

## **PARTICIPANT INFORMATION SHEET**

**Version 1.3, August 7<sup>th</sup> 2024**

**Study title:** Sustainable futures for prosthetic limbs: Perspectives on the lifecycle and afterlife of a prosthesis

**Name of Researcher:** Ms Lesley Davidson & Dr Vikranth Nagaraja

**Invitation:** We would like 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 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 the study?**

We are seeking insights from a diverse range of stakeholders to deepen our understanding of the lifecycle of prosthetic limbs. Whether you're a prosthesis user, a caregiver, a healthcare professional, or a professional in the prosthetics industry, your perspective is valuable. We're interested in learning what happens when prosthetic limbs are no longer needed. We hope to explore ways of enhancing their environmental sustainability. We're interested in learning:

- What typically happens when prosthetic limbs are no longer needed
- Your thoughts on the best way to manage unused prosthetic limbs
- Discussing options like keeping, donating, recycling or returning prosthetic limbs to the NHS/manufacturer
- Your preferences regarding the end-of-life arrangements for prosthetic limbs such as burial or cremation

### **Why have I been invited to take part?**

We've invited you to contribute because of your relevant experience with upper and/or lower limb prosthetics. This may include being a prosthesis user, caregiver, healthcare professional, or industry insider. You may for example be:

- A professional involved in prosthetic prescription
- Have experience of retrieving, recycling, refurbishing or handling Prostheses, for example through funeral care services
- Working in the Prosthetics industry such as an engineer, designer or manufacturer.
- Working as an associated healthcare professional supporting users during their rehabilitation (e.g. Nurses, Occupational Therapists or Physiotherapists)
- Working for charities or other organizations that support people that use upper and lower limb Prosthetics

- Or similar relevant background

You cannot take part if:

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

### **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 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 and focus group in a video call, but do offer a face-to-face meeting if preferred. You can have a family member or friend present if you like.

Interview and focus groups will explore your views on aspects of the life and afterlife of a Prosthetic limb. This may include some discussions around what could happen at end-of-life decisions relating to Prosthetics such as:

- General attitudes towards a Prostheses
- Choices relating to whether to keep or donate a Prosthesis
- What are the pathways or processes for Prosthetic donations
- Attitudes towards a Prosthesis pre-owned by someone else
- What currently happens to/how are prosthetics managed after a person passes
- Challenges around collecting Prosthetics for re-use
- Understanding the manufacturing lifetime of a Prosthetic
- Understanding choices, processes and opportunities for sustainability and attitudes towards the afterlife of a prosthesis and how the limb fits into this

If you agree to take part and are suitable for the study, we will arrange a date for the interview/focus group. At that time we will explain the study once more and answer any questions you may have. We will then ask you to sign a Consent Form and email it to us before the interview/focus group begins. If we see you face-to-face you may sign on the day but before we begin.

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

The interview will take a maximum of 1 hour, the focus group 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 your views on Prosthetics during the limbs life and at the end of life. For some this may be a difficult topic and may evoke feelings of sadness. At the focus group, some people may wish to share religious perspectives. 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 immediately and/or you can leave the focus group at any time.

### **What has been done to minimize risk of contracting Coronavirus (Covid-19)?**

The project follows government and university guidelines and has been risk assessed to mitigate the risk of contracting Covid-19. Researchers have completed relevant training and are committed to their approved protocol. The study's protocol has been developed to minimize physical contact with participants and to minimize hand-over of items to participants.

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

There is no direct benefit to participants. However, it is hoped this study will inform understanding of what choices users, families and professionals may wish to take at the end of a limbs life and perhaps at the end of a prosthesis users life. This in turn may have the potential to inform future policies around end-of-life care and sustainability in Prosthetics.

### **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 supervisors [L.p.j.kenney@salford.ac.uk](mailto:L.p.j.kenney@salford.ac.uk) and Vikranth Nagaraja (email: [v.harthikotenagaraja@salford.ac.uk](mailto:v.harthikotenagaraja@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 carer, GP, or family members, and whether you do or do not take 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.

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

The research is being organised by the University of Salford.

**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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