



The PIC Bone Information Study

Health Professional Information Summary

1) What is the PIC Bone Information Study?

The Information Study will be embedded in the PIC Bone study and look at patient experience of diagnosis and care when they attend hospital with a painful limb. We will use the findings to identify ways to enhance the experience of diagnosis, including communication about investigations such as x-rays and scans, for families in the future.

2) Why am I being invited to take part in the Information Study?

You are being invited because you are involved in caring for children when they attend hospital with a painful limb.

3) What does the Information Study involve?

We are asking health professionals to take part in a focus group discussion about their experiences of investigations and caring for children when they have a painful limb. This will usually involve a discussion with about 5-6 other health professionals and 1-2 researchers. Focus groups will likely take place by video-conference and last about 1 or 1.5 hours. With your permission, we will audio-record the focus group.

4) Do I have to take part?

No – participation is voluntary. Your employment or legal rights will not be affected if you say no.

You can withdraw from the Information Study without giving a reason. You can also ask for your data to be destroyed but if you withdraw after the analysis has begun it may not be possible to remove your data from the study.

5) What about confidentiality?

Information collected during this study will be kept confidential. Apart from the information study team, no one will know what you have said. In order to contact you during the information study, we will collect contact details for you. These will be stored securely and destroyed at the end of the information study.

Audio-recordings will be typed out by a transcription agency approved by the University of Oxford's information security team and with a confidentiality agreement in place, but we will take out identifying details like names and places before analysing the transcripts. The audio-recordings will be deleted



following transcription. You will not be identified in any reports from the PIC Bone study or the Information Study.

6) What are the possible risks and benefits of taking part?

We hope this study will benefit future families when their child attends hospital with a painful limb. We do not anticipate any risks.

7) Who is involved with the study?

The PIC Bone study is funded by the National Institute for Health and Care Research (NIHR). The University of Oxford is the Sponsor for the study, and has overall responsibility for its management.

Professor Bridget Young and <researcher name> at the University of Liverpool are running the Information Study.

8) How will the data collected about me be stored and used?

All data collected for the Information Study will be securely stored at the University of Liverpool. Professor Bridget Young, who is based at the University of Liverpool, will be custodian of all data for the Information Study.

Anonymised transcripts of focus groups will be stored at the University of Oxford and University of Liverpool for 5 years.

Your contact details will be destroyed at the end of the Information Study.

The results will be used to inform diagnostic care for children with painful limbs. These will be published in scientific journals, but it will not be possible to identify any individuals from these reports. We will send you a summary of the results at the end of the study, if you would like one. The study results will be made available on the study website when the study is finished. [Insert study website URL]. You can also view an animated study explainer video on this website

9) Who can I contact for further information?

If you have any questions at any time about the PIC Bone Information Study, please contact: <researcher name and email address>.

 **PIC Bone**
Imaging in Paediatric Osteomyelitis**What will happen if I don't want to carry on with the study?**

If you do not agree to be part of this study, you can change your mind at any time and can contact the research team using the contact details on the last page of this sheet.

Consent

We will ask you to sign a consent form, indicating you agree to taking part in the study.

To do this, we will send you a remote consent form via email or post for you to sign and return.

We don't mind which way you chose!

**What if there is a problem?**

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

If you remain unhappy and wish to complain formally you may contact the University of Oxford Research Governance and Assurance Team office on 01865 616480, or the director of RGEA, email RGEA.Complaints@admin.ox.ac.uk.

Who is involved with the study?

- A group of surgeons, doctors and scientists who have many years of experience with working with children and young people in the healthcare setting.
- They work with the Surgical Intervention Trials Unit (SITU) in Oxford who will help manage the project. The SITU team have experience with bone and joint research.
- Generation R (a network of Young People's Advisory Groups) are also supporting the design and delivery of this study.
- The study is funded by a grant from the National Institute for Health and Care Research, an organisation that supports research involving children and young people.
- The study is sponsored by the University of Oxford and has been reviewed by your local hospitals research department.
- The University of Oxford and University of Liverpool will be using information from you to undertake this study and will act as joint data controllers for this study.
- **The study has also been reviewed by the XXXXXXXXXXXX NHS Research Ethics Committee who have issued a favourable ethical opinion for study.**



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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 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) 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. 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>.