Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR)

Patient Reported Outcome Measures (PROMs) Pilot

Grace O’Donohue – Project Manager

AOANJRR
AOANJRR Team

• Director – Professor Stephen Graves

• Deputy Directors - Professor Richard de Steiger, Mr Peter Lewis, Professor Ian Harris

• Manager – Ms Cindy Turner

• AOA team
  o Research Coordinator, Project Manager, Project Officer, Project Coordinator, Administration Officer

• SAHMRI team
  o Project Manager, Data Managers, Statisticians, IT personnel, Data Administrators

• University of South Australia
AOANJRR Background

- Owned by the Australian Orthopaedic Association
- Data collection commenced in 1999 (Hip and Knee only)
- Full national implementation completed in 2002
- Other joints were added in 2007
- Permanently funded by the Federal Government (Federal legislation 2009)
Federal Quality Assurance Activity

- Ensures absolute confidentiality of data held by AOANJRR
- Ensures freedom from subpoena
- Prevented from releasing information that could identify a patient, surgeon or hospital
Purpose

- To define, improve and maintain the quality of care for recipients of joint replacement

  - Information is used to inform surgeons, health care professionals, government, orthopaedic companies and the community
Data Collection

HIP FORM

Australian Orthopaedic Association
National Joint Replacement Registry

Place PATIENT DETAILS label here and/or if any patient details are not available on the hospital label please complete below:

Surname: ________________________  Female: [ ]  Male: [ ]
First Name: ________________________  Middle Initial: ______
Address: ______________________________________
Hospital Patient No.: ________________________  Post Code: ______
Medical No.: ________________________  Div No.: ______
Name of Hospital: ________________________  Suite: ______
Consultant Surgeon Code: ________________________
Weight (kg) ________  Height (cm) ________  ASA ________

PLEASE COMPLETE THIS SECTION IN FULL

OPERATION DATE: __/__/____  LEFT: [ ]  RIGHT: [ ]

OPERATIVE APPROACH (pick one box only):

Patient: [ ]  Lateral: [ ]  Anterior: [ ]  Other: [ ]

PRIMARY HIP [ ]  REVISION HIP [ ]

DIAGNOSIS:

Osteoarthritis: [ ]  Rheumatoid Arthritis: [ ]
Other Inflammatory Arthritis: [ ]  Osteonecrosis/Muscular Necrosis: [ ]
Developmental Dysplasia: [ ]  Fractured Neck of Femur: [ ]
Tumour aroma: [ ]  Other reason: [ ]

ACETABULAR COMPONENTS

(Mark relevant boxes, place company labels on colored areas or complete details by hand)

COMPANY: ________________________
Prosthesis Name: ________________________
Cat/Ref No.: ________________________
Lot No.: ________________________

COMPANY: ________________________
Prosthesis Name: ________________________
Cat/Ref No.: ________________________
Lot No.: ________________________

COMPANY: ________________________
Prosthesis Name: ________________________
Cat/Ref No.: ________________________
Lot No.: ________________________

ACETABULAR CEMENT

NO [ ]  YES [ ]

CEMENT NAME: ________________________

(Use company label or complete details if more than one mix is used, use only 1 label)

(Complete by hand, labels not required)

SCREWS:  NO [ ]  YES [ ]  Number used: ______

Please return form to: Locked Bag 2, Hutt St Post Office, ADELAIDE SA 5000
Data Quality

• Completeness

• Correctness

• Validation:
  - Verify against other external data sources particularly for core data
  - Availability of stakeholders own information
  - Implement Data Quality Systems (Front and Back end)
Primary outcome measure

• Death
• Revision

• Reasons for revision
• Types of revision

• Analyse for Patient, surgeon, hospital, and prosthesis factors that impact on revision
Timely and appropriate delivery of data

- Annual Report
- Ad hoc requests
- On-line access
Why PROMs?

