



Pressure Ulcer Prevention at Home 2 Project

Testing New Resources to Support Pressure Ulcer Prevention

Please let us know if you need this information in another format
(e.g. large print or audio)

We are inviting you to take part in a research project called Pressure Ulcer Prevention at Home 2. Before you decide if you want to take part, we would like to give you some information.

Take as long as you need to read this information and feel free to discuss it with others. If you have any questions, please contact a member of our team (contact details below).

You will find more details in an 'additional information' document. You don't have to look at that extra information, if you don't want to. However, you might find it useful if you still have questions, either now or in the future.

Study Contact Details

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Thank you for taking the time to read this information!

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Pressure Ulcer Prevention at Home 2 Study: Field Test	PIS 1a Interviews	1.0	21/04/26

About the project

This research project is about pressure ulcer prevention. However, you do not need know anything about pressure ulcers or research to take part. We hope to involve a range of people with different kinds of knowledge and experience. This could include people with disabilities, carers, health or social care professionals or those working in relevant charities and community groups.

Pressure ulcers (sometimes called bedsores or pressure sores) are patches of damaged skin and tissue. They are often caused by lying or sitting in one position. Health conditions which limit movement can put people at risk of getting pressure ulcers. They range from small red skin patches to big open wounds. Most pressure ulcers can be prevented, if people have the right support. People with long term conditions often live at home and self-care, with little or no contact from health professionals. At the moment, many of those people don't get much pressure ulcer prevention support.

We have developed some resources (a website and a paper guide) to help people prevent pressure ulcers at home. We are looking for people to test out the new resources and tell us what they think.

Who can take part in the research?

We have developed resources for different groups of people including service users, carers, personal assistants, health and social care professionals and third sector partners. There is more information about each group below. You need to live in the UK to take part in this research.

1. Service Users – Adults with a long-term, neurological condition, which limits movement. For example:

- Multiple Sclerosis
- Spina Bifida
- Spinal Cord Injury
- Muscular Dystrophy
- Cerebral Palsy

2. Carers - People who provide unpaid care / support for an adult with a long-term neurological health condition, which limits movement (see above for example conditions). This could be as a family member or friend. You do not have to have cared for someone with a pressure ulcer to take part.

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3. Personal Assistants (PAs) - People who are employed (or have previously been employed) to support an adult with a long term, neurological health condition, which limits movement (see above for example conditions). You do not need to have supported someone with a pressure ulcer to take part. PAs are often well placed to spot and help manage pressure ulcer risk. However, they are rarely represented in health research, despite their expertise. We want to address that by speaking to PAs.

4. Health or Social Care Professionals whose role is relevant to pressure ulcer prevention or support for long term neurological conditions. This can be front line professionals or people in managerial or strategic roles.

5. Third Sector Partners – Representatives, volunteers, or staff from organisations whose work is relevant to this project. By third sector we mean organisations like charities, community groups and peer support groups.

What will happen if I take part?

We want to check whether the new pressure ulcer prevention resources are relevant, understandable and useful. We are looking for people to use the website or paper guide and provide some feedback during an interview. There are 2 types of interviews. You can decide which one you would like to do:

1. An informal chat with a researcher about your experience of using the website or paper guide.
2. A think aloud interview. This involves using the website together with a researcher and discussing your thoughts and feelings as you go through it. You would also be invited to complete a template that helps you to develop your own pressure ulcer prevention plan.

Your feedback will help us identify things that are not clear and things we can improve. There are no wrong or right answers. The researchers you speak to may have a similar background to yourself (i.e. service user, carer, PA, health or social care professionals). All researchers have been specially trained and are supported by the University of Leeds team.

Some interviewers will work in pairs, so you may be invited to talk to 2 people. You are also welcome to bring someone along. Interviews will take approximately 45 minutes. Please let us know if there is anything we can do to make interviews more accessible or comfortable for you. You can choose whether you are interviewed face-to-face (at an accessible, convenient location) or virtually (via phone or video call). You can take a break or stop at any time.

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What information will you collect about me?

