

# AOA PROMs Pilot Project Final Report

20th February 2020

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# 1.Executive Summary

This pilot project assessed AOANJRR's capacity to directly consent patients and collect pre and post-operative Patient Reported Outcome Measures (PROMs) which could be integrated within the AOANJRR. Participants would be those patients receiving elective hip, knee and shoulder arthroplasty. The aim was to determine feasibility, stakeholder engagement and to identify barriers to achieving a high level of data completeness and accuracy. The purpose has been to inform decisions on viability and make specific recommendations to optimise a national collection of this data.

In Australia and internationally, the importance and benefit of PROMs data for both individual patient care and assessment of the quality and cost effectiveness of healthcare delivery has become more appreciated. A major limitation preventing wider use of PROMs data has been the inability to continuously collect and disseminate this information to all relevant stakeholders in a comprehensive and financially sustainable manner. These issues were a central consideration in the development of AOANJRR's approach.

Critically important to the success of the study has been the successful design, development and implementation of an automated electronic data capture platform now known as RAPID (Real time Automated Platform for Integrated Data capture). It was necessary for this platform to obtain online consent, be user friendly, be flexible and modifiable, to integrate with existing AOANJRR ICT systems and have the ability to report data in real time to all stakeholders including individual patients.

RAPID was purpose built in-house by SAHMRI ICT to meet the needs and purpose of the pilot and to be scalable to collect self-reported patient data nationally. The decision to use a custom designed product rather than use commercially available products was made following a feasibility and risk assessment and consultation with national and international experts in PROMs and registry data collection. During the pilot multiple enhancements were developed and deployed, each providing additional functionality to address identified issues in a timely manner and optimise both data collection and reporting. Development remains ongoing and is only possible because of the early decision to design and develop in-house.

The pilot study has shown that *RAPID* is a very effective data collection and reporting platform. When patients are registered and consented, 97.8% completed pre op data entry and 79% complete data entry 6 months after their joint replacement surgery.

The Pilot identified that there was hospital variation in patient registration. Current registration including all hospitals is 60.2% in the 12+ month period. The proportion of patients registering has continually improved since the pilot commenced. Many hospitals are achieving high registration rates with some approaching 100%. The registration of patients into the system has primarily been a hospital driven process. It takes time for hospitals to become familiar with the system and to get the registration processes in place in both hospitals and surgeon room practices. An important outcome of this study has been the ability to identify approaches that work well and those that don't. Applying those learnings to assist hospitals to enhance registration has been very effective. This is evident by the continuous improvement which is evident overall, by state, public and private sectors, and for all joint types.

This pilot was undertaken to assess the feasibility of AOANJRR establishing national data collection for patients having joint replacement surgery. Careful consideration of how to optimise national implementation has been undertaken and a list of recommendations developed. These are provided below.

## **Overcoming Barriers - Recommendations**

- 1. Continue to have flexible recruitment arrangements with sites to cater for variability of preadmission processes. Acknowledging that communication and relationship building with the person responsible for registration of patients is critical to success.
- 2. Increase communication with all surgeons and specifically shoulder surgeons to ensure the maximum number of patients are registered both in and out of pre-admission clinics.
- 3. Encourage sites to pre-register patients en masse prior to pre-admission clinics (dependent on the site) to minimise the resource burden on hospital/clinic staff.
- 4. Continue to match PROMs registrations to data already collected by the AOANJRR or other resources and use data linkage to other government datasets where practicable to ensure the burden of data collection is minimised.
- 5. Continue to enhance the RAPID system based on feedback from site staff and patients to increase efficiency and maximise ease of use.
- 6. Review site training, educational material and induction documentation to ensure these meet the needs of new site staff to address staff turnover and leave requirements.
- 7. Continue to record the need for support to complete PROMs for patients for ongoing monitoring purposes.
- 8. Remove the option for landline contact only, as phone call follow-up will not be sustainable in a national rollout.
- 9. Ensure adequate project resources are in place within the AOANJRR to establish and maintain the required support and to communicate with sites during the implementation of a national rollout.
- 10. Ensure new sites have a clinician contact point within the site as part of a national rollout.
- 11. Continue a governance structure that provides expert clinical input and access to the networks of the AOANJRR throughout the national rollout.
- 12. Continue to allow patients undergoing non-elective joint replacement to contribute PROMs whilst acknowledging that the process of collecting these in emergency departments is challenging.

