# Use of registries in trauma and orthopaedics

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#### Abstract

Registries can be useful in both trauma and elective orthopaedic practices. The information acquired can be used to monitor clinical practice, ameliorating patient outcomes. Cross-linking between registries also ensures the highest level of data quality and amasses increasing quantities of data for analysis.

Successful registries depend on a variety of factors including adequate funding, trained staff and local leadership with engagement of key local stakeholders. Registries should have a clear purpose, be meticulous about data guality and ensure good utilization of the data held. Hip and knee arthroplasty and fracture registries have become well established in the UK, proving to be valuable resources for data assessment, reviewing outcome measures and benchmarking of the implementation of best practice guidelines. In more recent years, some registries have been used to highlight and compare the outcomes of surgical practices of individual practitioners. Data from individual organizations have also been published and opened to public scrutiny. The publication and interpretation of registry data can have a significant effect on the public's interpretation of individual as well as collective clinical practice and hence it is imperative that clinicians be familiar with the principles and practices of registries including data entry, analysis and interpretation.

Keywords arthroplasty; database; data entry; data protection; data quality; funnel plot; hip fracture; outcomes; registry; scoring systems

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#### Introduction

Registries have more recently gained increasing popularity, frequency and significance. The use of registries has become compulsory in some health organizations and this is driven by national government initiatives as well as local and regional incentives and penalties. Familiarity of the clinician with the data entry, analysis and interpretation of data outcome measures generated from registries into which their data have been input, is imperative. This would ensure that the data have the best chance of reflecting the actual picture of clinical practice and are not a misrepresentative statistical view. The final outputs, open to public perusal, can lead to undesirable individual scrutiny.

#### **History of registries**

The Mayo Clinic in the USA pioneered the first arthroplasty registry in 1969. However, the first national arthroplasty registry was commenced by Sweden in 1975 and other countries have followed. Led by the UK in 2007, hip fracture registries have also started to become more prevalent (Table 1). These registries have become major determinants in the management and resource provision of these patient cohorts with the implementation of processes such as best practice tariffs. With these tariffs, data entry was incentivized, driven by performance targets, as hospital trusts would receive payments based on submitted proof of their activities. This resulted in increased compliance with data entry and data quality.

#### Utilization

Registry data must be up to date to have a genuine influence on current practice. Registry data are used in the evaluation of injury management, trauma protocols, hospital statistics, assessing patient outcomes as viewed from standardized patient feedback and identification of the frequency of an individual procedure. Registry data can also serve in monitoring the use of devices and implants determining which devices may require recall, identifying patients at risk for complications and further procedures, assessing comparative effectiveness of devices and procedures as well as data acquirement for research studies.<sup>1</sup>

#### Reliability

Registry data must be reliable as they may serve as a basis for prospective analysis of national and international trauma and elective care. Coding plays an important role in the reliability of data entry and has economic effects in relation to tariff payments and requisitioning of finances. The use of local audit can assist in determining and maintaining the integrity of data. Quality improvement programmes utilizing standardized audit filter assessment to identify records with erroneous data can assist in data quality. Reproducible methods to evaluate data quality are also necessary.<sup>2,3</sup> The systematic and frequent validation of registry data against other databases must be part of the strategy of improving the reliability of data.

#### **Registries and healthcare funding**

The desire for quality care with minimum cost has resulted in the evolution of registries to track implant survivorship and

### Commencement of arthroplasty and hip fracture registries

#### Arthoplasty registries

1975 Sweden (TKA)

2007 UK (NHFD) 2012 Irish (IHFD)

Hip fracture registries

1979 Sweden (THA) 1980 Finland (TKA &THA) 2015 Australia and 1987 Norway THA New Zealand (ANZHFD) 1995 Denmark (THA) 1998 New Zealand (THA & TKA) 1997 Germany 1997 Denmark (TKA) 1999 Australia (THA & TKA) 1999 New Zealand (Shoulder & elbow) 1999 Sweden (Shoulder & elbow) 2001 Canada (THA & TKA) 2001 Romania (THA) 2002 Slovenia (THA, TKA, Uni Knee) 2003 England/Wales (THA & TKA) 2003 Slovakia 2004 Switzerland 2007 The Netherlands (THA & TKA) 2007 Hungary 2009 Portugal (THA)

ANZHFD, Australia and New Zealand Hip Fracture Database; IHFD, Irish Hip Fracture Database; NHFD, National Hip Fracture Database; THA, total hip arthroplasty; TKA, total knee arthroplasty.

