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Original article

Current state of anterior cruciate ligament registers

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ABSTRACT

Purpose: The purpose of this work was to report the main characteristics and results of all active anterior cruciate ligament (ACL) reconstruction registers along with the differences between them.*Methods:* We systematically searched on Google and Medline via PubMed to identify ACL registers. National or regional registers were included if they were active and took into account ACL reconstructions. The main results and characteristics, namely the number of inclusions, exhaustivity, data collection methods and results dissemination methods were determined. The collected information was then submitted to each register for validation.*Results:* Four registers (3 national, 1 regional) were identified that routinely included every ACL reconstruction procedure. Register data were collected either through dedicated websites or on paper forms. All the registers used the same two outcome measures, namely the revision rate and a subjective patient score (KOOS score). Register results were made available through scientific publications or annual reports. The main differences between registers were in the graft choice and presence of associated meniscus and cartilage injuries.*Conclusions:* Although there are only a few ACL reconstruction-specific registers, their scientific contribution is undeniable thanks to the quality of the collected data and the organization and collaboration between registers. Their impact on health care and science should grow in the future.

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1. Introduction

Over the years, anterior cruciate ligament (ACL) reconstruction surgery has become a reliable surgical procedure aimed at restoring knee stability and preventing meniscus and cartilage deterioration [1–3]. Despite the large number of randomized studies on this topic, many aspects of ACL reconstruction, such as the choice of graft type and fixation method, are still controversial [4,5]. Moreover, there is little information available on long-term results and revision rate. The costs incurred and the reported surgical complications accentuate the need to have an effective, exhaustive surveillance tool [6].

Registers are observational study tools with many advantages. They are used to examine patient-related information and allow for long-term prospective follow-up of the surgical techniques and the implants used [7]. Unlike randomized studies, registers are able to detect adverse events early on, even rare ones, to limit the consequences for patients and costs for the healthcare systems [8]. Registers also give surgeons the possibility of receiving feedback

about their professional practices, while providing the health authorities with a surveillance tool [9,10].

The first orthopedic registers were created in Scandinavia in the 1970s to evaluate hip and knee arthroplasty [11]. Over the years, these registers have relied on extensive expertise in data collection and patient follow-up to better understand factors affecting the survival of joint implants [9,12]. These registers have also inspired new registers on shoulder arthroplasty, femoral neck fractures and arthroscopic ACL reconstruction.

The purpose of this work was to report the main characteristics and results of all active anterior cruciate ligament (ACL) registers along with the differences between them. The working hypothesis was that active anterior cruciate ligament reconstruction registers have already contributed to better evaluations of this surgical procedure.

2. Materials and methods

2.1. Identification of ACL reconstruction registers

From December 2012 to January 2013, a systematic search was performed to identify all of the ACL reconstruction registers that were active at that time. Included were all registers evaluating

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Table 1
Methods of results dissemination used by the various ACL reconstruction registers and their website address.

	Language(s) used on website/Internet address	Annual report available on website Last year of publication Language	Number of publications in peer-reviewed journals	Median impact factor of publications [min–max]	Other scientific production	Surgeon feedback
DKRL	Danish English http://kea.au.dk/en/qualityassessment/clinicaldatabases/danishhiparthroplastyregistry/	Yes 2009 Danish	6	2.2 [2.1–3.7]	Thesis	Yes
NKRL	Norwegian English http://nrlweb.ihelse.net/eng/	Yes 2010 English	14	2.2 [0–4.1]	Presentations Posters Thesis	Yes
SNKRL	Swedish English http://www.artroclinic.se/scripts/cgiip.exe/WService	Yes 2012 English	10	2.2 [2.1–3.7]	Presentations Letters	Yes
KP ACLRR	English http://xnet.kp.org/permanentejournal/nirw-work_ext/Registries/acl.htm	NR	12	3.2 [2.2–3.7]	Presentations Posters	NR

NR: not reported.

anterior cruciate ligament reconstruction (primary or revision) that were active at the time of the study and included patients on a regional or national scale. Any registers that were inactive at the time of the study were excluded.

Two web searches, one using Google and the other using Medline via PubMed, were performed. The following keywords were used: “ACL and register”, “ACL and registry”, “ACL reconstruction and register”, “ACL reconstruction and registry”. In addition to these web searches, the registers listed on the EFORT website (<http://www.eart.org>) were analyzed to determine if any of them included ACL reconstruction procedures. Once the registers had been identified, we looked at the various register websites to collect information about how they operate. The keywords used for the Google search were the exact register names (Table 1).

