A comparison of the minimum data sets for primary shoulder arthroplasty between national shoulder arthroplasty registries. Is international harmonization feasible?

Ricardo Aveledo¹, Phillip Holland¹, Michael Thomas²,
Fiona Ashton¹ and Amar Rangan^{1,3,4}

Abstract

The aims of this study were to identify the common components of the Minimum Data Set (MDS) of current national shoulder arthroplasty registries that could be pooled for analysis; and to determine whether further harmonisation of data collection across these registries would be feasible. Copies of primary shoulder arthroplasty MDS forms, annual reports, and other publications from national shoulder arthroplasty registries were identified using internet search engines up to November 2016. Data relating to local or regional registries was excluded. There were nine national shoulder arthroplasty registries reporting a total of 97,388 primary shoulder replacements. All minimum data sets included patient identifiers, date of surgery, implant identification, laterality of surgery, indication and mode of implant fixation. At least 6 registries had common options within the categories of indication, implant fixation and previous operations. Most discrepancies were seen in categories for additional interventions, outcome measures, and intra-operative complications. As numbers within individual registries are relatively small, international collaboration would harness the global strength of knowledge and experience in shoulder replacement. Several similarities were identified between the current national registries that could become unified with only minor changes by a few registries, highlighting the potential feasibility of MDS harmonisation.

Keywords

arthroplasty, arthroplasty registry, international harmonization, shoulder

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Introduction

The use of shoulder arthroplasty is rising in tandem with an ageing population, as well as its association with arthritis, rotator cuff tears and fragility fractures. Joint registries have been implemented to monitor the performance of implants used for arthroplasty, the effectiveness of different types of surgical techniques, indications for arthroplasty, the incidence of complications and to analyze risk factors.^{1–3} Registries are continuously reviewed and updated to define, improve and maintain quality of care.⁴ Some of these registries have been able to detect inferior results before they are reported in conventional studies.^{5–8}

¹Department of Trauma & Orthopaedics, James Cook University Hospital, Middlesbrough, UK

²Department of Trauma & Orthopaedics, Heatherwood and Wexham Park Hospitals, Ascot and Slough, UK

³Department of Health Sciences, University of York, York, UK

⁴Faculty of Medical Sciences & NDORMS, University of Oxford, Oxford, UK

Corresponding author:

A. Rangan, Room 12B38, Academic Centre, James Cook University Hospital, Marton Road, Middlesbrough TS4 3BW, UK.
Email: amar.rangan@york.ac.uk

The National Joint Registry (NJR) for England, Wales, Northern Ireland and the Isle of Man was established in 2003 and is currently the largest joint registry in the world. Collection of data on shoulder arthroplasty was introduced in the NJR in April 2012. The NJR reported an analysis of 5221 primary shoulder replacements and 83,886 hip replacements performed during 2015, with an up-to-date cumulative total of 17,199 and 796,636 respectively.⁹ The Australian Shoulder Registry started data collection in 2004 although full national collection was not implemented until 2008. It is currently the largest shoulder registry and has reported 32,406 shoulder replacements performed up to 31 December 2015, as published in the 2016 annual report.¹⁰ The relatively small data set on shoulder arthroplasty in any single registry poses challenges for analysis that could potentially be overcome by pooling data from national registries, although this would require harmonization of the available data to do so.

Some countries have already seen advantages in harmonizing their data collected for hip and knee arthroplasty.¹¹ Since 2007, the Nordic Arthroplasty Registry Association¹² has been collaborating and pooling data from the Danish, Norwegian and Swedish registries, providing a larger data set for the monitoring of new and existing implants.¹³ Finland joined the project in 2010. A code set was defined for the parameters that all registers had in common, and data were re-coded within each national register, according to the common definitions. After patients had been anonymized, the data were merged into a common database.

The aims of the present study were to identify the common components of data sets from current national shoulder registries that may be pooled for analysis, as well as determine whether further harmonization of data collection across shoulder registries would be feasible.^{14,15}

Materials and methods

A computerized search was performed to identify existing shoulder arthroplasty registries and their published reports using Internet search engines of Google (www.google.co.uk) and Bing (www.bing.com) up to November 2016. The electronic databases of PubMed, CINAHL and EMBASE were accessed through the Healthcare Databases Advanced Search within the National Institute for Health and Care Excellence. In addition, representatives of the national registries were contacted for clarification where required. Data relating to any national shoulder arthroplasty registry was included, although we chose to exclude any data pertaining to local or regional registries.

