

The PIC Bone Information Study

Interview Information Summary for Young People (12-15 years)

1) What are we asking you to do?

We are inviting you to take part in an interview with a researcher about what happened when you recently went to hospital with a painful arm/leg.

Please take time to decide whether or not you want to take part. You can talk to your parents about it, or contact us if you have any questions.

2) Why have I been asked to take part?

We are asking you because you recently went to hospital with a painful arm/leg.

3) Do I have to take part?

No, it's up to you. If you don't want to take part that's fine – no one will mind.

4) What do I need to know about the interviews?

The researcher will ask you what you thought about the care and tests (e.g x-rays or scans) you received and what it was like having a painful arm/leg. We'll use the information you give to improve things for young people in the future.

5) What will happen if I take part?

You'll talk with a researcher from the University of Liverpool. This will probably take about half an hour. Your mum/dad will also chat with the researcher.

You can decide whether the interviews take place in-person (usually in your home), by video call or telephone. You can also decide if you want your mum or dad with you when you talk to the researcher.

The researcher will ask you if they can record the sound of the interview. If there are any questions you don't want to answer, just tell the researcher and they will move to the next question. You can also stop the interview at any point.

The study results will be made available on the study website when the study is finished. [Insert study website URL]. A link to the website will also be provided via email or text message. You can also view an animated study explainer video on this website.

6) What will happen to all the information about me?

All information you give us will be kept private. The only time we might need to tell someone is if we were worried about you.

We will use a number instead of your name when we write up the findings so that you can't be identified and no one will know what you have said.

7) How to contact us?

Please get in touch with <Information Study researcher name and email> if you would like more information.

How will information about me be used?

UK Data protection regulation requires that we state the legal basis for processing information about you. In the case of research, this is 'a task in the public interest.' The Universities of Oxford and Liverpool are the data controllers for the information study and are responsible for looking after your information and using it properly.

Your data will only be shared among members of the research team, though audio recording of interviews may be transcribed by an approved University transcriber. It will not be shared with anyone else except with your consent or as required by law.

The forms with information about your interview responses will only identify you by a study number. Your personal information (for example, your name so that we can keep track of who has participated in the study) will be stored in a secure place, separate from your study file and will not be entered into the study database. The study data, with identifying information removed, will be securely stored in a locked office in the research office and on secure servers at the University of Oxford and the University of Liverpool. The Universities of Oxford and Liverpool have robust data security measures in place. This makes the risk of data breaches minimal. We will be using information from your medical records and will use the minimum personally-identifiable information possible. Any identifiable information will be retained for one year after the study has finished (5 years for anonymised information). The investigators agree not to attempt to connect your information back to you after the study is completed.

Interviews will be audio recorded, whereas in discussion groups the researcher will make notes only. We will not collect any data that can identify you (e.g. name, NHS number) during the interview. Audio recordings and handwritten notes will be transcribed, and any identifiers will be removed. We will not keep any codes or keys that link you to your anonymised data. Audio files and handwritten notes will be destroyed as soon as they have been transcribed. The transcripts will be stored with password protection by the University of Oxford and University of Liverpool. All data will be destroyed 5 years after the end of the research project. Audio files will be transcribed by a university approved transcription service. Our transcribers use a secure system for uploading audio files for transcription. They do not keep the audio recording.

When the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to the disclosure.

UK Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at <https://compliance.web.ox.ac.uk/individual-rights>.