2.2. Register methodology and primary data

This information was found on the register’s website and in its publications (Table 1). The main pieces of information collected were the register’s exact name, coordinating society or organization, year launched, register participants (surgeons, patients), data collection methods and exhaustivity rate. The following information was also collected: patient demographics (gender, age, BMI), number of ACL reconstruction procedures included (with distinction made between primary and revision procedures), associated injuries, type of graft used, associated procedures and outcomes (functional score, number of revisions, etc.).

2.3. Scientific productivity and results dissemination methods

The various methods used by registers to disseminate their results were recorded. Each register’s website was consulted to look for an annual report or a list of scientific publications based on the register’s results (Table 1). In parallel, a systematic PubMed (Medline) search was conducted to identify all the publications in peer-reviewed medical journals that were based on each ACL reconstruction register. The keywords used were the exact register names. Every English article that was referenced in PubMed and presented results derived from the registers in question was retained. Letters, comments, editorials and conference abstracts were excluded. The results of the PubMed search were then cross-referenced with the publication list taken from each register’s website to ensure exhaustivity and remove duplicates. The median

impact factor for each register was determined using the 2012 Journal Citations Reports (JCR).

2.4. Questionnaires sent to registers

In parallel, a questionnaire was sent by email to each register’s representative(s) to confirm the data that we had collected and correct any information as needed. A second email was sent 15 days later if no reply had been received to the initial message.

3. Results

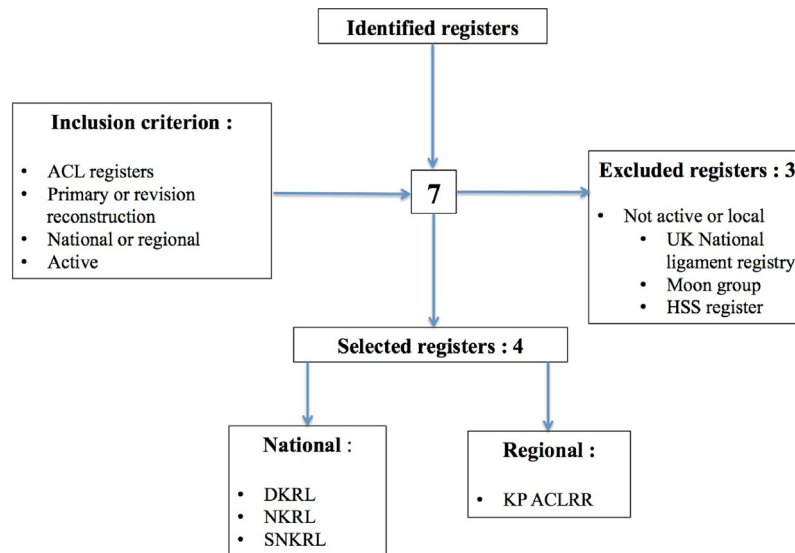
3.1. Register selection and how they operate

Of the seven registers identified, four met the inclusion criteria and were selected for the study (Fig. 1). Three of the registers were national Scandinavian registers: Swedish National ACL Register (SNKRL), Danish Cruciate Ligament Registry (DKKR) and Norwegian Cruciate Ligament Register (NKLR). The only regional register (Kaiser Permanente Anterior Cruciate Ligament Reconstruction Registry) was American and included 40 centres with 220 surgeons. The British register was not included in this study because it was not active at the time that registers were identified. The Moon register (which is truly a cohort study) and the local HSS register were excluded.

The main characteristics of the active registers are given in Table 2 [6,13–17]. These registers were mostly funded by government health authorities. For example, the cost to operate the Norwegian register in 2009 was about €80,000 [16]. Depending on the country, register participation was either mandatory or voluntary and data collection was performed either through a secured website or on paper forms (Table 2). Data collection was divided into two sections: one for the patient (self-evaluation) and one for the surgeon. The surgeon filled out a standard questionnaire immediately after the surgery, while the patient was required to fill out a questionnaire at regular intervals (Fig. 2).

3.2. Analyzed data and main register results

The main register results, namely the inclusions, are summarized in Table 3 [6,13,15,16,18–21]. All the registers used an objective outcome (revision rate) and a subjective outcome provided by the patient (Knee Injury and Osteoarthritis Outcome



DKRR: Danish register
 NKRL: Norwegian register
 SNKRL: Swedish register
 KP ACLRR: US Kaiser Permanente ACL reconstruction register

Fig. 1. Flow chart used to screen ACL reconstruction registers.

