

# The UK National Ligament Registry

## A paperless model for the future?

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### Overview

National Registries are becoming increasingly important and produce demographic and outcome data of interest to patients, surgeons, industry, insurers and National health systems alike. This outcome data will be in the public domain and therefore must be valid and robust. Existing ACL Registries have inherent problems with poor longer term compliance and rising costs.

In the UK, we set out to establish a web based paperless Registry which is managed by surgeons without central (governmental) involvement. Our aims were to have a Registry that allowed easy, logical data entry and a user friendly reports system that offered appropriate feedback to surgeons and patients alike. We report on the process and achievements.

### What is the UK National Ligament Registry?

The UK National Ligament Registry (the NLR), is designed to collect and store outcomes data relating to anterior cruciate ligament reconstruction surgery. It was officially launched at the BASK (British Association for Surgery of the Knee) annual meeting in March 2013, with the backing and support of the Executive and BASK members.

### The objectives of the NLR

The registry aims to:

- 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
- Improve the standard and quality of care in the UK as a result of all of the above

Currently, there is a lack of information regarding the number of procedures, functional outcome and complication rate following ACL reconstruction operations in the UK. The Registry aims to address this gap, creating standard best practice approaches and one central hub of clear and concise data. The result will be that this will:

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

### How does it work?

The Registry is a user friendly web based platform called AMPLITUDE that collects various outcome data from ACL reconstruction operations. The Registry platform is easily accessible via computer and tablet, simplifying the process for clinicians and patients.

The ‘registry route’ is simple, requiring small contributions from both surgeon and patient at different stages.

It also automatically prompts patients to fill in their information at scheduled times of treatment and rehabilitation, taking the hassle and stress out of clinical data collection for clinicians.

The registry is accessed through the website [www.uknlr.co.uk](http://www.uknlr.co.uk) (Fig 1) which contains background information, surgeon registration detail and also serves as large resource area for patients understanding the operation and rehabilitation.

#### In overview the data collection process is

1. When ACL reconstruction surgery is planned patients are registered on the program.
2. Patients receive an email link to securely enter details of their injury, sporting function and some base line functional scores. Alternatively data is collected on a computer/tablet on admission to hospital
3. Surgeons log-on after completion of surgery and enter the operative data
4. The program then emails the patient at various scheduled stages, prompting them to enter information for outcome scores (KOOS, IKDC subjective, Lysholm and Tegner activity levels)

### Why a registry?

When understanding outcomes following ligament reconstruction, it is important to analyse all relevant factors



that may have an effect. This could be anything from graft choice and surgical fixation, to patient factors and rehabilitation factors. Analysing a large number of patients for such factors should help raise the overall standard of care, benefitting patients, clinicians, the NHS and the industry.

### Who manages the data?

The data from the NLR is managed by the surgeons who input their patients. Backed by industry partner support, it will be overseen by the NLR steering group and a ‘general manager’, producing an independent annual report.

There will also be a research subcommittee appointed through the NLR steering group, with responsibility for deciding direction of research and managing data requests from external parties.

### What are the benefits?

#### For Patients

The collection of transparent patient based data allows the patients to be properly informed of:

- Potential outcomes and possible complications in their own treatment
- Clear metrics of the quality of actual outcome.

#### For Surgeons

Clinicians will have a framework to collect outcome data regarding their own ACL reconstruction practice, benchmarking it against practices across the NHS. The data can also be a valuable contribution towards each surgeon’s annual appraisal and revalidation.

Patient compliance in follow up, is also improved with the use of the Registry, enabling accurate and meaningful data collection.

#### For The NHS

The development of the NLR will provide accurate data regarding the current practice and technique of ACL reconstruction within the UK, including the number and types of reconstruction that are taking place.

The acquired outcome data enables comparison between established techniques and implants, as well as offers an opportunity to formally compare newer, less established techniques. All failures (ruptures) and the timing and mechanism of such failures will also be recorded and accessible for review.

Data regarding outcome of ACL reconstruction will aid Clinical Commissioning Groups when commissioning work from providers, in line with the new NHS Framework.

### Industry Partners

Through an annual report, Industry Partners will be able to better understand the market and market share, as well as 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.

### How does the NLR communicate?

- Through the website – [www.uknlr.co.uk](http://www.uknlr.co.uk) – where there is a large resource of information.
- NLR business cards are given to patients due to undergo the surgery accessible through the website.
- Through regular news updates in the e-newsletter ‘Crucial News’

### Current situation (March 2014)

- 213 consultants registered on the NLR.
- 65 consultants actively engaged
- 1,271 patients total new patients added
- Over 2,900 forms added to Amplitude.

### Conclusions

We have set up a new registry that has been successfully accepted by surgeons and patients by utilising key principles including early acceptance from national society, adequate financial support from national society and industry partners, design of a web based data collection system, selection of clear outcome data fields, and a readily available instant feedback results section.

We believe that early attention to set up detail has enabled a cost effective, paperless registry that will provide robust outcome data following ACL reconstruction which could then be used for research activities, the introduction of new techniques and products, and for other related knee surgical procedures.

Successful Registries which produce valid data can be established without Governmental funding but require a significant degree of surgeon input and careful design to ensure surgeon and patient compliance.

### Summary and further information

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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