Is There Anything to Learn from a National Joint Registry?



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KEYWORDS

- Ankle arthroplasty National joint registry Outcome Big data Compliance
- Data integration Elimination of bias Implant surveillance

KEY POINTS

- National Joint Registries (NJRs) eliminate potential bias due to the historic dominance of developer series.
- Concerns relate to over interpretation of data, compliance with revision reporting and the potential for mandatory publication of surgeon's specific data.
- Surgeon- and institution-based outcomes provide close to real-time feedback that can alter practice.
- NJRs have potential to independently monitor introduction of new implants and provide early warning of those performing poorly.
- Registries must be integrated with other robust data sets and adequately funded to audit compliance.

INTRODUCTION

National joint registries (NJRs) have been established in Northern Europe for over 20 years. Since then, many other countries have begun collecting and reporting national data for total ankle arthroplasty (TAA).

With relatively small numbers implanted, a large variety of available designs, and with any long-term reports dominated by designer groups, TAA is ideally placed to benefit from large national or even pooled national registries.

The existing registry-based literature has been reviewed with respect to what is already known. The potential positives and down sides of registry data are highlighted.

DEMOGRAPHICS OF NATIONAL REGISTRIES

National arthroplasty registries were first established in Sweden. Their knee register was founded in 1976 and hip register in 1979.¹ Since then, numerous countries

The author has nothing to disclose.

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Foot Ankle Clin N Am 22 (2017) 465–475 http://dx.doi.org/10.1016/j.fcl.2017.01.004 1083-7515/17/© 2017 Elsevier Inc. All rights reserved. have created national registries. Ankle replacements were added to the Swedish, Norwegian, and Finnish registries in the early 1990s.^{2–4} They were followed by New Zealand in 2000,⁵ Australia in 2007,⁶ and England and Wales in 2009.⁷ These registries are all embedded in their multi-implant national arthroplasty registries with an established culture of reporting.

National ankle registries have more recently been established in France, Denmark, Belgium, The Netherlands, and Germany. To date, these young registries are yet to get close to the greater than 85% coverage recommended for national registries.^{1,8}

In the United States, big data repositories such as Medicare have been used to identify trends in TAA,⁹ but incomplete coverage and lack of specific information erode their value. A national registry was launched in 2010 but does not currently include TAA,¹⁰ and it remains to be seen whether it will achieve wide acceptance.

The European Foot and Ankle Society, in cooperation with the European Arthroplasty Register, is setting up an umbrella registry based on implant tracking.¹¹ This has potential to provide more robust audit of national registry compliance.

This article is restricted largely to established national registries with extensive coverage and current annual reports in English.

WHY HAVE A REGISTRY?

The aim of a national registry is to decrease the socioeconomic burden associated with failure and morbidity. This is achieved through several mechanisms (Box 1).

The Generalizability Cascade

Across all arthroplasty, designer groups or those affiliated with implant companies report better results when compared with registries.¹² There are many potential reasons for this, including surgeon experience, the designer's better appreciation of the nuances of the device, and several potential sources for bias. This is certainly true in TAA. About 50% of cases in outcome reports come from designer groups,¹³ with an average 9- to 10-year survival of 84% to 95%.^{14–17} Equivalent data from registries are more sobering (Table 1).

Expressed another way, the annual failure rate of surgeon designers is 1.1% compared with nondesigner series 1.7% and finally national joint registries of 3.2%. This hierarchy of survival data represents the generalizability cascade.²⁰

Often overlooked as an alternative explanation for inferior registry survivorship is the inclusion of an array of devices with proven inferior survival.

Box 1

Benefits of registries

- i. Generalizable outcome data-all surgeons, no exclusions, no conflict of interest
- ii. Timely feedback to individual surgeons and institutions
- iii. Monitoring the performance of types of TAA and surgical techniques close to real time
- iv. Provide a warning system for early failure
- v. Allow easy identification of patients for recall or more in-depth research
- vi. Potential to expand data collection with (a) patient-reported outcome measures and/or (b) groups such as fusion or supramalleolar osteotomy

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