# Infrastructure Development - Recommendations

- 13. Maintain adequate IT support within the SAHMRI ICT Team to ensure that enhancements can be made quickly, and efficiently as new functions are required.
- 14. Continue ongoing development of dashboard displays of real-time data to meet the needs of all stakeholders.
- 15. Maintain stakeholder confidence in the system by continued use of Australian Orthopaedic Association (AOA)/AOANJRR branding, high level IT security and stability of the online platform.

# **Platform Usability - Recommendations**

- 16. Ensure all future modifications to RAPID do not increase the burden and maintain the usability for all users.
- 17. Review patient feedback regularly in a more structured process to ensure a broad range of views are captured.
- 18. Continue to monitor the proportion of patients who require assistance to complete their PROMs.

# **Optimising Patient Registration - Recommendations**

- 19. Ensure the system remains flexible enough to adapt to different site pre-admission processes.
- 20. Implement close monitoring of registration rates for each site as they join the national rollout and ongoing.
- 21. Ensure adequate resources are in place to provide the required support for new sites to become familiar with the PROMs and RAPID.

#### **Data Linkage - Recommendations**

22. Continue PROMs collection with a minimum dataset to minimise the burden of data collection and utilise data linkage to other government datasets to enhance the value of data collected.

# **Development of Reporting Models - Recommendations**

- 23. Continue to explore new ways to present real-time data via the online dashboards. It is essential that data are provided to stakeholders in a format that could potentially form the foundation for change of practice and improved patient outcomes.
- 24. Ensure patient input and feedback guides future patient reporting developments.

# Platform Development: Registry Nested Clinical Trials (RNCT) - Recommendations

- 25. Continue to increase the capability of RAPID to deliver RNCTs.
- 26. Broaden access to the trial capability within *RAPID* to enable a greater number of Australians to electronically access trials across geographical areas that would otherwise not have this opportunity.

# Improving Clinician and Patient Engagement - Recommendations

- 27. The communication approach used engaging hospitals via a frequent, open and personal methods was highly effective and should be utilised in the national rollout.
- 28. To ensure the administrative load of the national rollout is manageable, individual hospital agreements and individual ethics approvals should be avoided unless deemed necessary by individual hospitals.
- 29. To ensure high levels of hospital participation in a national rollout, approval for PROMs collection as a Federal Quality Assurance Activity is recommended to ensure the burden of ethics and site approvals is not overwhelming.
- 30. Expand education and promotion of the online dashboard data for all RAPID users to increase engagement with the data.

# 2. Background and Rationale

The AOANJRR was established in 1999 to improve outcomes for patients undergoing joint replacement surgery in Australia. The AOANJRR is federally funded and operates as a Federal Quality Assurance Activity (QAA 14/2016). It has almost complete data on all hip and knee replacement procedures performed since it achieved full national implementation in mid-2002. Data collection was expanded to include shoulder arthroplasty procedures in April 2004 and has documented almost all shoulder arthroplasty procedures Australia-wide since November 2007. These data are externally validated against patient-level data provided by all Australian state and territory health departments. A sequential, multilevel matching process is used to identify any missing data which are subsequently obtained by follow-up with the relevant hospital. Each month, in addition to internal validation and data quality checks, all primary procedures are matched to any subsequent revision involving the same patient, joint and side. Data are also matched bi-annually to the Australian National Death Index data to identify patients who have died.

The AOANJRR has identified best practice with respect to prosthesis choice, surgical technique, and patient selection. Making this information available to relevant stakeholders, including surgeons, has proven to reduce post-operative complications and subsequent revision surgery.

The Registry analyses data to report on a subset of patients that have had a revision procedure. However, patients' perspective of the outcome of their surgery is not recorded. It is becoming increasingly apparent that to achieve further improvements in joint replacement surgery and more efficient healthcare delivery, there is a need to undertake more comprehensive assessments using a wider range of outcomes.

The new model of Value Based Healthcare that utilises information obtained directly from recipients of healthcare services is being increasingly promoted and used both in Europe and the U.S.A. <sup>1</sup> Value in healthcare is defined as the health outcomes achieved per dollar spent. The model promotes the goal of increasing value by increasing quality, rather than simply decreasing cost. <sup>1</sup> For this goal to be achieved, it is necessary to measure patient reported outcomes such as pain, function, health-related quality of life and complications.

