

Why registries analysing cruciate ligament surgery are important

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National quality registries have been used in several medical specialties to improve healthcare worldwide.^{1–8} Owing to the inferior clinical results associated with some hip prosthesis designs in the early 1980s,⁶ nationwide Hip Arthroplasty Register (Norwegian Arthroplasty Register, NAR) was established in Sweden, in 1979, and in Norway, in 1987, with implant revision as the main end point.¹ The purpose is the early detection of inferior results caused by implants, cements or surgical techniques.^{1 3 6} In 1994, the Norwegian registry was expanded to include all joint replacements.³ In 1995, two studies^{1 3} described implant inferiority at an early stage, a finding only possible through registry studies.

The Hip Arthroplasty Register is based on a simple reporting system (approximately 1 min to complete a single-page registration form) and hospitals are provided with continuous feedback from the registry.^{1 2} These two factors are believed to explain why the compliance rate of nearly 100% has not declined during 30 years of operation.^{1 2} Immediately after each operation, the surgeon completes the registration form, which is mailed to the NAR office. Patient identification and the different procedures, including the type of implant and cement used, are specified on the registration form. Feedback to the surgeons and recently to the public is given as annual national reports. In addition, each hospital receives a report on its own activities and results, which can be compared to the national average. A wide range of studies have been published based on the NAR database.^{1 3 6} To date, national registries have been established in Norway, Sweden (1979), Finland (1980), Denmark (1995), Australia (1999), New Zealand (1999),

Canada (2000), Romania (2001), and England and Wales (2003).

REGISTRIES FOR KNEE LIGAMENT SURGERY

The year 2004 saw the first surveillance system to monitor the outcome of knee ligament surgery in a predefined population—the Norwegian Knee Ligament Registry (NKLR).² Evidence from the Scandinavian joint replacement registries indicated that a national knee ligament registry could be highly beneficial. First, treatment outcome can be improved through feedback to the hospitals and surgeons from the registries. Second, there are still several unresolved issues related to cruciate ligament surgery and post-operative rehabilitation methods. Some of these can and should be addressed by conducting properly designed randomised controlled trials (RCTs). However, due to practical, financial or other restraints such studies are often not possible. Also, some questions can only be answered by large cohort studies. This includes the detection of procedures and devices that result in premature failure. Third, a large cohort study can be used to identify prognostic factors associated with good and poor outcomes. Data from the Norwegian Registry show a very high compliance rate;^{9 10} this type of registry can be run in the country with 5 million inhabitants for approximately US\$150 000 a year, excluding the local costs in each hospital or clinic.

THE SCANDINAVIAN EXPERIENCE

With this background, the NKLR was started in June 2004 and is owned by the Norwegian Orthopedic Association (NOA), with a steering committee appointed jointly by NOA and Oslo Sports Trauma Research Center. It is run by the NAR with funding from the Norwegian Government.

Registry data is collected using registration forms completed by the surgeon immediately after surgery. All surgeries on cruciate ligaments in Norway and all later knee surgeries performed on these knees are to be reported to the registry. In case of a revision or if other subsequent surgery is performed, they are linked to the index operation by the patients' unique personal identification number.

Reporting is voluntary and the registry in Norway receives forms from 35 public hospitals and 9 private hospitals.¹¹ The patients included in the registry must have signed an informed consent before surgery. The NKLR has the end point revision or total knee replacement and follow-ups at 2, 5 and 10 years with subjective Knee injury and Osteoarthritis Outcome Score (KOOS). The completeness of registration to the NKLR for anterior cruciate ligament reconstruction (ACLR) and revision ACLR during the years 2008 and 2009 was found to be 86% in a study comparing the data in the NKLR to the Norwegian Patient Register and the electronic patient charts for public and private hospitals.¹¹

The Danish and Swedish registries followed in 2005. They are organised in a similar manner. The three registries survey a population of approximately 20 million people.¹² The results show that in 10 years of operation, approximately 85% of all patients undergoing cruciate ligament surgery are included in the registry.¹³ Based on these data, it may be expected that the registries in the Nordic Countries each year will enrol approximately 6–7000 primary ACLR cases in addition to revisions. Unfortunately, at this stage, non-operatively treated ACL-deficient knees are not included in the registries for practical reasons, but trials are undergoing in Sweden where approximately 2000 non-operative ACL ruptures have been included at this stage.

TIME FOR AN EVEN BROADER COLLABORATION

Patient registries are established to improve the standard of healthcare and should be used in as many countries as possible. Internationally, registries in many new areas are surfacing.^{14–16} In the USA, there are large local and regional registries. Studies show small differences in epidemiology and outcome from nationwide European registries.^{9 10 12 17 18} One vision is to have a common international registry for knee ligament surgery supported by, for example, ESSKA and ISAKOS. For countries that need a separate database due to legal reasons, the software could be the same for all countries. In a very short time, a huge amount of data could be obtained and fruitful international comparisons would be possible. Currently work is going on with ESSKA to create a registry for children ACLR. So far, no registries have included non-operatively treated ACL injuries, but there are trials going on in Sweden which may correct this missing link.

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Specifically, registries are meant to serve three specific purposes (1) to improve treatment outcomes through feedback to the hospitals and surgeons, (2) to detect procedures and devices that result in premature failure^{13 19} and (3) to identify prognostic factors associated with good and poor outcomes.^{20–23} However, to serve these purposes, the accuracy of the outcome measures used is critical. The arthroplasty registries use revision surgery as the sole end point. Thus, patients may have a poor result without this being registered. In contrast, in addition to revision surgery, the knee ligament registries, therefore, also include routine follow-ups with patient-reported KOOS. KOOS are collected preoperatively from the patients, as well as after 2, 5 and 10 years. The intention is to detect inferior results and early failures, regardless of whether the patients with a failed graft decide to go through revision surgery or not. The KOOS is commonly used to evaluate the outcome following ACLR. KOOS data from more than 20 000 patients are available from ACL registries in Sweden, Norway and Denmark. Data from these registries show postoperative mean KOOS corresponding to mild pain (mean scores 84–89), moderate to mild symptoms (60–86), no problems with activities of daily living (90–97), moderate to mild problems with sport and recreational activities (63–78) and moderate to mild reductions in knee-related quality of life (60–69) at 1–2 years following reconstructive surgery.^{24 25} KOOS <44 has been defined as a failed ACLR thus enabling the registries to detect failures that are not undergoing a revision. KOOS has been criticised for including too many questions and for having limited ability to differentiate between patients due to its initial development for degenerative knee conditions. However, at this stage a simpler outcome instrument more focused on ACL deficiency symptoms is not available.

Data from cruciate registries can be combined with data from registries on knee arthroplasties, thereby using surgically verified severe osteoarthritis as an additional end point for ACLR treatment.

Although the registries published epidemiological data the first few years, current publications are concentrating on the effect of additional ligament, cartilage and meniscal injuries on the ACLR revision rate and patient-reported outcome measure (PROM) result. Additionally, at this stage we can see the effect of the graft choices, fixation devices, various forms of rehabilitation and influence of

pharmaceuticals on the final results of the surgery^{13 19 25–31} based on analyses of >40 000 ACLRs. Today the ACL registries play an important role in decisions on surgical procedures, fixation devices and rehabilitation protocols. As the registry information becomes increasingly transparent, results from each hospital and clinic and ultimately from each surgeon on ACLRs should improve patient care.

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Editorials

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