

15 years of the Scandinavian knee ligament registries: lessons, limitations and likely prospects

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High-quality national health registries provide the opportunities to: (1) improve patient outcomes by giving medical units and clinicians relevant feedback about their work; (2) detect inferior treatments and (3) identify prognostic factors associated with both good and bad outcomes. The Scandinavian knee ligament registries were established in 2004 and 2005, include data from 70 000 patients,¹ and have led to more than 70 studies publications already (2019). This editorial reflects on lessons learnt, limitations identified and what the future may hold.

LESSONS LEARNT

Two systematic reviews including all studies from the registries focused on factors associated with (1) additional anterior cruciate ligament (ACL) reconstruction and (2) patient-reported outcomes after ACL injury and reconstruction are summarised in table 1.^{2,3}

There is a balance in health registry studies between the large number of patients that decrease the type-II error (false negative) risk, and the multiple analyses and similar questions that are addressed which increase the type-I error (false positive) risk. Registry data are also susceptible to confounding interactions, some of which are unknown. Nevertheless, the registries

produce results that reflect day-to-day practice owing to two key factors, a high rate of coverage (proportion of medical units who participate in relation to all eligible medical units) and completeness (proportion of target population in the registry). However, it must be remembered that the response rates from patient-reported follow-ups are a persistent challenge for health registries, where at some time points response rates are as low as 40%–50% in the Scandinavian knee ligament registries, potentially introducing selection and attrition bias.

The knee ligament registries play an important role in decision-making on surgical treatment, which indirectly also can affect rehabilitation outcomes. In order to stay up to date with new insights, the registries have gradually developed over the years by asking surgeons to report more variables. There is still room for improvement as new surgical techniques are frequently introduced, and there has been less development on the patient-reported sections in the registries. A dynamic process is needed to ensure that variables in the registries remain relevant when new insights appear, despite the risk of variability in data and additional time required for the surgeons to register data. To further develop, we would like to emphasise that collecting patient demographics on the type and frequency of physical activity they perform, and their occupation is crucial to better understand our patients with ACL injury. These data are currently not available in the registries, but the unique personal identity number used for all individuals in Scandinavia allows for combining data between registries. This means that data from the Scandinavian knee ligament registries can be combined with other registries to enable analysis of complex interactions, allow greater analytical power and give clinical insight. For instance, to assess both rehabilitation and return to

sport outcomes within the Scandinavian registries.⁴

LIMITATIONS IN OUTCOME MEASURES

The three most used outcome measures in the Scandinavian registries have been: (1) event of revision ACL reconstruction; (2) the European Quality of Life-Five Dimensions and (3) Knee injury and Osteoarthritis Outcome Score (KOOS). Although revision ACL reconstruction is a sole endpoint, it will underestimate the true failure rate since not all patients undergo a revision reconstruction. The KOOS has been debated as it is not specific to patients with an ACL injury.⁵ A recent publication from Ingelsrud *et al*⁶ reported that the minimal important change (MIC) in the KOOS subscale sports and recreation is 12.1 and in quality of life is 18.3 points. Reviewing the results from the registries, it becomes obvious that the change in KOOS seldomly exceeded the MIC. This is worrying. We are currently assessing whether the potential wash-out effect of the KOOS can be countered by determining which items from the KOOS subscales are more relevant and responsive to patients with an ACL injury. If successful, the data from several hundred-thousand follow-ups over 15 years can be re-evaluated. To do this, we may need to consider changing the patient-reported outcome in the registries to a responsive and condition-specific instrument. Interestingly, an improvement in KOOS which exceeds the MIC has been observed in patients receiving high-quality rehabilitation.⁷ Unfortunately, rehabilitation quality is not currently reported in the registries, leaving us with a need for a more sensitive outcome in the Scandinavian knee ligament registries, or a suggesting that we should develop a physiotherapy section in the registries.

