

## **Participant Information Sheet Narrative Interview**

**Project title:** Everyday Cyborgs 2.0: Law's Boundary-work and Alternative Legal Futures

**Research team:** Professor Muireann Quigley (Project Lead), Dr Rachael Dickson, Dr Joseph Roberts, Dr Laura Downey, and Dr Dominic Berry.

*This research has been approved by the University of Birmingham Research Ethics Committee, approval number ERN\_18-1426.*

### **Why have I been given this information sheet?**

You have been given this information sheet because we believe that you have an attached or implanted medical device and would like to invite you to take part in our research. This information sheet outlines the purpose of the study and provides a description of your involvement and rights as a participant, if you agree to take part. Please ask the researcher any questions you may have about this information prior to making a decision and signing the consent form.

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

'Everyday cyborgs' is a term that can be used to describe people with attached and implanted medical devices. This includes people with a wide range of devices; for example, joint replacements, pacemakers, insulin pumps, and limb prostheses. Some devices use smart technologies such as computer software and Wi-Fi. They collect, analyse, and transmit data. However, their use creates some difficulties for the law. This project addresses a range of questions that remain unanswered about how the law ought to accommodate such devices. These questions include:

1. Should internally implanted devices be viewed as part of the person or as mere objects (or something else)?
2. Should damage to a prosthetic limb that is connected to a person's nervous system (neuro-prostheses) be seen as personal injury or damage to property?
3. Who ought to control/own the software run, and data generated, by implanted medical devices?
4. How should the law deal with risks around unauthorised third-party access to devices (sometimes known as 'hacking')?

The project will use a range of different methods to help us better understand these challenges and to come up with possible answers. To answer these questions, we would like to speak to people at the centre of this project, self-identified persons with attached or implanted medical devices.

**Who can take part?**

Anyone aged 18 and over who self-identifies as a person with an attached or implanted medical device.

**Do I have to take part?**

No. It is your choice whether to take part or not.

**What will happen if I take part?**

You will be asked to meet with the researcher at your preferred location (your home, local café, University of Birmingham), date, and time. The interview will be audio recorded using a small recording device.

The researcher is likely to take some notes whilst you are speaking. This is nothing to worry about. These are clues and questions the researcher might ask you to elaborate on or to clarify information.

A narrative interview means that the researcher will ask you to tell them your story in relation to living with your device. There is no pre-set agenda for the meeting and you should tell us about what you think is important and what you are comfortable sharing. You do not have to answer any questions that you are not comfortable answering. This interview should take about an hour, but it is okay if you need more or less time to tell your story. Please remember that you do not have to answer any questions you are not comfortable answering or share information you are not comfortable sharing.

If it is not possible to meet face to face for any reason, the researcher will suggest meeting via a video call platform like Zoom or Skype.

**Will you cover my expenses?**

We will cover your travel costs to attend the interview and subsistence expenses for any meals you need to purchase as you make your journey.

These expenses will be paid in accordance with the University of Birmingham's expenses policy. The researcher will provide you with a form to complete. Please keep the receipts for your travel and meals.

The project team will work to ensure your claim is processed quickly so you receive your reimbursement as soon as possible. Once authorised, payments are processed weekly and paid into your nominated bank account by BACS.

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

There are unlikely to be any direct benefits for you as a result of taking part, although many people enjoy taking part in research and value the opportunity to tell their stories, speak to other people with shared experiences, and contribute to research that might benefit others.

Long term, the results of this research may influence law and policy, which might affect you directly or indirectly.

### **What are the risks of taking part?**

Sometimes the discussion might touch upon issues that you find upsetting, and if you have had any difficult or traumatic experiences with your medical device, the discussion may bring back memories of that. If you feel upset, you can leave the interview (temporarily or for good) or it will be paused. If you wish, we can help you to seek support if needed. A list of organisations that offer support is attached at the end of this document.

### **How will information about me be used?**

The interview will be audio recorded using a digital recorder. This allows the researcher to listen to the interview later and transcribe it (write it down, word for word). We will send your audio recording to a University approved transcription company to help us accurately transcribe the discussion.

The transcript will be analysed, and we will draw conclusions about what you felt about the issues discussed. This will be written up into publications and presentations, and we will very likely use some of your anonymised direct quotations to provide evidence for our conclusions.

At the end of the project, you can choose to receive an executive summary of our findings. You can let us know if you would like to receive this in the consent form that you sign. You will also be able to access details about the project outputs on the project website <https://blog.bham.ac.uk/everydaycyborgs/>.

### **Who will have access to my data?**

Only the research team will have access to the original data. Anonymised transcripts of the data may be made available to other researchers who could benefit from our research. Anonymised transcripts would be available to other researchers through national data service, i.e., the UK Data Archive. This will only happen with your permission. You may indicate whether you are happy or not with this using the consent form.