Before the interview, we will ask you to fill out a brief, anonymous questionnaire about yourself. It will ask for personal details e.g. age, gender, ethnicity, health conditions or caring experience. If you are involved due to your work (e.g. health professional, charity or community group) you will also be asked about that role.

The questionnaire is voluntary, and you can decide which questions you want to answer. You can fill out the questionnaire yourself (on paper, online or via email) or talk through it with a researcher. This information helps us to see the kinds of people who are taking part, and to identify who else we need to speak to.

We would like to audio record interviews and will check you are happy with this before we begin. We may transcribe (write up) our conversations and will also take some notes.

Do I have to take part?

No, taking part in this project is voluntary. You may withdraw at any time, without giving a reason.

If you decide to take part, you will be given this information to keep. You can either provide your consent in writing, by email (see attached consent form), or verbally (which will be audio recorded). You are free to change your mind at any time.

Will information about me be kept confidential?

Yes, we take privacy very seriously and follow strict rules about how we handle personal information. All the information we collect will be kept on a secure server at the University of Leeds for at least 5 years. Any information that we share outside of the research team will be anonymised. We will never share identifiable information (e.g. names or contact details) without your explicit permission.

If you tell us that you are experiencing serious harm, abuse or neglect, then we are obliged to pass that information on to relevant social care services. We would also break confidentiality if you tell us about the abuse or neglect of someone else, including if we believe you are at risk of harming others. We would only break confidentiality in serious cases, and we would tell you first.

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There is more detailed information about how we use personal data in our privacy notice: <https://dataprotection.leeds.ac.uk/research-participant-privacy-notice/>. Please let us know if you would like a hard copy of this information. You can also read more about how we handle, store and share information in a separate document called 'additional information'.

What support will I get?

Please let us know if you have any access, communication or other support needs. We are happy to adapt things to help people take part in a meaningful way. This includes the use of interpreters and / or translators, if needed. It's fine to bring someone along to your interview for additional support. For example, a friend, family member or support worker. If you wish, you will be able to chat to university researchers outside of the interview. We can talk to you about how things are going and signpost to additional support, if needed.

We can offer a £30 voucher, as reimbursement for your time and out of pocket expenses. If you are contributing as part of a paid role (for example a health professional doing an interview in work time), we can only cover out of pocket expenses. In order to claim the voucher, you will need to provide some personal information, including a UK postcode. Please let us know if you have any questions about that process.

Are there any disadvantages or risks if I take part?

We don't think there are any risks involved in this study. However, we are asking you to give some of your time. You may also choose to share some information about your health or the health of people you support. We realise that health can be a sensitive topic for some people. You can take a break at any point.

What are the possible benefits of taking part?

You will be contributing to research about pressure ulcer prevention resources. We hope this research will lead to better support for people in the future.

Who is doing the research?

Our research team is made up of service users, carers, PAs, researchers based at universities, healthcare professionals and charity partners. The original idea for this research came directly from people with personal experience of pressure ulcers.

This research is funded by the National Institute for Health Research (NIHR). The University of Leeds is the sponsor, which means they have overall responsibility for the project.

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Who oversees this research?

This research is funded by the National Institute for Health Research (NIHR) and is being organised by the Clinical Trials Research Unit (CTRU) at the University of Leeds. The Sponsor of the study is the University of Leeds, which means they have ultimate responsibility for the research.

This project was reviewed by the National Institute for Health Research before they gave us funding. In addition, all research with humans is looked at by an independent group of people called a Research Ethics Committee. Ethical approval has been obtained from the School of Medicine Research Ethics Committee (Ref 4401). This committee exists to protect the safety, rights, wellbeing and dignity of people who take part in research. This research has also been reviewed by service users, carers, PAs and health professionals. An independent steering committee help to oversee the research and report any issues to the funder.

What if I have a complaint?

If you have any questions or concerns, please contact the research team:

PUPstudy@leeds.ac.uk or 0113 343 0282. If you remain unhappy and wish to complain formally, please contact The University of Leeds Sponsor Representative at: governance-ethics@leeds.ac.uk.

What happens next?

If you are interested in taking part, or have any questions, please contact our study team.

You may also want to look at the 'additional Information' document.

Laura McLarty (Research Fellow)

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