A patient reported outcome is defined as any report of a patient's health status that comes directly from the patient without interpretation by others. Incorporating PROMs into population-based healthcare not only enables the inclusion of this critically important patient perspective but also broadens the range of outcomes that can be evaluated. Collection of PROMs specifically in joint replacement patients has the capacity to provide meaningful information on the extent of pain and disability prior to surgery, as well as the extent and timing of recovery and the presence of complications. The successful collection, knowledgeable interpretation and integration of PROMs with other outcomes holds great promise for improving the benefit and cost-effectiveness of healthcare delivery. There is increasing interest in Australia from a wide range of stakeholders, including surgeons, institutions, governments, payers and consumers in the collection of these data.

The growing enthusiasm for collecting PROMs in population-based studies has in part been driven by the long and successful experience of using these outcome measures in clinical trials. They have improved the understanding of patient, device, surgeon and institutional factors associated with the success, or otherwise of these studies. The collection of PROMs has also provided the opportunity to better define indications for treatment, as well as evaluate comparative cost-effectiveness based on quality of life improvement.

Translating the successful use of PROMs data into population-based studies has major advantages. Most importantly, it has the potential to improve the comparative assessment of healthcare outcomes within community, national and international settings. This information can be used to enhance outcomes whilst also assisting in the design, delivery and funding of health services by aligning clinical outcomes and patient satisfaction with value and efficient, best practice care.

However, there are major challenges in effectively collecting and utilising this information in a population-based setting. Timing of data collection, selection of specific PROMs questionnaires/instruments, consent processes, data collection mechanisms, data security, required data completeness, analysis and interpretation, integration with other outcome measures, approaches to stakeholder feedback and cost minimisation are just a few of the many important considerations. To ensure the effective implementation of a national PROMs collection program, there is a need to design, develop and test a comprehensive approach that addresses all relevant issues.

In Australia, hip and knee replacements as well as shoulder procedures are the most common reasons for overnight hospital stays, after childbirth and rehabilitation.<sup>3</sup> Based on recent growth, the incidence of total knee replacement (TKR) and total hip replacement (THR) for osteoarthritis is estimated to rise by 276% and 208%, respectively, by 2030.<sup>4</sup> According to AOANJRR data, 65% of joint replacement procedures are undertaken within the private healthcare system, therefore, it is important that any national program aiming to improve value and efficiency includes both the public and private sectors.

# 3.Introduction

In mid-2016, the AOA and AOANJRR approached private health insurers, hospital operators and government health departments (state and commonwealth) to consider a collaborative arrangement that would enable PROMs to be collected for patients undergoing joint replacement and to incorporate these data into the AOANJRR database. These data would be available to the AOA and relevant stakeholders to drive change and improvement in outcomes for patients undergoing joint replacement.

Following consideration by the AOA Board, it was determined that the AOANJRR was uniquely placed because of its unrivalled expertise and its established professional, research, government and stakeholder networks to successfully implement a national PROMs collection program. The Board determined that the development of a proposal to assess the feasibility of collecting PROMs be progressed incorporating wider stakeholder involvement and support from not only the health insurance industry but the private hospital sector and state government health departments. In addition, to ensure clinician input and ownership of the program, the AOA Research Foundation was asked to become a formal contributor to the pilot.

A multi-stakeholder approach to funding the pilot study was implemented. An initial funding plan proposed that 25 sites nationally be recruited for participation. Due to over-subscription and high levels of interest, the pilot study commenced in September 2017 with 44 hospitals nationally. Government and private hospital sectors, small and larger hospitals, metropolitan and regional hospitals from all states/territories were represented. SAHMRI ICT Department was engaged to build the electronic data capture system now known as *RAPID*:

Real-time Automated Platform for Integrated Data capture

# 4. Aim(s) of the Study

This pilot project aimed to test the feasibility and stakeholder engagement for collecting PROMs and incorporating this with procedure data already collected by the AOANJRR.

The aim of collecting PROMs data was to aid improvement of the quality and cost-effectiveness of healthcare delivery at a national level. Before this can be achieved it is essential to establish that these data can be collected accurately, efficiently and affordably.