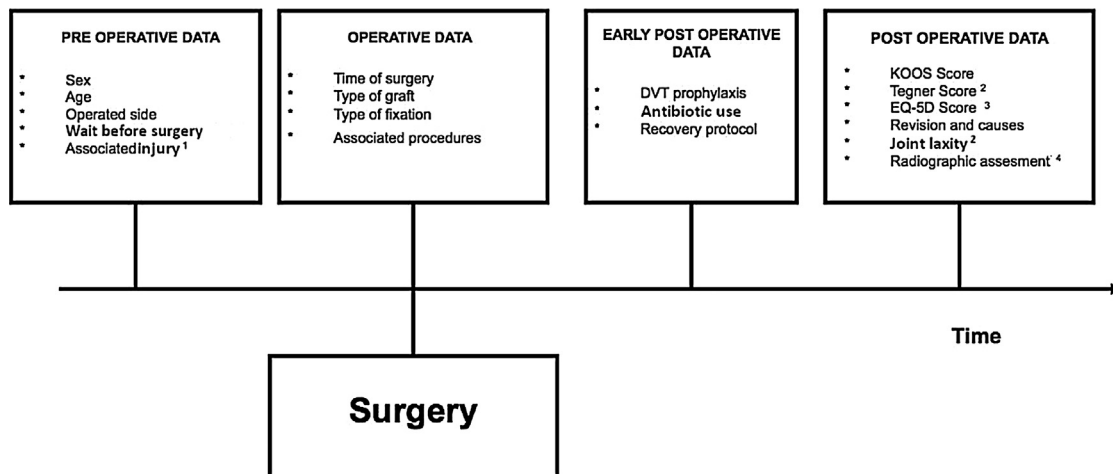


Fig. 2. Main pre- and postoperative data collected by the ACL reconstruction registers. 1. Associated injury: cartilage, meniscus tear. 2. Joint laxity and Tegner Score in Danish register only. 3. EQ-5D Score in Swedish register only. 4. Radiographic assessments in Danish register only.

[KOOS] Score). Overall, the KOOS score was determined preoperatively and then at 1, 2 and 5 years after surgery. The exhaustivity rate was greater than 85%; it was nearly 90% in the American and Swedish registers in 2012. However, the exhaustivity of the patient responses could not be evaluated.

The registers revealed that the majority of operated patients are male and that the primary cause of ACL rupture and revision is a sports injury. However, the type of sport varies by register. In Scandinavian countries, the top sport for ACL injuries is soccer, followed by skiing and handball. Soccer, American football and

Table 2
 General characteristics of the included ACL reconstruction registers.

Register/Country	Year started	Scope	Type of surgeon participation	Data collection method	Patient consent	Financing
DKRL Denmark	2005 [6]	National [6]	Mandatory [6]	Web-based reporting [6]	No [6]	Public [6]
NKRL Norway	2004 [15]	National [15]	Voluntary [16]	Paper-based reporting [15]	Yes [15]	Public [15]
SNKRL Sweden	2005 [18]	National [18]	Voluntary [18]	Web-based reporting [18]	No [18]	Public [18]
KP ACLRR USA	2005 [17]	Regional [17]	Mandatory [17]	Paper-based reporting [17]	NR	NR

NR: not reported; DKRR: Danish register; NKRL: Norwegian register; SNKRL: Swedish register; KP ACLRR: Kaiser Permanente ACL reconstruction register.

Table 3
Main results collected by the ACL reconstruction registers.

Register/Country	Primary ACL reconstruction (number)	Revision (number)	Meniscus injury rate	Cartilage injury rate	Combined cartilage & meniscus injury rate	Type of graft used
DKLR Denmark	14,943 [13]	1099 [13]	39% [13]	17% [13]	NR	GT: 85% [21] PT: 11.5% [21] Allo: 0.2% [21]
NKLR Norway	14,064 [21]	749 [21]	48.5% [15]	25.2% [15]	15.3% [15]	GT: 63% [21] PT: 37% [21] Allo: 0.04% [21]
SNKLR Sweden	22,589 [18]	1431 [18]	42% [18]	27% [18]	15% [18]	GT: 95% [18] PT: 5% [18]
KP ACLRR USA	15,101 [14]	1091 [14]	60.8% [14]	25.2% [14]	NR	Auto: 57.6% [14] GT: 53.7% [14] PT: 44.7% [14] Allo: 42.4% [14]

GT: gracilis tendon; PT: patellar tendon; Allo: allograft; Auto: autograft; NR: not reported.

basketball are the main causes in the regional American register [6].

