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Current national hand surgery registries worldwide

Development of hand surgery registries

Registries in orthopaedic surgery were introduced in the late 1960s by the Mayo Clinic followed on a national level in Sweden in 1975, Finland in 1980 and Norway in 1987. Registries initially concentrated on knee and hip arthroplasties, which have been expanded to many other surgeries and favour epidemiological research and medical device surveillance.

The first national data collection in hand surgery was established in Norway in 1994, focusing on wrist, carpometacarpal and finger arthroplasties (Havelin et al., 2000), followed by the Australian registry which began collecting data on wrist arthroplasty patients in 2008. The first hand surgery registry for all patients undergoing hand surgery was started in Sweden (the HAKIR registry) in 2010 (Arner et al., 2016).

Present-day registries can be divided into two categories: arthroplasty registries and general hand surgery registries. The majority of registries focus on arthroplasty patients, traditionally including wrist prostheses and more recently patients with trapeziometacarpal, metacarpal and phalangeal prostheses. General hand surgery registries include patients undergoing any types of soft tissue or bone hand surgery. Registries are increasingly being used to report socio-economic insights and technique validation in high-volume surgical interventions (Zimmerman et al., 2019). Despite the various existing registries internationally, little to no collaboration has existed between the various registries. Data remain scarce and endpoints are heterogeneous, making comparison between registries difficult.

The practice of hand surgery has largely relied on level IV evidence. Research articles of level IV and V evidence have accounted for 83% of hand surgery clinical studies, with case series (level IV) being the most common (Sugrue et al., 2016).

Hand surgery registries may play a greater role in future hand surgery research, enable comparison of patients between centres/countries, map patients with rare surgical indications or novel techniques, and provide information to improve cost-effectiveness and surgical outcomes. The scope of these registries has evolved from only implant monitoring in arthroplasty surgery, to epidemiological, patient safety and health policy monitoring.

Databases of current hand surgery registries

We used the member list of the International Society of Arthroplasty Registries and the European Federation of National Associations of Orthopaedics and Traumatology (EFORT) website to identify national hand surgery registries. Additionally, we searched the internet (www.google.com) and Medline to identify other registries. Potential registries were pooled, and the most current annual reports were reviewed. Registries were eligible if they included patients with degenerative disease or trauma to the hand or wrist and included both surgical and conservative treatments.

After review of the publicly available reports, contact was made with a member of the registry committee, and a questionnaire was sent to gather more specific information on each registry. Furthermore, information on baseline characteristics, including demographics such as age at surgery, sex, body mass index and comorbidity as assessed by the American Society of Anesthesiology score, was included as well as registry outcomes and the use of patient-reported outcomes. Finally, demographics and completeness data of each registry were recorded. The chosen endpoint for data collection was the 31 December 2019.

Six national registries from Norway, Australia, Sweden, United Kingdom, the Netherlands and Germany were eligible for inclusion, all of which are publicly funded. The Norwegian national registry is the oldest, founded in 1994, followed by the Australian registry in 2008 and the Swedish HAKIR founded in 2010.

The Australian registry only assesses wrist arthroplasties. The Swedish HAKIR and the UK

Table 1. Characteristics of each national registry.

Country	Norway	Australia	Sweden	United Kingdom	Netherlands	Germany
Registry	NAR	AOANJRR	HAKIR	UKHR	LROI	HTR
Year started	1994	2008	2010	2011	2016	2018
Age	All		All			All
Speciality						
Orthopaedic surgery	x			x	x	x
Hand surgery	x	x	x			x
Plastic surgery	x	x		x	x	x
Inclusion criteria						
Degenerative OA	x	x	x	x		
Post-traumatic OA	x	x	x	x		
Prosthetic arthroplasty	x	x	x	x	x	
Non-prosthetic arthroplasty			x	x		
Non-operative treatment				x		
All hand surgery interventions			x	x		x
Objective						
Descriptive	x	x		x	x	x
Research	x	x	x	x	x	x
Post market surveillance	x	x		x	x	x
Comparable effectiveness evaluation	x	x	x		x	x
Quality improvement	x	x	x	x	x	x
Benchmarking	x	x		x	x	x
Best practice	x	x	x		x	x
Cost evaluation	x	x			x	x
Registry data input						
Lifestyle				x		
Clinical	x	x	x	x	x	x
Genetic						
Environmental		x				
Patient-reported outcomes		x	x (adults only)	x		
Imaging					x	
Biological						
Costs						x
Obtained from						
Patients (e.g. questionnaires)			x	x		
Health care providers	x	x	x	x	x	
Industry (e.g. implant details)	x	x				
Indirectly via linkage to						
Electronic health records		x			x	
Administrative data		x		x	x	
Mortality data	x	x	x		x	
Funding						
Government	x	x	x			
University						
Other institution				x (BSSH)	x	x (DGH)