We obtained all data components for primary shoulder replacements reported by each registry that met the

study inclusion criteria. Copies of the data collection forms (defined for purposes of the present study as the Minimum Data Set (MDS) from national shoulder registries were obtained and translated into the English language where necessary. All components of the MDS recorded by each national registry were entered on a spreadsheet using Excel, version 12.0 (Microsoft Corp., Redmond, WA, USA) for comparison.

Each individual registry's MDS was analyzed to identify the number of components currently collected in common across the registries and then ranked accordingly. Feasibility of further harmonization was then determined by identifying the extent of changes required to replicate a single comprehensive MDS across all registries.

Results

Nine national shoulder arthroplasty registries were identified, from Australia, Denmark, Finland, Netherlands, New Zealand, Norway, Portugal, Sweden and the UK.^{9,10,16–23} Based on their latest reports, a total of 97,388 primary shoulder replacements was recorded across the nine national arthroplasty registries. The number of procedures reported by each registry, as well as the duration of data collection, is shown in Figure 1.

A number of additional local and regional shoulder arthroplasty registries were also identified, some with relatively high numbers, such as the Kaiser Permanente Shoulder Registry based in California, USA, with over 6000 recorded procedures.²⁴ However, because they

Figure 1. Number of primary shoulder arthroplasty procedures reported by each national registry and years of data collection.

were not national registries, data from these registries were excluded from the present study.²⁵

Seven of the identified countries have national registry MDS forms that are specific to shoulder arthroplasty, whereas Australia and Finland use a generic national joint replacement registry form that is shared with other joint replacement procedures. A summary of the categories of the data set collected by each registry's form is provided in Table 1.

Patient and procedure identifiers

The most common patient identifier recorded by all but the Portuguese registry, was an assigned unique patient identification number. The patient name, sex and date of birth are collected by all registries; however in some cases, such as in the Netherlands, Denmark, Norway and New Zealand, these data are obtained from the health care systems' database using the patient identification number; alternatively, a patient identification sticker is incorporated into the form supplying this information. Date of surgery is reported across all registries, with Denmark being the only registry not to also document the hospital where surgery is being undertaken. The responsible surgeon is recorded by just over half of these registries.

Pre-operative assessment

Five of the identified national registries (Australia, UK, Netherlands, Norway and Portugal) collect data for patient's American Academy of Anaesthesiologists grade.²⁶ The Portuguese Registry is unique in its collection of additional pre-operative details, including physical activity level, body mass index and associated co-morbidities.

Additional interventions

Details of certain additional interventions were recorded by four registries: UK, Sweden, Netherlands and Denmark. All four had the following options in common: humeral bone graft, rotator cuff repair and glenoid bone graft. Long head of biceps (LHB) tenotomy was recorded by three registries. LHB tenodesis, subacromial decompression (SAD), acromioclavicular joint excision and bone graft (not specified) were present in two of the forms. Lastly, only one form gave the option of biological glenoid resurfacing.

Surgical indication

All nine registries collected data on the indication for surgery (see Supplementary information, Appendix A), although there is some variation seen in the options

available within this category. Indications of osteoarthritis, rheumatoid arthritis, inflammatory arthropathy and 'other indications' were available on all registries. The majority of registries also included rotator cuff arthropathy, acute trauma, avascular necrosis (AVN), trauma sequelae and post-traumatic arthritis.

Other options on indications for surgery, with greater variation seen between the registries, were malignancy, dysplasia and dislocation.

Previous operations

Only two registries did not collect data regarding previous surgery (Australia and Finland). Of the seven registries that did collect such data, the most common categories were stabilization ($n=6$ registries), rotator cuff repair ($n=6$), open reduction and internal fixation of a fracture ($n=5$), SAD ($n=5$) and 'other' ($n=5$). (see Supplementary information, Appendix B)

Surgical factors

All registries recorded details on implant cementation, but in different formats (see Supplementary information, Appendix C). Sweden and Portugal recorded cementation without distinguishing between implant components. The UK and Netherlands took a similar approach, with the additional option of hybrid fixation. The remaining five registries collected data on the nature of fixation specific to each component. Table 1 reveals significant variations in recording of other surgical variables (including the use of perioperative antibiotics, the duration of surgery and mode of anaesthetic used) between the identified registries.

Intra-operative complications are recorded by only four registries: the UK, Sweden, Denmark and Norway. The Portuguese national registry provides a free text area for additional notes on the procedure, including details of operative complications, although this was not a mandatory field. Finland and Sweden also had a section in their registries for additional notes but with no prompt to specifically record operative complications. New Zealand and the Netherlands did not provide any space for additional notes.

