

Investigating the transition from paediatric to adult services and the management of ongoing care of adults with osteogenesis imperfecta

Participant Information Sheet

Dated: 19/03/20

You are being invited to take part in some research. Before you decide whether or not to participate, it is important for you to understand why the research is being conducted and what it will involve. Please read the following information carefully.

What is the purpose of the research?

I am conducting research on the transition from paediatric health services to adult health services for people with Osteogenesis imperfecta (OI) also known as Brittle Bone Disease. The purpose of the study is to understand how people with osteogenesis imperfecta manage moving to adult services and how this move affects the care they receive. Your participation in this study will take approximately one hour and thirty minutes, there will be a rest break if needed.

Who is carrying out the research?

The data is being collected by Chloe Morgan, a PhD student in the Department of Public Health, Policy, and Social Sciences, Swansea University, under the supervision of Professor Joy Merrell and Dr Darren Edwards. The research has been approved by the College of Human and Health Sciences Research Ethics Committee.

What happens if I agree to take part?

I will invite you to join an online focus group. In the online focus group, we will be discussing experiences regarding transitioning from paediatric to adult services and experiences of managing osteogenesis imperfecta as an adult. Additionally, I will ask for some background information including your age, sex, type of osteogenesis imperfecta and what region of the UK you live in.

Consent will be required and recorded through the signing of a consent form.

There will be a maximum of eight people in the focus group. The focus group will be video and audio recorded and transcribed but all data will be anonymised. Once the video recording has been transcribed the recording will be deleted.

If more than the required number apply to participate, participants will be chosen on the basis of type of osteogenesis imperfecta, this will be done as it is important that all types of OI are included in this study.

Are there any risks associated with taking part?

The research has been approved by the College of Human and Health Sciences Research Ethics Committee. There are a few risks associated with your participation.

Firstly, becoming fatigued during the focus group as it will last around one hour and thirty minutes. If this is the case, a short break/s will be provided during the group discussion.

Secondly, it is possible that the discussion may be distressing for some if they have had difficult experiences. Both myself and the other participants will all have OI and should have an understanding of the difficulties faced. Therefore, will be able to offer peer support to any participants who become distressed.

Finally, although most people do enjoy group discussions, you will not directly benefit from being involved in the study. However, I plan to develop a guide for people with OI to aid

transition to adult services. It is hoped that this guide will be beneficial for other people with OI in the UK.

Data Protection and Confidentiality

Your data will be processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. Your data will only be viewed by the researcher/research team.

All electronic data will be stored on a password-protected computer file in Swansea University. All paper records will be stored in a locked filing cabinet. Your consent information will be kept separately from your responses to minimise risk in the event of a data breach.

Please note that the data I will collect for this study will be made anonymous, once the video recording has been fully transcribed and checked for accuracy, the video recording will be deleted. At which point, only anonymised electronic copies of the focus group transcript will be retained, thus it will not be possible to identify and remove your data at a later date.

What will happen to the information I provide?

An analysis of the information will form part of my report at the end of the study and may be presented to interested parties and published in scientific journals and related media. Please note that all information presented in any reports or publications will be anonymous and unidentifiable.

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary – you do not have to participate if you do not want to. If you decide to participate, but later wish to withdraw from the study, then you are free to withdraw, without giving a reason and without penalty. However, if you withdraw after the discussion begins, any contributions you make cannot be removed but will still be anonymised.

Data Protection Privacy Notice

The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data, and can be contacted at the Vice Chancellor's Office.

Your personal data will be processed for the purposes outlined in this information sheet. Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you.

The legal basis that we will rely on to process your personal data will be processing is necessary for the performance of a task carried out in the public interest. This public interest justification is approved by the College of Human and Health Sciences Research Ethics Committee, Swansea University.

The legal basis that we will rely on to process special categories of data will be processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

How long will your information be held?

The research data will be preserved and accessible for a minimum of 10 years after completion of the research.

What are your rights?

You have a right to access your personal information, to object to the processing of your personal information, to rectify, to erase, to restrict and to port your personal information. Please visit the University Data Protection webpages for further information in relation to your rights.

Any requests or objections should be made in writing to the University Data Protection Officer:-

University Compliance Officer (FOI/DP)
Vice-Chancellor's Office
Swansea University
Singleton Park
Swansea
SA2 8PP
Email: dataprotection@swansea.ac.uk

How to make a complaint

If you are unhappy with the way in which your personal data has been processed you may in the first instance contact the University Data Protection Officer using the contact details above.

If you remain dissatisfied, then you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: -

Information Commissioner's Office,
Wycliffe House,
Water Lane,
Wilmslow,
Cheshire,
SK9 5AF
www.ico.org.uk

What if I have other questions?

If you have further questions about this study, please do not hesitate to contact us:

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