NAR: Norwegian arthroplasty registry; AOANJRR: Australian Orthopaedic Association National Joint Replacement Registry; HAKIR: Handkirurgiskt Kvalitetsregister; UKHR: United Kingdom Hand Registry; LROI: Landelijke Registratie Orthopedische Implantaten / Dutch Arthroplasty Registry; HTR: Hand Trauma Registry; OA: Osteo-arhtritis; BSSH: British Society for Surgery of the Hand; DGH: German Society for Hand Surgery.

registries record all performed hand surgery interventions, whereas the German registry includes trauma patients only. The Dutch and Norwegian registries include wrist and finger arthroplasties.

All registries collect information on patients treated at university, community and private hospitals and on the surgical speciality in charge of the surgery. General characteristics of all included registries can be found in Table 1, and the collected baseline variables are shown in online Table S1. The outcomes assessed by the majority of registries include revision rates and surgical complications, and are shown in online Table S2. The Swedish HAKIR registry is currently the only registry reporting on patient-reported outcomes for all included patients.

The total number of patients in all the included registries was 125,323. The mean ages of the patients included in the registries at the time of surgery varied between 43 and 61 years (online Table S3). Men accounted for approximately 50% of included patients in all registries, except for the Norwegian registry where 20% were men. Completeness of registries varied between 5% for the UK registry and 99% for the Australian registry.

Some features of hand surgery registries in each country

All registries except for the German Trauma Registry included wrist and trapeziometacarpal arthroplasties. Data from these patient groups are the most widely reported and have the most complete follow-up. The Swedish HAKIR registry assesses information on all hand surgery interventions, in which 116,320 operations for 87,425 patients had been recorded in HAKIR at the end of 2019. The Swedish registry has been able to monitor treatment outcomes up to 1 year and was the first to include patient-reported outcomes. In 2019 the Swedish registry reported on more than 10,000 patients undergoing open carpal tunnel release and was able to assess the effect of diabetes on patient-reported outcomes (Zimmerman et al., 2019).

The Norwegian registry includes over 5000 patients thus far. Being the oldest existing registry, with a primary focus on arthroplasty surgery, it has been able to publish long-term follow-up results for various arthroplasty categories. In one study based on data from the Norwegian registry, 479 carpometacarpal joint replacements over a 17-year period were compared, and conclusions on long-term implant survival were shown (Krukhaug et al., 2014).

In this review we found that men accounted for 50% of included patients in all registries except for the Norwegian registry, where 20% were men. This finding may be due to the start date of this registry in 1994, during which time most of the joint replacements for hand and finger were due to inflammatory conditions such as rheumatoid arthritis, which occurs far more frequently in women.

Benefits from hand surgery registries

Hand surgery registries are becoming more popular, and recent research from other fields shows the potential for high-quality research, better patient care and increased possibilities for device surveillance, as has already been demonstrated with the large-joint-arthroplasty registries. There are still big differences between existing registries, with only a minority including patient-reported outcomes, and most reporting information only on arthroplasty operations. There is a potential for collaboration between countries to increase the quality of existing registries, with the aim of increasing research quality in hand surgery. We call for the formation of a global hand registry network to act as a platform for collaboration and data harmonization and to create a set of standards to ensure the quality of present and future registries in this field.

With the use of registries, as we have seen with the long-standing registries from Norway and Sweden, we can overcome the small samples size by pooling patients together, standardizing variables and data collection, and thereby increasing the quality of research in hand surgery. Registries can be used to improve surveillance of new medical devices (Class IIb/III), compare outcomes of traditional and novel techniques, enable the conduct of registry-nested trials, and compare outcomes between clinics/providers (Larsson et al., 2012). Apart from valuable data concerning operative procedures, registries provide useful information regarding the frequency and patterns of trauma, medical care supply and quality management to improve medical treatment and to allow for benchmarking.

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Supplemental material Supplemental material for this article is available online.

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