Outcome measures

Baseline pain and functional levels are established pre-operatively by six of the national registries (Table 2). The patient-reported outcome measurement (PROMs) tools currently being utilized are: the Oxford Shoulder Score by the UK, New Zealand Norway and the Netherlands; the EuroQol-5D Quality of Life score by Sweden and the Netherlands; the Western Ontario Osteoarthritis of the Shoulder (WOOS) score by

Table 1. Data collected by each national registry.

	Australia	UK	Sweden	New Zealand	Netherlands	Denmark	Norway	Portugal	Finland	Total
Date of surgery	X	X	X	X	X	X	X	X	X	9
Laterality	X	X	X	X	X	X	X	X	X	9
Gender	X	X	X	X	X	X	X	X	X	9
Indication	X	X	X	X	X	X	X	X	X	9
Fixation (cement)	X	X	X	X	X	X	X	X	X	9
Prosthesis brand	X	X	X	X	X	X	X	X	X	9
Patient ID number	X	X	X	X	X	X	X	X	X	9
Patient name	X	X	X	X	X	X	X	X	X	9
Date of birth	X	X	X	X	X	X	X	X	X	9
Prosthesis lot number	X	X	X	X	X	X	X	X		8
Hospital	X	X	X	X	X		X	X	X	8
Previous surgery		X	X	X	X	X	X	X		7
Surgical approach		X	X	X	X	X	X	X		7
Stem		X	X	X	X	X	X	X		7
Bone graft		X	X	X	X		X	X	X	7
Glenoid component	X	X	X	X	X			X		6
Cuff condition		X	X	X	X	X		X		6
Consultant	X	X		X	X			X		5
Antibiotics				X		X	X	X	X	5
ASA grade	X	X			X		X	X		5
Additional surgery		X	X		X	X				4

(continued)

Table 1. Continued

	Australia	UK	Sweden	New Zealand	Netherlands	Denmark	Norway	Portugal	Finland	Total
Intra-operative complications		X				X	X			3
Surgery duration				X		X	X			3
Anaesthetic type		X					X			2
Physical activity								X		1
Patient pathologies								X		1
Patient consent		X								1
Anticoagulants							X			1
Operating theatre				X						1

ASA, American Academy of Anaesthesiologists; ID, identification.

Sweden and Denmark; and the Numeric Rating Scale for Pain which is unique to the Netherlands.

Discussion

There are currently nine national shoulder arthroplasty registries, with the Australian registry having the largest number of shoulder replacement procedures collected since 2004. The National Joint Registry for England, Wales, Northern Ireland and the Isle of Man started recording shoulder arthroplasty procedures in 2012 and currently has the second largest data set. The third highest number of procedures is included in the Swedish National Shoulder and Elbow Registry, which was established in 1999 and has reported 12,989 operations. This is followed by Denmark, with 10,290 primary shoulder replacements since 2004, and the New Zealand Joint Registry, with 7305 procedures recorded since 2000. The Portuguese national shoulder registry was created in 2009, although we identified a gap in their annual reports between 2010 and 2012. Outside of this missing data, they report on 335 primary shoulder replacements since 2009.

The longest running registries are the Finnish Arthroplasty Register, established in 1980, with 3550 shoulder replacements; the Norwegian Arthroplasty Registry, which was extended to include shoulder replacements in 1994, with 6897 procedures recorded; and the Swedish National Registry established in 1999. The most recent national register is in the Netherlands, which was created in 2014, when 2077 shoulder replacements were analyzed, and now has 6590 procedures recorded.²⁷

Data set similarities

All of the minimum data sets between registries include patient identifiers, sex, date of surgery, implant identification, laterality of surgery, indication and implant fixation mode. However, even within these areas of common interest, the details of data collection vary to such an extent that only limited pooling of data for analysis may be feasible. Surgical indication, for example, unanimously includes options for osteoarthritis and inflammatory arthropathy, and at least six registries (66.7%) document further indications, including rotator cuff arthropathy, acute trauma, post-traumatic arthritis, trauma sequelae and AVN. Between the registries, there are then a further six different indications, each only acknowledged by two or three separate registries. In addition, all MDS forms have the free text option of choosing 'other indication'. A similar pattern is seen when considering the incidence of preceding shoulder surgery, and methods of implant fixation.

Table 2. Patient-reported outcome measurements used by national registries.

Outcome measure	UK	Sweden	New Zealand	Denmark	Norway	Netherlands	Total
OSS*	X		X		X	X	4
WOOS*		X		X			2
EuroQol 5Q-5D		X				X	2
						X	1

*NRS.

