UK National Ligament Registry (NLR)

Launched March 2013: www.uknlr.com

The UK National Ligament Registry was launched at the BASK annual meeting in March 2013, with the backing of the Executive and the BASK members.

The Registry is designed to collect data on the outcome of knee anterior cruciate ligament reconstruction surgery and is modelled on the successful Scandinavian registries which have been in place for the last 8 years.

Objectives

The objectives of the Registry are to:

- Improve the standard and quality of care provided to patients in the UK
- Collect relevant demographic data
- Identify any current or emerging trends in practice
- Identify failing techniques / devices at the earliest opportunity
- Provide functional outcome data and complication rates

Currently there is a paucity of information regarding the number of procedures, functional outcome and complication rate following Anterior Cruciate (and other) Ligament reconstruction operations in the UK. The Registry aims to address this and in doing so:

- Help patients (and surgeons) understand the outcome
- Identify standards of practice
- Identify techniques / implants that do not do well
- Provide information to commissioners to guide the production of a high value pathway.

Revision ACL and other ligament reconstructions may be included later.

How does it work?

The Registry is entirely web based so that all data is entered directly on line. The hub is the website www.uknlr.com and this gives full details of the procedures.

The simple stages are:

- Patients due to undergo ACL reconstruction surgery are registered by the hospital or the surgeons secretary.
- Patients are then invited to enter details of their injury and some base line functional scores directly on line by email or on a computer/tablet on admission to hospital
- Surgeons log-on after completion of surgery and enter the operative data
- The program emails the patient at 1,2 and 5 years to collect outcome scores (KOOS, IKDC subjective, Lysholm and Tegner activity levels)

Why a registry?

In understanding outcome following ligament reconstruction it is important to analyse all relevant factors that may be considered to affect outcome including graft choice, surgical / fixation techniques, patient factors and rehabilitation factors. Level I trials are ideal but complex to initiate and perform. Registry data provides a substantial amount of information directed towards answering questions and raising overall standards of care, for the benefit of patients, clinicians, the NHS and industry.

Benefit to patients

Transparent patient based data is required to inform patients of potential outcomes and possible complications in addition to being able to offer patients clear metrics of the quality of actual outcome. These types of data do not exist at present for ACL reconstruction within the NHS and the creation of the UK National Ligament Registry will provide a mechanism to address this deficiency.

Benefit to surgeons

The NLR will offer an established framework for clinicians to collect outcome data regarding their own ACL reconstruction practice, benchmarking it against practice across the NHS. This information could be a valuable contribution towards each surgeon's annual Appraisal and Revalidation.

Many surgeons already collect outcome data but the issue of patient compliance, the actual effort of chasing patients and the subsequent data analysis often proves difficult for individual surgeons to undertake fulfilling and meaningful analysis.

The NLR will provide the structure and the means for such data analysis - by emailing the patients automatically. Any surgeon's pre-existing and stored demographic and outcome data could also be migrated across onto the program using specifically designed software.

Benefits for the NHS

The development of the NLR will provide accurate data regarding the current practice and technique of ACL reconstruction within the UK today, including the number and types of reconstruction that are taking place. The acquired outcome data (KOOS, EQ 5D, Tegner activity score and subjective IKDC score) will enable a comparison between established techniques and implants and offer an opportunity to formally compare newer, less established techniques. It will also allow comparison to other established Registries outside of the UK.

All failures (ruptures) and the timing and mechanism of such failures will be recorded and accessible for review. Data regarding outcome of ACL reconstruction will be important information for Clinical Commissioning Groups to consider when commissioning work from providers, in line with the new NHS Framework.

Benefits for Industry Partners

Through an annual report Industry will be able to better understand the market and market share in addition to understanding comparative outcome analysis. Each supporting company will have access to detailed outcome data for their particular implants, leading to an excellent platform for the controlled introduction of new implants and techniques guided by a nationally acceptable and impartial Registry framework.

Who manages the data and runs the Registry?

The data from the NLR will be owned and managed by the surgeons who input their patients. Backed by industry partner support, it will be managed by the NLR steering group of surgeons and a general manager, producing an independent annual report. Bluespier, a highly experienced medical database and management company, through their operating platform Amplitude, will be running the program.

There will be a research subcommittee appointed through the NLR Steering Group. This will have responsibility for deciding the direction of specific areas of research utilising the registry data and of managing requests for data from external parties.

Is it mandatory?

It is not currently mandatory but it is envisaged that with understanding of its value and with the forthcoming pressures of revalidation, the requirement of Clinical Commissioning Groups and Insurance Companies for outcome data, all surgeons will be part of it.

How does a surgeon get started?

Surgeons should:

- Go to www.uknlr.com and register on the 'medical professionals' page
- Ask their administrative team and research to register as well (surgeons will be asked to acknowledge their access)
- Follow instructions in the welcome email pack which provides the required information for hospital management, along with log in details
- Download the getting started document form the download section of the website
- Call the help line on the website for any help steering through the setting up process
- Watch out for news updates in the regular newsletter 'Crucial News'

A further option is the ability to request NLR business cards to give to patients in clinic drawing their attention to the website which provides information on the ACL and rehabilitation. Cards can be requested through the website

Summary and further information

Detail on the National Ligament Registry and on the Anterior Cruciate Ligament along with application forms for registration and forms for downloading, are available on the website www.uknlr.com.

The UK national ligament registry has been designed by surgeons for the benefit of patients. It is an exciting collaborative project significantly contributing to understanding and outcome following anterior cruciate ligament reconstruction.

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