# 5. Study Objectives

The objectives of the pilot project were to:

- Understand barriers to and enablers for PROMs data collection with a view to informing a broader implementation plan
- Develop infrastructure to facilitate data collection e.g. a web-based portal to enable direct data entry
- Develop an electronic system that is user-friendly, easy for patients and hospital staff to access
- Test patient response rates and identify optimum data collection methods for PROMs
- Trial data matching processes between currently collected AOANJRR procedure data and PROMs data
- Develop reporting models for feedback to stakeholders (surgeons, patients, the public, participating institutions, project sponsors)
- Develop a platform for RNCT in joint replacement surgery
- Test patient and clinician engagement with the data

# 6.Implementation

# Phase One - Development

The development phase was anticipated to run for approximately 9 months and whilst 'go live' was delivered on time, due to the nature of this type of project, development has been ongoing throughout the pilot. To ensure the project continues to address emerging project and site needs and is expected to continue through a national rollout.

This phase included:

- Establishment of project governance
- Finalisation of funding and contracts
- Budget planning
- Recruitment
- Selection of PROMs
- Development of project documentation
- Identification and recruitment of hospitals
- Obtaining approvals
- Design, testing and deployment of an electronic PROMs data collection system (refer to Section 7 for further information)
- Training

#### **Project Governance**

The project governance was finalised by the end of October 2017. The following groups were established to provide project oversight:

- PROMs Pilot Steering Committee this committee met quarterly throughout the project to provide support and guidance for the project specifically around the achievement of project objectives. Terms of reference were drafted and finalised after the first meeting. The committee consisted of representatives from AOA, AOANJRR, SAHMRI, Commonwealth Department of Health, Australian Arthroplasty Society, as well as all project funders (private health funds, private hospital operators and state governments) and consumer representation.
- PROMs Pilot Working Group this group initially met fortnightly and changed to every four
  weeks once the project was implemented and running smoothly. The group provided expert
  advice around the design and implementation of the project and troubleshooting input for
  practical issues identified during the pilot. The membership consisted of AOANJRR and SAHMRI
  staff as well as external researchers and orthopaedic surgeons who have expertise in PROMs
  collection.

International PROMs Instrument Subgroup – the group was established at the beginning of the
project to give advice about which PROM instruments should be included in the project and
the pre and post-operative timing of their administration. The group consisted of national and
international experts in PROMs collection as well as Australian orthopaedic surgeons and
AOANJRR staff.

# **Funding and Contracts**

All funding and contract negotiations were finalised prior to July 2018. The AOA Board decided that a broad health sector stakeholder group should be engaged for this project as this would establish a wide leadership base to foster the use of value-based healthcare in Australia. The diversity of the funding group proved beneficial to the project as a diverse group of hospitals were engaged through stakeholder connections. This also provided the opportunity for seed funding to develop and implement the electronic data collection system and appropriate population-based analytics. Stakeholders participating in the project would benefit by being able to contribute to the development of the program with access to data based on criteria established by the AOA. A total of \$1,034,000 was secured to run the two-year pilot. The majority of the funding obtained was required to develop the electronic data capture system, RAPID, which was designed, built and tested by SAHMRI ICT.

# **Budget Planning**

The annualised budget was submitted to the Steering Committee at the end of November 2017. Budget updates were provided at each quarterly Steering Committee meeting.

The project delivered in line with the budget at all timepoints. The budget was in surplus at the end of the pilot period. This has allowed for the retention of key staff members and sites that are participating in the pilot are continuing to collect data whilst funding negotiations are underway for a national program.

#### **Staff Recruitment**

Recruitment for an AOANJRR Project Manager was finalised by October 2017. SAHMRI utilised a current ICT team member to commence the project and finalised recruitment for a second ICT team member in December 2017.

As the project developed and the scope increased, it was evident that additional resources were required. Additional SAHMRI team members dedicated to the project included a Senior Data Manager (0.8FTE) and a Statistician (0.6FTE).