ACL reconstruction techniques also vary among registers (Table 3). Scandinavian registers revealed that nearly only autografts are used during primary reconstruction and revision procedures. A hamstring graft was the most common choice in all the registers, but the rate of use varies among registers. There is a net preference for allografts during revision procedures in the regional American register (Table 3). The rate of meniscal injury was higher in the regional American register than in the Scandinavian registers (Table 3).

3.3. Scientific productivity and results dissemination methods

The website for each register has a key role in disseminating the information and scientific results obtained from the collected data (Table 1). One of the distinctive features of Scandinavian registers is that they provide annual reports, which are published on a fairly regular schedule. These annual reports are available free of charge in PDF format. The activity and main results at a given time point are included. All the registers publish their results in high-impact orthopedic journals, for example, the *Journal of Bone and Joint Surgery* or the *American Journal of Sports Medicine* (Supplementary data). All the registers give the surgeons an opportunity to review their own data and results through their website (Table 1).

4. Discussion

There were only four active national or regional registers devoted to ACL reconstruction at the time this study was carried out. These registers saw the light of day in Scandinavia, along with joint arthroplasty registers [12,22]. The primary reasons are the small size of these countries, their culture, tight control over health regulations along with the identification of each patient by a unique national health service number [16].

These registers are highly-organized structures that result in greater than 85% exhaustivity rate. The Scandinavian registers have also developed a very close scientific collaboration because they operate in a similar manner and their surgical practices are the same [16]. Large differences between the Scandinavian registers and the regional American register were identified [15]. Firstly, there are differences in the cause of ACL rupture and the number of associated meniscal injuries [23]. There is also a large difference in the type of graft used. Despite a higher revision rate, more than 40% of the grafts used for primary reconstruction are allografts in the regional American register. This rate is 79% for revision procedures. Conversely, allografts are very rarely used in Scandinavia and are mainly limited to multi-ligament knee reconstructions [15,23]. These differences can be explained by the price of these grafts, their

greater availability in the United States and also each country's culture. These differences also point to the scientific relevance of performing comparative studies and collaborations between registers [23].

Registers have become the benchmark for observational studies and have led to significant progress in the evaluation of surgical practices [7,24]. One of their main strong points is that they better reflect on daily practice than do results published by renowned surgeons [25].

Since registers have been launched, their results have been the subject of various publications or annual reports that have improved our understanding of the science involved in ACL reconstruction. These registers have shown that the worse functional scores after anterior cruciate ligament reconstruction occur in patients with associated cartilage injuries [25]. They have also shown that the waiting period between injury and reconstruction plays a crucial role in the appearance and frequency of meniscus and cartilage injuries, which is increased in younger patients at the time of the ACL rupture [6,16].

Another strong point of these registers is that the main outcomes combine the revision rate and a patient-derived functional outcome score (KOOS) [26]. This endpoint makes it possible to detect poor functional results, such as changes in the activity or competition level, which do not necessarily lead to surgical revision but still alter a patient's quality of life [6,27].

This study has several limitations in how it was performed and how its results were interpreted. Since we could not directly access the register databases, we used data derived from publications or information on their website. However, we contacted each of the registers to ensure that the information was correct. The exhaustivity rate seems to be very high, but it only takes into account data provided by the surgeon during the preoperative phase. In the Swedish register, the exhaustivity rate for the KOOS score at 2 years reported by the patient was only 41% among a cohort of 8584 patients [28]. The surgeon's experience is not recorded, but it is known to directly affect the quality of the outcomes [29]. The definition of a reoperative was not the same in the various registers. In the regional American register, this definition only comprised repeated reconstructive surgery. In the Swedish register, it included every type of post-reconstruction surgery (additional meniscus surgery, knee lavage, etc.) and was left up to the surgeon's judgment. These differences and unknowns can create bias and problems when interpreting the results.

Another significant limitation of these registers is the lack of radiological evaluation and systemic joint laxity measurements (Fig. 1). Only the Danish register includes this type of evaluation during the monitoring of operated patients. A radiological evaluation could provide information about the tunnel positioning (main cause of failure) or the appearance of osteoarthritis secondary to

ACL rupture [30,31]. Joint laxity measurements could be used to quantitatively measure the knee joint's stability and determine if the procedure was successful or not [32].

In summary, this study identified four registers (three national and one regional) that routinely included arthroscopic anterior cruciate ligament reconstruction cases. These registers have already greatly contributed to improving our understanding of this surgical practice, which confirms our initial hypothesis. Given the large number of included patients, quality of the collected data and collaboration between registers, the scientific contribution of these registers should increase in the future and should stimulate the development of new registers.

Disclosure of interest

The authors declare that they have no conflicts of interest concerning this article.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.otsr.2014.07.020.

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