- Support from health sector stakeholders

- AOANJRR currently uses Revision, Reason for Revision and Death as its principle end points

- Limits – only identifies a subset of patients that have had an unsuccessful procedure

- PROMs provide quality information on the extent of pain and disability prior to surgery as well as the extent and timing of recovery
Test the feasibility of collecting PROMs from all patients undergoing joint replacement in Australia

• Challenges:
  o Timing
  o Which PROMs?
  o Consent
  o Data collection
  o Data Security
  o Data Completeness
  o Analysis and Interpretation
  o Integration with existing data collection
  o Approaches to Stakeholder data feedback
  o Cost minimisation
Participating Sites

- Approximately 50 hospitals throughout Australia are participating in the pilot
  - Public/Private
    - 18 Private Hospitals
    - 32 Public Hospital
  - State breakdown
    - 16 NSW
    - 10 QLD
    - 8 VIC
    - 6 TAS
    - 5 SA
    - 4 WA
    - 1 ACT
Project Details

- Data will be collected pre-operatively and at 6-months post-op (this may be extended in national roll out)
- All follow-up will be undertaken by the AOANJRR
- Surgeons will be able to access individual patient results
- Real-time aggregated data will be available via secure online dashboards
An international expert working group was formed to recommend which PROMs should be included:

- **Health Status (pre & post-operatively)**
  - EQ-5D-5L

- **Joint Specific (pre & post-operatively)**
  - Oxford Scores (Hip, Knee and Shoulder)
  - *New 12-item HOOS and KOOS (optional)*
  - Two numerical pain scales (affected joint, lower back/neck)

- **Additional questions (pre-operatively)**
  - Two Co-morbidity Questions
  - Three Expectation Questions

- **Additional questions (post-operatively)**
  - One Change Question
  - One Satisfaction Question
Electronic PROMs System

- The AOANJRR has developed a custom design electronic system which will allow flexibility of PROMs collection
- Consent is collected electronically
- Questions are presented one at a time with a progress bar to display completeness
Site Recruitment

- Nine ethics approvals obtained which cover all sites
- Surgeons approached first to ensure they are happy to participate
- 43 sites fully approved
  - Average of 148 days between first approach to surgeons and full hospital approval
- Commenced data collection on 30th July 2018
- 39 of the 50 sites have commenced
  - Hospital pre-admission clinics
  - Surgeon Private rooms
  - Data collected externally and provided to the AOANJRR
Data Collected

Patient Recruitment

- 2078 patients registered
- 191 patients declined to participate
- 8% decline
- 2078 patients registered
Data Collected

Procedure Collections

- 294 pre-op PROMs pending
- 1920 completed pre-op PROMs
- 87% completion
Data Collected

- 199 <55
- 618 55-64
- 809 65-74
- 494 ≥75

- 1367 Knee
- 756 Hip
- 91 Shoulder
Variation between Sites

- Sites who are utilising iPads to collect data from patients in a centralised pre-admission setting are achieving a better response rates.
Variation between Sites

- However, sites who are not utilising an iPad but are explaining the project well to patients are achieving a good response rate also.

**Procedure Collections**

<table>
<thead>
<tr>
<th>Hospital C</th>
</tr>
</thead>
</table>

![Procedure Collections Chart](chart.png)
Summary MRFF

- The Rapid Translation MRFF grant has enabled the Registry to develop dashboard infrastructure necessary to deliver the data collected through the PROMs project directly to stakeholders.

- The data is made available immediately to patients, hospitals and surgeons via real-time secure electronic dashboards providing the information necessary to translate this data into clinical practice and improve outcomes.
Dashboard Development

- The first dashboards released provided:
  - Patient recruitment rates
  - Pre-operative questionnaire completion rates
  - Patient Age demographics
  - Procedure Joint

- Stratified by hospital - where the user has privileges to see individual hospital-level data
The Patient Dashboard was the first outcome data dashboard to go live (1st November) this dashboard is currently displaying pre-operative data with comparisons to the entire dataset for that joint or age bracket.

It was felt it is important to enable patients to see something in return for their efforts

Feedback to date is very positive

Patients value being able to see where they are positioned relative to other joint replacement patients nationally.
Compare Your Results

Here you can compare the answers you have given with the responses given by other people having the same procedure.