THREE SUGGESTIONS TO GUIDE FUTURE REGISTRIES

- 1. Actively recruit patients undergoing non-operative treatment:** Ten years ago, Granan *et al*⁸ reported that as many as 50% of patients who sustain an ACL injury are treated with rehabilitation alone. Only one study on patients with non-operative treatment has been published from the Swedish registry—patients with non-operative treatment had inferior KOOS across nearly all subscales in a cross-sectional analysis.⁹ Researchers

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Table 1 Primary findings of the systematic reviews on the Scandinavian knee ligament registries

Patient-related factors	Younger patients report superior knee function and have an increased risk of additional ACL reconstruction The risk of revision ACL reconstruction does not differ between sexes; however, females have an increased risk of contralateral ACL reconstruction.
Treatment-related factors	Over 90% of all ACL reconstructions in Sweden and over 80% in Denmark are performed with hamstring tendon autografts. In Norway, the majority of ACL reconstructions were performed with patella tendon autografts in 2016. Hamstring tendon autografts are associated with small but superior short-term knee function compared with patella tendon autografts. Studies reporting on graft choice reported an increased risk of revision ACL reconstruction for hamstring versus patella tendon autograft. Risk of ACL revision is reduced by 14% for every 0.5 mm increase in hamstring graft diameter.
Injury-related factors	Concomitant injuries are associated with inferior patient-reported knee function. Concomitant cartilage injuries are associated with a reduced risk of revision ACL reconstruction

ACL, anterior cruciate ligament.

and policy-makers acknowledge the selection bias for this patient group to date. We need to learn more about the characteristics of these patients and whether they reach acceptable function and reasonable clinical outcomes.

2. **Perform randomised controlled trials (RCTs) in patients who are recruited into the registry:** Registry-based RCT is an innovative and promising method that can be performed using data from the Scandinavian knee ligament registries. This method is particularly suitable for effectiveness trials, where studies will benefit from recruiting patients during regular healthcare visits, produce generalisable results and at low cost, compared with conventional RCTs.¹⁰ However, this will require update of the registries which include challenges to secure data quality and collect of consent from participating patients and centres. One example is the Thrombus Aspiration during ST segment Elevation myocardial infarction trial, a large-scale registry-based RCT, which used the Swedish Coronary Angiography and Angioplasty Registry for trial conduction to determine the effectiveness of percutaneous coronary intervention alone compared with intracoronary thrombus aspiration and primary on 30-day mortality.¹¹ As there was pre-existing information in the registry, participant enrolment was rapidly completed, no patient was lost to follow-up for the outcome assessment, and the cost of the study was only US\$50 per patient approximately.
3. **Collaborate internationally:** International collaborations among ACL registries would allow multiregistry analyses of large cohorts

with highly generalisable data.¹ This will require global standardisation of data elements. If we can achieve that, we will be able to answer more thoroughly new questions such as the efficacy of treatments on specific subgroups of patients. As the registry information becomes increasingly transparent, the results from the worldwide ACL registries will aid in the clinical practice to improve patient care.

The Scandinavian knee ligament registries are well on their way with all three suggestions with studies both in planning and analysis stage. The success of the Scandinavian knee ligament registries has always been made possible by the clinicians reporting data to the registries and the friendly relationship among the registries. We will continue working as a team to overcome the challenges in front of us. We are stronger together.

Contributors EHS, ES and KS have substantially contributed and are primarily responsible of drafting the work and revising the manuscript. LE, ML, MF and JK have supported the drafting of the work and revising it critically for important intellectual content.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

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To cite Hamrin Senorski E, Svantesson E, Engebretnsen L, et al. *Br J Sports Med* 2019;53:1259–1260.

Received 29 August 2018
Revised 19 March 2019
Accepted 23 March 2019

Published Online First 9 April 2019

Br J Sports Med 2019;53:1259–1260.
doi:10.1136/bjsports-2018-100024

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