#### **PROMs Instrument Selection**

The International PROMs Instrument Subgroup met five times between November 2017 and January 2018 to discuss which PROMs instruments and additional questions should be included in the pilot project. The following key considerations were taken into account by the group when making recommendations:

- Ease of data collection for patients
- Ease of score interpretability for stakeholders
- Ability to compare results with other datasets and published data both nationally and internationally
- Availability of population 'norms'
- Licensing requirements, flexibility to implement nationally
- Integrating with current PROMs collection methods already utilised by orthopaedic surgeons

The AOANJRR leveraged valuable relationships to engage national and international experts in PROMs collection to advise which PROMs instruments should be collected and which versions of these PROMs instruments were optimal. The final selection of PROMs meant that the AOANJRR could easily integrate with other PROMs collections already in place around the country and make international comparisons. The selected PROMs take patients approximately 10 to 12 minutes to complete ensuring that the project is easy to implement in a busy clinical setting.

# **Project Documentation**

The project plan was drafted by the AOANJRR Project Manager in collaboration with SAHMRI project staff. A draft was submitted to the working group at the end of October 2017 and the document was finalised on 10 November 2017. The plan was constantly reviewed throughout the project to ensure milestones were met.

The communication plan was drafted by the AOANJRR Project Manager and reviewed and approved by the PROMs Pilot Working Group and Steering Committee by mid-November 2017.

The planning documentation was critical to ensure the project stayed on track and milestones were met. Any modification of dates that were set at the beginning of the project required justification by project team members. Ethics committees reviewing the project requested only minimal changes to the project documentation.

#### **Patient Selection**

All patients scheduled for hip, knee and shoulder replacement procedures, both primary and revision procedures, were eligible. The analysis of the cohort was restricted to hip/knee/shoulder joint replacement procedures with a primary diagnosis of osteoarthritis (OA). For an explanation and further analysis of other diagnoses excluded from the pilot analyses, please refer to Section 10 (Outcomes).

# Identification and recruitment of hospitals

In order to test the system thoroughly, the pilot project aimed to include a broad cross-section of hospitals from:

- All Australian states
- Both public and private sector
- All sizes small (<100 beds), mid-range (100-499 beds) and large (>500 beds)
- Urban and regional areas

Hospitals were recruited where they:

- Volunteered to participate
- Were suggested by surgeons as possible participants
- Were approached by the AOANJRR and invited to participate based on successful previous collaborations or known data collection efforts

Initially, the scope of the project was to include 20 to 25 sites in the pilot. However, due to the enthusiasm of surgeons and sites wanting to participate, as well as the support received from state governments, 44 sites across Australia were recruited. A waiting list of hospitals was implemented due to the high levels of interest.

The process for recruitment and approval of hospitals included:

- The AOANJRR initially approached orthopaedic surgeons at nominated sites to ensure they were well informed about the project and happy to participate.
- The hospital executive was contacted, and endorsement was received

The initial communication with the orthopaedic surgeons and hospital executives was vital in successfully recruiting hospitals and obtaining ethics and governance approvals in a timely manner.

#### **Obtaining Approval**

The AOANJRR is a declared Federal Quality Assurance Activity which means that some hospitals collect Registry data as a quality assurance activity instead of the standard ethics approval process. As this is was a pilot project, the AOANJRR was required to obtain ethics approvals that would cover all participating sites.

Eight ethics approvals were obtained between January and March 2018 which covered all 44 participating sites. Where required, site governance approvals (n=26) were also obtained for participating sites. Ethics and governance approvals were progressed in a timely manner due to prior endorsement from orthopaedic surgeons and hospital executives.

However, gaining the required approvals remains a difficult process to navigate when implementing a national project despite significant work undertaken to streamline the ethics and governance process for research projects in Australia. Multiple ethics approvals are required to cover public hospitals in states that have not agreed to the National Mutual Acceptance scheme as well as for private hospitals. States use a mixture of online systems and manual processes to review and approve applications and requirements of the different committees are constantly changing. Whilst some governance offices seem to have streamlined processes others still take a considerable time to review applications and submit feedback which can delay project start dates.

Most delays caused by ethics and governance reviews are unavoidable. However, having a dedicated project manager to implemented rigorous systems to track applications and approvals was critical for obtaining approvals in a timely manner and keeping the pilot on track.

