

Patient Information

12-15 years old



A study about bone and joint infections and how best to diagnose them

What is the PIC Bone Study?

PIC Bone is a research study run by surgeons, doctors, and scientists. They want to better understand how useful different types of scans (MRI and ultrasound) are in identifying a painful limb with suspected bone or joint infections. This helps them to develop a clinical pathway to make sure patients like you get the right tests at the right time. This study is called a “cohort” study, which means that we follow your progress closely over the next 3 months.



Here to help

The study is the work of a big team. The team includes:

- Paediatric surgeons who operate on bones and joints
- Paediatric doctors who work especially with children and young people
- Scientists who work on bone and joint-related research involving children and their parents/caregivers
- Generation R (a network of young people supporting the design and delivery of research)
- Research people like statisticians, and people who run large research projects

**This study does NOT involve
any extra tests!**



- **Most importantly, patients & parents too!**

We would like to ask you and your family if they could help us with this study over the next 3 months.

Why me?

Your doctor thinks you might have a bone or joint infection, but it is not always easy to tell if the type of symptoms you have are due to a bone or joint infection or something else. Scanning bones and joints is one-way doctors try to identify these infections. We want to know which doctors use which scans and assessments and how helpful they find them.



Do I have to take part?

No! If you don't want to get involved, don't worry! You'll just have treatment as planned by you and your doctors and we won't ask for any further information.

What do I have to do if I say Yes?

- We would be grateful if you and your parent/carer could speak to the doctors and nurses about the study
- If your parent/carer is happy for you to join the PIC Bone study, they will be given a consent form to sign online (or on paper, if preferred).
- And you can sign one too if you want to.

We'll collect information about the assessments you have at the hospital, and we would like to give you and your parent/carer a call in 3 months to see how you got on. We'd also like to contact you about future research that you might be eligible for, but only if you and your parent/carer are happy for us to. You could sign an assent form if you want to.

This information will be collected by a team at the University of Oxford. Your name, phone number and your NHS number will be kept safe and secure so no one else can see information about you.

You can change your mind whenever you want to. Just let us, or your doctor know and we won't ask for any further information.

What are the advantages of taking part?

Although the research will not help you directly, we hope that the results that the research group get from the study will lead to better care and outcomes in the future for other children with possible bone or joint infection. 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.

Who's running this study?

Surgeons, doctors and scientists in Oxford are helping run this study. An organisation called the National Institute for Health and Care Research (NIHR) have given them some money to run the study. The NIHR give money to lots of people to help them improve treatments for children in the UK.

The data will be entered into a GCP compliant data collection system and stored in a database on the secure server at the University of Oxford, accessible only to members of the research team based on their role within the study. The database and server are backed up to a secure location on a regular basis.

All contact will come from the research team in the first instance. However, agreeing to be contacted does not oblige you to take part in future research, and you can be removed from this register at any time you wish.”

How will my information 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 University of Oxford, based in the United Kingdom is the data controller and is responsible for looking after your information and using it properly.

We will be using information from your medical records and will use the minimum personally-identifiable information possible. We will keep identifiable information about you up to the point at which you turn 16 years of age (if your parent/carer consents to future contact) otherwise any identifiable information will be kept for one year after the study has finished (5 years for anonymised information). Research documents with personal information, such as consent forms, which will be held securely at the University of Oxford for (5 years for anonymised information) after the end of the study. However, if your parent/carer agrees to your details being held to be contacted regarding future research, we will retain a copy of the consent form until such time as your details are removed from our database but will keep the consent form and your details separate.



All electronic patient-identifiable information, including electronic consent forms, will be held on a server located in an access-controlled server room at the University of Oxford

The local NHS Trust will use your details, e.g., name, NHS number, home address, and contact details to contact you about the research study, send link to consent form and study website, and make sure that relevant information about the study is recorded. A copy of your parents’ paper informed consent form (as applicable) will remain in your medical records at the NHS sites for as long as these are held.

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>.

**THANK YOU
FOR
READING THIS LEAFLET!**

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