

National Ligament Registry

Patient Information

What is the National Ligament Registry? This is a database of information about anterior cruciate ligament (ACL) reconstruction and repair collected across the UK. This will help us to find out which operations work best by observing the outcomes of surgery as measured from questionnaires and monitoring of any complications.

Do I have to participate? No, your consent is entirely voluntary and if you prefer not to participate, your medical care will be unaffected. Your personal details in particular cannot be kept without your consent. You can withdraw at any time, or request access to your data either:

Through the National Ligament Registry website: <http://www.uknlr.co.uk/> or

By emailing customer.support@amplitude-clinical.com

What would I be asked to do? You are asked to complete questionnaires before and after surgery. This is why your email address is important as we will send links to these questionnaires when they are due.

What data is collected?

1. Personal details are needed in order to link you to your surgery and the outcome, and in case you need any further ACL surgery in the future so that your surgeon knows what previous surgery you have had. The sensitive personal information stored include name, gender, date of birth, postal address, email address and NHS number.
2. In addition, we store information about your general health, diagnosis, surgical procedure and your answers to the questionnaires.

Data are stored long-term in case information arises in the future regarding particular operations or diagnoses that makes it in patients' best interests that we contact them.

Who is the data controller? This data is jointly controlled by the National Ligament Registry and British Orthopaedic Association (BOA).

Is my data stored securely? Your personal details are treated as confidential and will be stored safely. Your personal details will not be available to anyone outside the National Ligament Registry, the BOA and its secure IT provider, with the following exceptions:

(1) The National Ligament Registry may approve a specific research project related to your diagnosis or surgery allowing researchers to contact you to ask for further information or to take part in a study. You would be free to decline and again this would not affect your care



(2) Your data may be linked to other national health databases. Transfer of identifiable data outside of the European Economic Area is not permitted. *Anonymised* data, your identifying details removed, may be released to approved organisations.

How will my data be processed? We process the data which participating patients provide to improve our understanding of orthopaedic problems and of their treatment, thus helping us provide future patients with the best care. The BOA and National Ligament Registry are responsible for all acts of processing. We retrieve and analyse your data so that we can compare large numbers of patients, usually removing anything that can identify you as an individual. Such analysis may have to be performed by a specialised third party, in which case they will be bound by the same high security standards and legal contract, whether identifying details had to be included or not. Your surgeon and his / her clinical team can also access and analyse your data to check they are individually giving good care.

You will not be identifiable within the results of any analyses which are shared, and any transfer of data will be encrypted. All studies using data from the Registry are recorded on the National Ligament Registry website.

Children: Monitoring the outcome of surgical procedures in children is as important as it is for adults. It is the child's parents or guardian who is asked to consent for data to be collected.

Where can I find out more information? The National Ligament Registry website (<http://www.uknlr.co.uk/>) contains more information including details of any studies and any information obtained through analysis of the Registry data. If you want to see what data is stored on you, please write as detailed below;

Contact Details:

Visit our website <http://www.uknlr.co.uk/>

Send an email to: customer.support@amplitude-clinical.com

I HAVE READ THE INFORMATION SHEET AND I CONSENT TO:

- Personal details being recorded in the National Ligament Registry and controlled by the National Ligament Registry and the BOA.
- My data being accessed by other medical professionals in the future who are involved in my medical care.
- My data being processed for the purposes set out in the patient information leaflet.

I UNDERSTAND THAT:

- Information in the Registry will be used to look at the outcomes of treatment and anonymised results will be published.
- The BOA, National Ligament Registry or other UK NHS bodies may contact me in the future using the information and data submitted to provide me with information about my health.
- Researchers authorised by the National Ligament Registry may contact me in the future to ask for further information or to invite my participation in other studies.
- I can ask for my details to be removed at any time and can request access to my personal data.
- My anonymised health data may be linked to other health databases relevant to the purposes of the Registry.

I agree: (please tick to confirm consent)

Name: _____

Email: _____

DOB (DD/MM/YYYY): _____

Date (DD/MM/YYYY): _____

Signature: _____