

# USER AGREEMENT AND DATA POLICY

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# **National Ligament Registry**

# **User Agreement**



#### **Objectives**

The National Ligament Registry is the UK's first web based registry dedicated to ACL reconstruction. It has been designed by UK surgeons primarily for the benefit of our patients.

The registry automatically collects outcome data for patients undergoing ACL reconstruction, giving surgeons instant access to their patients' results.

The registry's aims are simple. Data collected will be used to provide better insight, knowledge and understanding to aid the continuous improvement of surgical outcomes. Particular research will focus on a deeper understanding of the nature of injury, the identification of trends in practice, tracking and monitoring new developments and detecting techniques that may have suboptimal outcome at the earliest opportunity.

For surgeon users, the registry provides a tool for monitoring patient outcomes effectively. You can link functional outcome data and complication rates to better advise patients on expectations, complete your own research or analysis of your performance and create reports for your appraisal and revalidation purposes. The overall analysis of the collected data will be organised through the appointed steering group.

#### **Registry Principles**

- The NLR is an independent registry, governed by an independent, not-for-profit organisation, under the direction of knee surgeons in partnership with stakeholders.
- The NLR committee will establish the policies and procedures that will govern data use, dissemination, and reporting, including the relationship with organisations external to the registry, such as the BOA Quality Outcomes Committee, Department of Health, patient groups, and Industry partners.
- Initial core data elements to be captured by the registry will be defined with input from stakeholder groups.
- The NLR believes that for the most comprehensive collection of core data, the reporting system must maximise existing data collection systems and rely upon participating hospitals, and individual surgeon members for submission of data to the registry.
- The security of registry data, patient privacy and data integrity are of the utmost importance and will be protected by the manner of the Data Protection Act 1998, data access policies, and technical safeguards in partnership with the developer and data processor Amplitude Clinical.

• The NLR believes that the analysis and interpretation of registry data must be objective and scientific.

## **Terms and Conditions of Usage**

By using the National Ligament Registry (NLR) you are agreeing to comply with and be bound by the terms and conditions of use set out below. These shall constitute NLR's relationship with you in relation to the Registry. If you disagree with any part of the terms and conditions you must not use the Registry.

The terms 'National Ligament Registry', 'us' or 'we' refer to the owners of the National Ligament Registry whose contact.

The term 'you' refers to the user or viewer of the NLR.

The use of this online Registry is subject to the following terms of use:

- The content of this Registry is for your general information and use only. It is subject to change without notice.
- The Registry contains material which is owned by or licensed to us. This material includes, but is not limited to, the design, layout, look, appearance and graphics. Reproduction is prohibited other than in accordance with the copyright notice, which forms part of these terms and conditions.
- All trademarks reproduced in the Registry, which are not the property of, or licensed to the operator, are acknowledged on the website.
- Anyone wishing to retrieve data from the NLR for research purposes must contact the NLR Steering Group for approval to do so.
- The NLR must be acknowledged as the source of data in any publication (including electronic versions) in which NLR data is used.
- If data provided by the NLR for more than one Hospital/Centre are to be used in a publication, the NLR Steering Group must be able to review the manuscript and must agree details of the submission including appropriate authorship, nomination of contact person and details of the review process to be followed for the manuscript.
- Where consensus between authors cannot be reached concerning the interpretation of NLR data the document shall be circulated to the NLR Steering Group for discussion and resolution.
- Undergraduates, trainees, fellows and post graduates are encouraged to use NLR data; however a consultant who is a member of the Registry must be leading the project
- Unauthorised use of this website may give rise to a claim for damages and/or be a criminal
  offence.
- Your use of the Registry and any dispute arising out of such use are subject to the laws of England, Northern Ireland, Scotland and Wales.
- Computer Misuse Act 1990 Unauthorised access to this system is an offence.

#### **Data Protection Policy**

The NLR enables collection of personal data related to patients undergoing ACL reconstruction. All data is to be collected in pursuance of the above Objectives, following the Registry Principles.

All data is subject to the Data Protection Act 1998.

The National Ligament Registry Steering Group is the Data Controller and Amplitude Clinical is the Data Processor under Data Protection rules. Your [user] must ensure all of your patients are appropriately consented.

The National Ligament Registry is registered with the Information Commissioner's Office (ICO) and recommend that you also register with the ICO.

Use of the registry requires you to abide by the Data Protection Act 1998 and to meet the following requirements:

- You will ensure appropriate security of your login details, and will contact Amplitude Clinical immediately if you suspect a breach of security.
- You will ensure that explicit patient consent is sought, given and recorded.
- You understand that failure to correctly indicate the acquisition of consent will lead to the deletion of identifying data upon your patients' records.
- You are entirely responsible for indicating patient's consent where this is done nonelectronically.
- All data will be accurate, and up to date.
- Only necessary and appropriate data will be recorded.
- You only grant access to appropriate individuals under your account, and that you remain responsible for the data entry upon your patients entered by said individuals.
- You only download stored information via reports, for appropriate use. This can include but is not exclusive to audit, research, and teaching purposes.
- Patient identifiable data can be obtained for a single patient and this must be kept secure in accordance with the Data Protection Act (1998) at all times.
- Express Research and Ethics approval must be in place for specific research data to be utilised.
- By using the Registry under these Terms and Conditions, you agree to anonymised use of
  your data for the purposes of the NLR's pursuance of the above Goals and Objectives under
  the Registry Principles.

#### Disclaimer

Every effort is made to keep the Registry running smoothly. The NLR and Amplitude Clinical take no responsibility for, and will not be liable for, the website being temporarily unavailable due to technical issues beyond our control.

## **Copyright Notice**

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