

## **PARTICIPANT INFORMATION SHEET**

**Version 2.3: August 7<sup>th</sup> 2024**

**Title of study:** Breakdown and Repair of Upper and Lower Limb Prosthetics: Experiences in the UK

**Name of researcher: Lesley Davidson**

We are excited to invite you to take part in a research study. Before you decide whether to take part, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information. Ask questions if anything you read is not clear or you would like more information. Please give yourself at least 24 hours to consider taking part.

### **What is the purpose of this study?**

We are looking for people to share their experiences and/or knowledge of repair and maintenance services for upper and lower limb prosthetics in the UK. We want to know more about:

- Your views on why prosthetic limbs break down
- What impact it has when a limb breaks down
- What it's like for users accessing repair and maintenance support
- Experiences accessing repair services – are they positive, or negative?
- What it's like for clinicians or manufacturers providing repair and maintenance services
- Your views on how services could be improved.

We hope that learning more about these experiences will help us understand what's currently happening to users when they try and access repair and maintenance services. This may in turn lead to recommendations for service improvements or potentially inspire more durable prosthetic limb designs.

### **Why have I been chosen?**

We have invited you to take part because you have relevant experiences with prosthetics for the upper limb. You may be for example:

- A prosthesis user
- A friend, family member or carer of someone with a Prosthetic.
- Working for charities or other organisations that support people that use Prosthetics.

- A professional involved in prosthetic prescription with experience of providing access or services for repairs and maintenance.
- A manufacturer providing repair and maintenance support or services
- Or someone with a similar relevant background

You cannot take part if:

- 1) You have no relevant experience
- 2) You are not able or willing to consent to taking part
- 3) The study has finished

### **Do I have to take part?**

No, taking part is voluntary. If you agree to take part but later change your mind, you can stop being part of the study at any time, without giving a reason, but we will keep the information about you that we already have.

### **What will happen to me if I take part?**

We will be asking you to take part in a 1:1 interview, or a focus group with the researcher. Let us know which option you prefer. Focus groups will depend on availability. We plan to do interviews in a video call, but can offer face to face meetings if preferred. You can have a family member or friend present if you like. Interview and focus groups will explore your views and experiences of breakdown and repairs including aspects such as:

- General discussion about types of upper limb prosthetics and durability
- Your views on why prosthetic limbs break down
- What impact it has when a limb breaks down
- Fixing prosthetic limbs
- What it's like for users accessing repair and maintenance support
- Experiences accessing repair services – are they positive, or negative?
- What it's like for clinicians or manufacturers providing repair and maintenance services
- Your views on how services could be improved.
- Suggestions for prosthetic design improvements

If you agree to take part and meet the criteria for the study, we will schedule an interview or focus group session. Prior to the session, we will explain the study once more and answer any questions you may have. You will be asked to sign a Consent Form, which you can email to us beforehand if the session is online. Alternatively, if the session is in person, you can sign the form on the

day of the session. Note: If remote signing isn't feasible for you, the researcher can sign on your behalf before the session begins.

### **How much of my time will it take?**

The interview will take a maximum of 1 hour. Focus groups will take a maximum of 2 hours.

### **Expenses and payments**

We offer £20 for participating and travel expenses if the focus group or interview is held in Salford. We can only pay via Bank Transfer and this can take 6 weeks to arrive. Payments are made via the University payroll.

### **What are the possible disadvantages and risks of taking part?**

This study is exploring experiences of prosthetic limbs breaking and accessing or providing support. If these have been negative or challenging experiences, it may be difficult to discuss these with the researcher. If you feel negatively affected at any point during the study, you can withdraw your participation at any time. If at any time you feel uncomfortable, we will stop the interview/focus group immediately.

### **What are the possible benefits of taking part?**

We don't expect you to benefit directly from taking part in the study. However, being able to share your knowledge and experience may be a positive experience. Participating will also give you an opportunity to share your ideas on how maintenance and repair processes could be improved. Results from the study may be used in the training of clinical professionals, may inform design teams, and/or may also influence future policy which could indirectly improve your and/or other user experiences in the future.

### **What if there is a problem?**

If there is a problem you wish to discuss, you may contact the lead researcher (email: [L.davidson3@edu.salford.ac.uk](mailto:L.davidson3@edu.salford.ac.uk)) or the project supervisor Prof Laurence Kenney [L.p.j.kenney@salford.ac.uk](mailto:L.p.j.kenney@salford.ac.uk). In case of a complaint, you can contact **Dr Katy Szczepura** (Chair of the Health Research Ethics Panel), Room L617, Allerton Building, University of Salford, M6 6PU (Phone: 0161-2952192; Email: [K.Szczepura@salford.ac.uk](mailto:K.Szczepura@salford.ac.uk)).

### **What if something goes wrong?**

This is very unlikely. However, the university has Public and Products Liability Cover in place.

**Is the study confidential?**

Yes. The research team complies with General Data Protection Requirements (GDPR), and we will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Findings will not be shared with your family member, GP, Prosthetist, colleagues, employer or carer, and whether you do or do not take part. If you are a prosthesis user, taking part will not affect any care that you receive, unless we deem you to be unsafe.

**How will my data be used?**

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you. We will store your anonymised data in the University of Salford data repository. When we publish in certain journals, we are required to give access to the anonymized data, however, you will not be able to be identified. You can find out more about how we use your information by emailing us or contacting the university's data protection officer Andrew Hartley at [A.Hartley2@salford.ac.uk](mailto:A.Hartley2@salford.ac.uk)

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

There is no danger to your leaving the study early. If you want to withdraw please notify Lesley Davidson, email: [L.davidson3@edu.salford.ac.uk](mailto:L.davidson3@edu.salford.ac.uk). Data collected up to that point may be used in the research.

**What will happen to the results of the research study?**

This study may form part of a thesis for Lesley Davidson. We will also report the findings of this study in the form of refereed publications and relevant academic conferences. We will keep the identity of participants confidential.

**Will I have the opportunity to find out about the results?**

A leaflet with a summary of the results will be shared with you once the results have been analysed and written up.

**Who is organising or sponsoring the research?**

The research is being organised by the University of Salford.

**Are there any benefits for participating?**

There is no direct benefit to participants. However, it is hoped this study will inform understanding of what expectations and improvements users and other stakeholders would like to see in the repair process. Results from the study may be used in the training of medical professionals or may also influence future policy changes which could indirectly improve other user experiences in the future.

**Further information and contact details:**

Thank you very much for taking the time to read this research information sheet. Please discuss this information with your family and friends if you wish. To volunteer for this study, or for further information, please contact:

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