### **Training**

Hospital/site training commenced in July 2018. Many hospitals do not pre-operatively review patients in the same way, therefore the project implementation processes had to be tailored for each individual site. Key personnel were identified at each site to assist with patient recruitment. The AOANJRR Project Manager met with hospital staff face-to-face where possible. Face-to-face training was an effective tool for engaging site personnel and helped AOANJRR staff to gain an understanding of how patients were reviewed pre-operatively at each site. However, face-to-face training was not always possible due to the geographical diversity of sites. In these cases, utilising web conference software that enabled video as well as the ability to share the screen was a useful tool. RAPID demonstrations were provided, and user guides were developed and made available to sites. The site training continued through to November 2018 to service the needs of each hospital joining the PROMs project. The commencement of data collection was staged to accommodate requirements of staffing resources, hospital site readiness and ethics approvals.

#### Phase Two – Data Collection

Data collection for the pilot commenced in July 2018 and was originally scheduled to run for 12 months. The data collection was extended to run until the fourth quarter of 2019 to accommodate the sites that started later as part of the staged implementation. The second phase of the project included:

- Development of data reports for monitoring project status
- Data collection
- Data management
- Development of data reports for stakeholders and data linkage
- Further development, testing and deployment of the electronic system, RAPID

#### Data Reports

From July 2018, AOANJRR and SAHMRI teams developed data reports for the PROMs Working Group and Steering Committee. The reports were under constant review during the pilot.

The PROMs Working Group received a project status report and data report at each meeting. The status report included updates on meetings held, approvals obtained, and the status of site data collection, as well as activities undertaken by the AOANJRR Project Manager, SAHMRI ICT team and data managers. The data report developed for the Working Group included information about patient recruitment and PROMs collection as well as some basic patient demographic information. Sites were monitored for patient recruitment and PROMs completion so that any issues could be identified in a timely manner. Patients requiring phone call follow-up were also tracked to determine the benefits of including this service for follow-up.

A quarterly report was developed for the Steering Committee. Once data collection commenced, information about patient recruitment and PROMs collection was included in the report.

#### **Data Collection**

Data collection commenced in July 2018 at five sites. The PROMs rollout was staggered with the final sites commencing in November 2018. All patients scheduled for hip, knee and shoulder replacement procedures, both primary and revision procedures, were eligible.

Throughout the data collection phase, the AOANJRR staff kept in close contact with orthopaedic surgeons and personnel assisting with patient registration to ensure sites were supported and were kept up-to-date with the progress of the pilot. A data summary was sent to sites regularly, so personnel were aware of how their site was tracking against the national data collection. If a site was identified with a high patient withdrawal rate, low registration rate, or a high phone call follow-up rate, the site was contacted and additional support measures put in place so processes could be reviewed and adjusted.

Patient registration into the RAPID system was reviewed regularly at each site. For patient registration rates to be determined, it was necessary for patients' joint procedure data to be entered into the AOANJRR database to be matched to the patient information provided in the RAPID (PROMs) system. This involved comparing the patient/procedure information between the two databases. Clerical review was undertaken by the Senior Data Manager to ensure relevant joint procedure information was matched to the RAPID procedure information. SAHMRI data management produced reports on patient registration and procedure registration rates at each hospital.

All sites were contacted in early 2019 to discuss their registration rates and process of patient registration into *RAPID*. Through this communication, some sites implemented changes to their processes to try and improve their registrations into the *RAPID* system. This also highlighted any modifiable barriers to patient identification and registration at some sites.

It was identified early in the Pilot that there was no standard way for hospitals/sites to review patients pre-operatively as there were many different staff involved in the recruitment and registration of patients. Staff turnover was identified as an issue impacting patient recruitment. A number of times, AOANJRR staff were unaware that a hospital staff member had left a site until a decrease in patient registration was identified. In these instances, it was identified that key project details were not communicated or understood when staff handed over the task to new personnel.

#### **Data Management and Statistics**

A project-specific data manager and statistician were employed by SAHMRI when data collection commenced. Tasks undertaken by the project data manager and statistician throughout the data collection phase included:

- Ongoing system testing
- Development of a data dictionary and system user manual
- Development of data management Standard Operating Procedures (SOPs)
- Implementation of data cleaning processes to ensure data accuracy
- Modification, development and enhancement of database queries
- Management of matching patient details in the AOANJRR database to the RAPID database
- Management of data issues e.g. duplicate records
- Review of externally collected export templates, converting the file into RAPID data format and uploading into the system
- Descriptive ad hoc data reports for the hospital sites and Project Manager
- Weekly reports on the PROMs data
- Contribution to the design and further development of the data collection system
- Process improvements to facilitate an improved data collection rate of PROMs at all time points

# **Data Quality Process**

Each week, a procedure matching activity was undertaken to match the AOANJRR procedure forms to the PROMs registered procedures. Discrepancies such as hospital location, surgeon name, joint type and side, and patient contact details were identified. Data were rectified in *RAPID* following validation from the delegated contact person at the relevant site.