### **How will you protect my confidentiality and anonymity?**

Your participation in this research will be kept confidential by the research team, and your personal information will also be kept confidential. The transcript of the interview will be anonymised. This means that your name, and any people, places, and organisations you mention will be altered as necessary to make sure you are not easily identifiable from the transcript or from any publication, presentation, or report. The purpose of anonymisation is to protect you and ensure nobody will be able to identify you from the data that we report in presentations or publications.

In addition to anonymising transcripts, the recordings will be stored on a password protected laptop, University server, and University owned cloud system. Recordings will be disposed of at the end of the project (approximately September 2025).

All signed consent forms and participant information sheets will be scanned and stored digitally in an encrypted folder on secure University systems.

In accordance with University guidelines, anonymised transcripts will be stored securely and kept for up to 10 years after the research has concluded for use in the future if you agree to it. All confidentiality and anonymity rules will continue to apply to the data.

Data collected may be shared in an anonymised form to allow reuse by the research team and other third parties (see ‘Who will have access to my data?’ heading for information on this). These anonymised data will not allow any individuals to be easily identified or identifiable.

It is in theory possible that if your experiences are unique, and someone who knows you very well were to read a publication or listen to a presentation, they may be able to identify you. However, this is very unlikely.

Confidentiality may not be guaranteed if you say anything to us that suggests you or somebody else might be at risk of serious harm. If this occurs, we may need to report it to relevant bodies. If this happens, we will make every reasonable effort to talk to you first.

### **What if I change my mind about taking part?**

If you would like to withdraw from the study you may do so any time during the interview or up to 12 weeks after the interview. If you wish for your data to be removed from the study and not used for the research you can email the project lead on: [m.quigley.2@bham.ac.uk](mailto:m.quigley.2@bham.ac.uk). You do not need to state why you wish to withdraw. One of the project researchers will send you confirmation by email that they have destroyed all of your data (deleting all electronic copies and shredding any paper forms). If you do not have access to email you may contact the project lead in writing at the following address: Birmingham Law School, University of Birmingham. Edgbaston, Birmingham, B15 2TT.

Nothing will happen to you if you change your mind and your wishes to withdraw will be respected. We will not ask any additional questions.

**Who is funding and organising this research?**

The Wellcome Trust is funding this project. The research is being carried out and organised by researchers at Birmingham Law School, University of Birmingham.

**What if there is a problem?**

If you have a concern about any aspect of this study, you may wish to speak to us and we will do our best to answer your questions. Please contact us by email on: [m.quigley.2@bham.ac.uk](mailto:m.quigley.2@bham.ac.uk). If you are unable to contact us by email you may write via post at: Birmingham Law School, University of Birmingham, Edgbaston, Birmingham, B15 2TT. The project team can arrange to contact you via telephone to discuss any concerns you may have.

If you remain unhappy about the research and/or wish to raise a complaint about any aspect of the way that you have been approached or treated during the course of the study please contact the research governance and ethics manager via email on: [researchgovernance@contacts.bham.ac.uk](mailto:researchgovernance@contacts.bham.ac.uk), or via post at Research Governance and Ethics Manager, University of Birmingham, Edgbaston, Birmingham, B15 2TT.

**Contact for further information**

If you have any questions, you can contact us on [everydaycyborgs@contacts.bham.ac.uk](mailto:everydaycyborgs@contacts.bham.ac.uk).

## Support Information

If you feel that you need medical and mental health support following this interview, here is a list of some helplines which can offer this help for free:

**Call NHS on 111.** If you urgently need medical help or advice but it is not a life-threatening situation. It is free to call. This includes mental health support needs.

**Call Ambulance on 999:** If you have urgent health or mental health needs please call the ambulance.

**Call Samaritans on 116 223:** If you are thinking about ending your life or are concerned about someone who may be, you can call for help any time of day or night. It's a free call.

### **Anxiety UK**

Phone: 03444 775 774 (Monday to Friday, 9.30am to 5.30pm)

Website: [www.anxietyuk.org.uk](http://www.anxietyuk.org.uk)

### **Men's Health Forum**

24/7 stress support for men by text, chat and email.

Website: [www.menshealthforum.org.uk](http://www.menshealthforum.org.uk)

### **Mental Health Foundation**

Provides information and support for anyone with mental health problems or learning disabilities.

Website: [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

### **Mind**

Promotes the views and needs of people with mental health problems.

Phone: 0300 123 3393 (Monday to Friday, 9am to 6pm)

Website: [www.mind.org.uk](http://www.mind.org.uk)