Your registered procedures: **Left Knee: 20/08/2018, Calvary Wakefield Hospital**

<table>
<thead>
<tr>
<th>Study</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Measure of health related quality of life</td>
<td>🕵️‍♂️</td>
</tr>
<tr>
<td>What you expect your health and mobility to be after the operation</td>
<td>🕵️‍♂️</td>
</tr>
<tr>
<td>Your level of lower-back pain</td>
<td>🕵️‍♂️</td>
</tr>
<tr>
<td>How well you can use your knee and how much pain it causes</td>
<td>🕵️‍♂️</td>
</tr>
<tr>
<td>Your level of pain in the joint being operated on</td>
<td>🕵️‍♂️</td>
</tr>
<tr>
<td>Your expected level of pain in the problematic joint after the operation</td>
<td>🕵️‍♂️</td>
</tr>
<tr>
<td>Questions about your knee related to activities and function</td>
<td>🕵️‍♂️</td>
</tr>
</tbody>
</table>
Patient Dashboard

Left Knee

Affected Joint Pain
Before your operation you answered: 7.
22% of people having this operation answered the same.

You answered

Worse Better

10 means the worst pain imaginable. 0 means no pain at all.

NATIONAL RESPONSES

Close

Previous Next

Left Knee

Affected Joint Pain
Before your operation you answered: 7.
21% of people your age having this operation answered the same.

You answered

Worse Better

10 means the worst pain imaginable. 0 means no pain at all.

NATIONAL RESPONSES

Close

Previous Next
Patient Dashboard

Left Knee

**MOBILITY**

Before your operation you answered: *I have moderate problems with walking around.*
47% of people having this operation answered the same as you.

![Bar chart showing the distribution of responses to the mobility question.](chart1)

Left Knee

**MOBILITY**

Before your operation you answered: *I have moderate problems with walking around.*
40% of people your age having this operation answered the same as you.

![Bar chart showing the distribution of responses for people of a specific age group.](chart2)
Patient Dashboard

Left Knee

PERSONAL CARE
Before your operation you answered: I have slight problems with washing or dressing myself.
24% of people having this operation answered the same as you.

You answered

Unsure: 0.36%
Severe problems: 0.72%
Moderate problems: 14.1%
Slight problems: 24%
No problems: 58.6%

Worse
Better

National responses
Others your age

Previous
Next
Close

Left Knee

PERSONAL CARE
Before your operation you answered: I have slight problems with washing or dressing myself.
21% of people your age having this operation answered the same as you.

You answered

Unsure: 0.012%
Severe problems: 0.012%
Moderate problems: 18.7%
Slight problems: 21.2%
No problems: 57.1%

Worse
Better

National responses
Others your age

Previous
Next
Close
Patient Dashboard
Next Dashboards

• The next stakeholder dashboard to go live (in the next week or so) will be:

• Surgeons:
  o Patient recruitment rates;
  o Pre-operative questionnaire completion rates;
  o Patient age demographics;
  o Procedure Joint;
  o Data for their own procedures at their various hospitals (instead of only being permitted to see system-wide data)

• If the patient has elected to share their results, surgeons can see the graphs from the patient’s perspective (in the same area of the interface where they can see the actual responses to the instruments).

• For procedures that have been matched to the Registry, we will be able to show a secondary dimensions to Patient age demographics (by including gender) and procedure joint graphs (by showing primary/revision).

• Comparison graphs of instrument responses (e.g. for a surgeon, their patients pre-operative Oxford Hip Score distribution vs the system-wide score distribution)
**Hip - EQ-5D-5L - MOBILITY**

Before their Hip procedure, the average response of your patients was **Moderate problems**. The national average response was also **Moderate problems**.

- National Procedures
- Your Procedures

**Chart Description:**
- **Unable to do:** 10% for National Procedures vs. 10% for Your Procedures.
- **Severe problems:** 30% for National Procedures vs. 31% for Your Procedures.
- **Moderate problems:** 33% for National Procedures vs. 45% for Your Procedures.
- **Slight problems:** 21% for National Procedures vs. 11% for Your Procedures.
- **No problems:** 6% for National Procedures vs. 8% for Your Procedures.

Compare to: National responses
Before their Hip procedure, the average response of your patients in the 65-74 age bracket was 74. The national average response for patients aged 65-74 was 76.
Next Steps

- Implement the project at all pilot sites by mid November 2018
- Continue to release additional dashboards
- Complete the electronic system build
  - Scalable so future Registry Nested trials can be run through the system
- Finalise pilot and release report 4\textsuperscript{th} quarter 2019
- Permanent National implementation – pending pilot findings and funding
Thank you