WOOS, Western Ontario Osteoarthritis of the Shoulder; OSS, Oxford Shoulder Score; NRS, Numeric Rating Scale.

MINIMUM DATA SET INTERNATIONAL PRIMARY SHOULDER ARTHROPLASTY REGISTRY	
PATIENT DETAILS	
Full name	
Gender	Female ☐ Male ☐ Not Specified ☐
Date of Birth	DD/MM/YYYY
Identification Number	
PROCEDURE DETAILS	
Hospital	
Operation Date	DD/MM/YYYY
Side	Left ☐ Right ☐
ASA grade	1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐
Indications for Implantation	Osteoarthritis ☐ Cuff Tear Arthropathy ☐ Inflammatory Arthropathy ☐ Acute Trauma ☐ Trauma Sequelae ☐ Avascular Necrosis ☐ Other ☐
Previous surgery	None ☐ Stabilisation ☐ Rotator Cuff Repair ☐ ORIF ☐ Subacromial Decompression ☐ Distal Clavicle Excision ☐ Other ☐
SURGICAL DETAILS	
Arthroplasty Design	☐ Conventional total (stemmed) ☐ Conventional total (stemless) ☐ Conventional hemi (stemmed) ☐ Conventional hemi (stemless) ☐ Resurfacing (total) ☐ Resurfacing (hemi) ☐ Reverse (stemmed) ☐ Reverse (stemless) ☐ Other
Fixation Type	Cemented Humerus ☐ Cemented Glenoid ☐ Both Components Cemented ☐
Approach	Delto-Pectoral ☐ AnteroSuperior ☐ Other ☐
Humeral Bone Graft	Yes ☐ No ☐
Glenoid Bone Graft	Yes ☐ No ☐
Rotator Cuff Condition	Normal ☐ Attenuated ☐ Absent/Torn ☐ Repaired ☐
COMPONENT LABELS	
PATIENT REPORTED OUTCOME MEASURES (e.g., Oxford Shoulder Score)	

Figure 2 Proposed Minimum Data Set form that includes the most common items collected in the current national registry forms.

When identifying that there are common components and areas of interest already present between the identified registries, it appears that registries could become more harmonized with only a few small changes within categories, such as indication for surgery, previous operative interventions and chosen method of implant fixation.

Data set differences

Registries that have a generic arthroplasty data collection form that is shared with other joint replacement procedures were found to contain significantly less data regarding indications for surgery, and other categories specific to shoulder arthroplasty.

The categories in which most differences were found were additional interventions, outcome measures and intra-operative complications. Only three registries specifically request data regarding intra-operative complications; however, the majority of other registry forms do provide designated space for surgical notes where this information may be recorded with free text at the discretion of the submitting team. Similarly, the data on additional interventions, as recorded by only four registries, have considerable variation among the available options.

PROMs have an important role in longitudinal analysis and monitoring of patients' clinical outcomes. However, these are not currently collected by three of the national registries and there is variation between the registries that do collect them. The Oxford Shoulder Score, which is a validated patient reported outcome measure in chronic shoulder pathologies,²⁸ is the most frequently used questionnaire within the identified registries.

The inclusion of additional interventions, intra-operative complications and PROMs would need substantial changes to the data collection within some registries. We also acknowledge that there would be difficulties with data analysis between registries as a result of differing baseline population characteristics and surgical indications. Comprehensive completion of a common MDS, however, would help collect these baseline characteristics from the different registries, which could be adjusted for during analysis. This would also be desirable to monitor international trends and inform future practice in shoulder arthroplasty.

Conclusions

The relatively small number of shoulder replacements recorded within individual national shoulder registries makes international collaboration desirable with respect to harmonizing data across registries to allow data pooling for analysis. We would recommend that

data are collected via a dedicated MDS form specific to shoulder arthroplasty procedures because there are a number of considerations that may not be common to other joint replacements. The authors of the present study have created an example of a MDS form (Figure 2) that includes the most common items collected in the current national registry forms. A number of important components were identified, such as patient demographics, indication for implantation, previous surgery, implant and procedure type, and methods of fixation that are already recorded by most registries, and these could be harmonized by mutual consensus. We recommend that this is carried out at the earliest opportunity to allow larger shoulder arthroplasty data sets to be analyzed.

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Ethical Review and Patient Consent

Not applicable to this article.

Supplementary Material

Supplementary appendices appendices A–C are available at: <http://journals.sagepub.com/doi/suppl/10.1177/1758573218755569>.

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