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Bathing Adaptations Research The BATH-OUT Study Carer Information Pack

A research study involving people having level access showers installed is taking place in Nottingham. We would like to invite you to take part in this 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.

Important things that you need to know:

- There is limited research on how housing adaptations, such as level access showers, help people and their carers to manage.
- There are often long waiting times for adaptations and waiting times vary in across the country.
- We want to investigate how adaptations impact on people and their carers and also the impact of waiting times.
- Your friend or relative is taking part in the study which involves:
 - A 50% chance that they will go onto the routine waiting list for their adaptations (usually around 3 months).
 - A 50% chance that they will not go onto the waiting list and instead we will begin planning the adaptations immediately.
- If **you** also take part in the study, we will complete some short questionnaires with **you** which we will repeat three and six months later.
- We aim to compare the people and carers in both groups (waiting list or immediate adaptations) to see whether it is possible to use this method in our research.

- If we show that it is possible then we aim to plan a bigger study.
- We may also want to interview you about your experience. This is a separate part of the study.

What is the purpose of the study?

We want to find out whether having a level access shower affects people's ability to manage their personal care and their emotional and physical health. We also want to find out whether waiting for a level access shower to be installed leads to loss of independence and more use of health and social care services. **We also want to find out if having a level access shower helps people – often referred to as 'carers' - who provide help and support (friends or relatives who provide support, not paid care workers) with their caring role and their emotional and physical health.** We are aiming to see whether we can use a method to randomly allocate people to different groups in order to carry out this research. 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 your friend or relative whom you provide help and support for, has agreed to be in this study. As part of their involvement in the study, your friend or relative (the person who has been referred for the level access shower) will be put into one of two groups by chance (randomly). There is a 50% chance of being in either group. The two groups are:

- **Routine Adaptations (waiting list)** – People in this group will go onto the usual waiting list and will be allocated to a project officer to plan their adaptations (level access shower) when they come to the top of the waiting list. The waiting list is usually around 3 months, however, it is important to note that this can vary.
- **Immediate Adaptations (no waiting list)** – People in this group will be allocated to a project officer to plan their adaptations (level access shower) as soon as possible and will not go onto the routine waiting list.

We are inviting everyone who is in a similar situation to you to take part.

What will happen to me if I take part?

If you choose to take part, a researcher will visit you at home and complete some initial questionnaires with you. This should take about 15 to 20 minutes. You will also receive two follow-up visits which will take place three months and six months after joining the study. These visits will be conducted by a member of the research team. They will discuss how you have been managing and also complete some further assessments of your physical and emotional abilities. Again, these should take 15 to 20 minutes each time. If

you would like another person to be present, this can be arranged. **These questionnaires are about your own health and wellbeing and are in addition to the questions we will complete with the person taking part in this study.** We can arrange this visit jointly with the person taking part in this study or we can carry out your visit separately. We will arrange this according to the preferences of you both.

We may also like to interview you about your experiences of the adaptations process. We would like to find out what you liked and did not like and see what you thought could be improved on. We would also ask about the difficulties you were having before the shower was installed. With your permission we would like to audio record the interview. The interview is a separate part of the study and you do not have to take part in this. There is a separate consent form and information sheet for the interview.

All health and social care services for you, and the person you provide help and support for, will continue as usual.

What will happen to me if I do not take part?

If you do not take part in the study all your health and social care services will continue as normal. The health and social care services of the person whom you provide help and support for will continue as normal. That person will still be eligible to take part in the study and your decision does not affect their involvement.

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. One of the study researchers will contact you within two days of receiving this information sheet, to ask if you would like to participate in the study. They 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 the care of the person for whom you provide help and support.

Will I receive any expenses or payments?

No. Participants will not be paid to participate in this study.

What are the potential benefits of taking part?

There may be no direct benefit to you. 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. The bigger study would aim to help social care and housing staff best use the resources available to them when treating people in their own homes.

What are the potential disadvantages and risks of taking part?

We do not anticipate that there are any risks involved in taking part. Some of the questions we need to ask will focus on your physical, emotional and mental health and your feelings about providing help and support to your friend or relative. There is a possibility that some people may find these questions intrusive. However, the researcher who visits you has received training in 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.

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 we will ask you whether you agree 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 during the course of the research is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may need to report this to the appropriate persons. However, we will discuss this with you before telling anyone else.

Will the research team have access to my health or social care records?

No. We will not need to access these records for this study.

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. However, if you withdraw then the information collected up to the point of withdrawal cannot be erased and this information may still be used in the project analysis. You, and the person you provide help and support for, will continue to receive treatment as normal from the occupational therapy and adaptations services, and other health and social care teams. If you withdraw from the study the person who was provided with the adaptations will continue in the study unless they also withdraw. If the person who received the adaptations withdraws from the study **before the adaptations have been completed**, you will also be withdrawn. If the person withdraws **after the adaptations have been completed**, you will be free to continue in the study unless you also withdraw.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally you can do this through the Nottingham City Council complaints procedure, the contact details are also at the end of this document.

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, presented at national and international conferences, and in patient newsletters. 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 project 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 researchers, service user representatives and staff from Nottingham City Council.

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
Nottingham City Council
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