There were three hospitals that provided their data electronically every two weeks. Prior to uploading the data, the file was reviewed for missing fields and errors. All data quality issues were verified by the hospital and corrected before importing the data into RAPID.

# 7. Development of Software

### System design

The AOANJRR worked closely with SAHMRI on the design and build of the *RAPID* system. Important considerations in this project were to develop a system that was efficient, cost-effective and scalable, which would require minimal input of time and resources from hospital and administrative staff and be user-friendly for patients. The system was designed to be flexible and work within multiple environments.

The system requirements included:

- User-friendly for an ageing cohort
  - Clear print with minimal instructions
  - o One-touch easy use
  - Limited scrolling
- · Access via smartphone, tablet or computer
- Access via hospital or clinic Wi-Fi or sim card connection
- Patient self-registration at home or hospital pre-admission clinics
- Hospital administrator registration of patients prior to or during pre-admission clinics
- Direct data entry by patients via smartphone, tablet or computer at home or hospital
- Hospital bulk entry of patient responses

The first software release went live in July 2018 which enabled users and hospitals to be set up and patient registration and completion of PROMs questionnaires to be undertaken on desktop computers, laptops, smartphones and tablets.

# Features of the system included:

#### Collection of Electronic Consent from Patients

Patients registered themselves or were registered by approved users. Once consented, patients logged in to the system and accessed a PDF of the consent statements for the study.

# Reminder System for the Completion of PROMs

Automated reminders were sent to patients to complete their PROMs. The system allowed for a set number of reminders to be sent pre and post-operatively by email or SMS, depending on the contact details provided by the patient during registration. Patients who had not completed their PROMs after 3 automated reminders, appeared on a list for phone call follow-up. The team undertaking the phone calls entered patients' responses directly into RAPID.

#### Collection of Data

The following instruments/questions were included in the pilot and could be found in Table 14 and Table 15:

- EQ-5D-5L and EQ VAS
- Oxford Hip, Knee, Shoulder Scores
- 12 item HOOS and KOOS (completion of these instruments was optional)
- Pain scales (0-10) for affected joint, lower back (hip, knee), neck (shoulder)
- Three expectation questions (pre-operative)
- Two co-morbidity questions (pre-operative)
- One question asking patients if they wanted to share their responses with their surgeon (pre-operatively and post-operatively)
- One satisfaction question (post-operative)
- One change question (post-operative)

Responses to questionnaires (pre-operatively and post-operatively) can be entered into RAPID either:

- Directly by patients
- By approved personnel
- By upload of bulk responses collected externally

RAPID allows for additional questions and time points to be added for other studies (e.g. Registry Nested Clinical Trials).

# **Dashboard Development**

Extensive work on the development of dashboards was undertaken during the project. Numerous mock-ups of pre and post-operative data display options were provided for consideration by the AOANJRR and PROMs Pilot Working Groups. The final dashboards used to display the PROMs pilot pre and post-operative data are described as follows:

#### **Patient Dashboard**

Patients could view their responses to completed questionnaires. They could see how their responses compared pre and post-operatively to other patients undergoing similar procedures and how they progressed after their procedure. Graphs could be selected to display all patients or only those of the same age and/or gender as the patient.

#### **Surgeon Dashboard**

Surgeons had access to individual patient responses via the surgeon portal, but only when the patient agreed to share their responses. These data could also be downloaded in an excel file. Surgeons could view recruitment data and PROMs collections either nationally, or by filtering for their own procedures. Displays included a breakdown by joint type, gender and age. Surgeons could also view a real-time display of how their patients progressed after surgery, compared to the national average for each joint type. Further filtering for gender, age and procedure type (primary/revision) was also available.

#### **Hospital Dashboard**

Hospitals could view patient registration data and aggregated PROMs outcome data either nationally or by filtering for their hospital. Displays included a breakdown by joint type, gender and age. Hospitals could also view real-time displays of how their patients progressed after surgery compared to national averages for each joint type. Further filtering for gender, age and procedure type (primary/revision) was also available.