#### Table 1

outcomes after joint replacement. This often involves collaboration of surgeons, insurers, and health systems to measure quality and outcomes. Participation in state and national registries can facilitate surgeons and hospitals to gain a financial advantage in insurers' quality programmes and payment models. Health care stakeholders will continue to increase the utilization of arthroplasty registries, to improve quality and control costs.<sup>4</sup>

#### **Trauma registries**

Hip fracture database registries pioneered by the UK in 2007 with the National Hip Fracture Database (NHFD), have now had significant influence on improving both morbidity and mortality statistics and have enhances knowledge about these injuries, the quality of care available and assist in reducing clinical variability, optimizing efficiency and reducing costs.<sup>5</sup> The implementation of best practice tariffs in 2011 has increased registry compliance and significantly improved patient care and outcome.

Military trauma registries developed to record combat trauma epidemiology and interventions have been used to guide training and optimize use of surgical capability, providing evidence-based guidance to military planning and medical intervention for the future.<sup>6</sup>

Low and middle-income countries (LMICs) can use trauma registries to guide injury prevention and trauma systems in highrisk populations. Standardized methodology and algorithms, in those trauma registries where complex metrics are infeasible to assess, can facilitate measurement of health disparities.<sup>7</sup> The trauma registry data acquired can help to inform policy-makers about trends in trauma, prevention, capacity and resource allocation.

#### Setting up a successful registry

The success of a registry is dependent on adequate funding, trained staff and the leadership of a local champion with engagement of key local stakeholders. It should have a clear purpose, be meticulous about data quality and ensure good utilization of the data.<sup>8</sup> Prospective data linkage between various established registries as seen with the National Joint Registry (NJR) and the London Implant Retrieval Centre (LIRC), can be used as a tool to feedback missing and erroneous data and so improve data quality.<sup>9</sup>

Association of the registries with national trauma and orthopaedic organizations assists in the robust organization of these registries, as this support ingrains an almost compulsory participation in them, hence bolstering their success. Political acknowledgement can then lead to data usage for policy change and implementation. See Figure 1.

#### The UK National Joint Registry

The established registries with long-term data, mainly from Scandinavia and the UK, now significantly influence implant choice and resource allocation. Support of the national trauma and orthopaedics associations has had a noticeable effect in the continued development of established registries. The dynamic process of re-invention and development is exemplified by the National Joint Registry (NJR) which collects information on joint replacement surgery and monitors the performance of joint replacement implants in England, wales and Northern Ireland with Scotland having it's own joint Registry. They are all well integrated into the fabric of orthopaedics across the UK.

#### **PROMs**

The use of patient-reported outcome measures (PROMs) has become increasingly important and this addition to established registries will undoubtedly ensure consistency among registries and improve data quality with respect to analysis and interpretation.<sup>10</sup> Patient-reported experience measures (PREM) are also used to gain patient's views on the outcome and experiences of a treatment.<sup>11</sup> The International Society of Arthroplasty Registries (ISAR) Patient-Reported Outcome Measures (PROMs) Working Group suggests the use of generic and specific PROMs which have been appropriately developed. It recommends that data be collected immediately before and 1 year post-surgery, that there be a lower limit of 60% for acceptable frequency of response and both non-responders and incomplete or missing data be documented.<sup>12</sup>

#### Scoring systems

These are important aspects of registry data. They can be validated or not validated and they include scores like the Oxford shoulder, hip and knee scores as well as quality of life scores alike the European Quality of life 5 dimensions (EQ5D) score. They give various degrees of subjective and objective information about patients' conditions and can be used most effectively Download English Version:

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