will do their best to answer your questions. You can contact Dr Phillip Whitehead, or Professor Marion Walker who are researchers on this study. Their contact details are given at the end of this document. If you remain unhappy and wish to complain formally you can do this through the Nottinghamshire County Council complaints procedure.

What will happen to the results of the research?

It is intended that the results of the research will be published formally in scientific journals and patient newsletters. We may use anonymized quotations from your interview as part of these reports. You will not be identified in any report or publication.

Who is organising and funding the research?

The research is being organised by The University of Nottingham. The research is funded by *The National Institute for Health Research – School for Social Care Research*. There is a steering group who meets regularly to advise the research team. The group includes experienced research therapists, service user representatives and staff from social care services.

Who has given permission for the study to be carried out?

All research in the NHS and Social Care sector is looked at by an independent group of people, called the Research Ethics Committee to protect your safety, rights wellbeing and dignity. This study has been reviewed and given favourable opinion by the Social Care Research Ethics Committee (ref: 16/IEC08/0017).

Further information and contact details for the study:

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Nottingham City Council Representation and Complaints Procedure

Have Your Say
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Loxley House
Station Street
Nottingham
NG2 3NG
Tel. (0115) 9155555
www.nottinghamcity.gov.uk/haveyoursay

Thank you for taking the time to read this information pack