#### Stakeholder Dashboard

Stakeholders included commonwealth and state government, hospital groups and health insurers. Stakeholders could view data on national recruitment and national PROMs collections. Displays included a breakdown by joint type and age. Stakeholders could also view real-time displays of national averages showing how patients progressed after surgery for each joint type. Further filtering for gender, age and procedure type (primary/revision) was also available.

## Integration of PROMs Data Collected by Third Parties

The Registry team reviewed and provided advice on the development of standardised templates for use by external sites to send PROMs data files to be imported into RAPID. Prior to upload and integration of the data into RAPID, the data management team conducted a thorough manual review of the data file. Discrepancies were queried and rectified.

#### **Effectiveness**

Creating a detailed software design document prior to commencing the build of *RAPID* was vital to ensure a high-quality system was deployed within the agreed timeframe. Although the project was scoped prior to commencement, additional features were added as deemed necessary by the project team. Deploying *RAPID* in a staged manner throughout the project enabled ongoing agile development.

The flexibility of RAPID proved highly important in reducing the resource impact on hospitals. Visits by AOANJRR project staff to hospitals and teleconferences during the rollout stage provided valuable insight into hospital processes and guided modifications to the system during the pilot. Modifications included the development of a time delay option and resumable data collection. This meant that patients who had commenced their PROMs but were called away to an appointment in a busy preadmission clinic could return and complete the PROMs with no loss of data. Enhancements such as this, based on feedback from hospital staff, proved very important in collecting data successfully. The resumable data collection function was able to be implemented within a matter of weeks of the identified need and request for this function.

Feedback provided by hospital administrators highlighted the efficiency of the patient registration and data collection system, indicating that it took 20-30 seconds to register a patient and 10-12 minutes for patients to complete their PROMs. Patient feedback indicated the system was easy to understand and use.

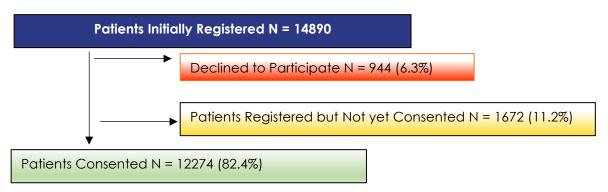
# 8. Assessment of Recruitment

# Registration of Patients and PROMs Completion Rates

A key goal in developing RAPID was to provide an uncomplicated user-friendly interface for hospital staff to register patients and for patients to easily register themselves. The high percentage of patient registration, and pre and post-operative PROMs completion (Figures 1-3), demonstrate the ease with which patients can be managed within the RAPID system.

In summary, almost 15,000 patients were initially registered into the *RAPID* System (Figure 1). Of these patients, 1672 (11.2%) had registered but had not yet consented at the time of dataset closure for this report. Of the patients who consented, pre-operative PROMs collection was complete for 97.8% of procedures (Figure 2). At the end of the pilot period, there were 5,293 post-operative PROMs collections due, of which 79.0% were completed (Figure 3).

Figure 1 Patients Registered and Consented into the RAPID system\*



<sup>\*</sup>Note: There were 884 patients (7.2%) who consented for 2 procedures and 3 patients (0.02%) who consented for 3 procedures. In total, there were 13164 consented procedures.

Figure 2 Pre-Operative PROMs Completion

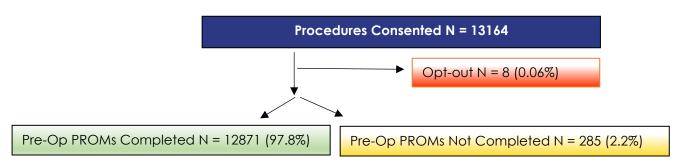
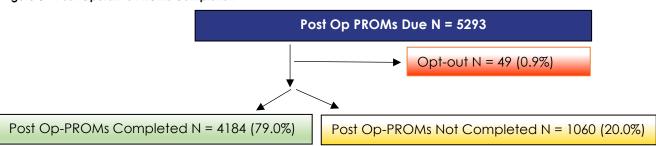


Figure 3 Post-Operative PROMs Completion



# **Registration Rates by Hospital**

When matching the RAPID registration data with Registry collected procedure data, it was evident that there was considerable variability between hospitals in terms of patient registration (Figure 4). The variation ranged from 10.0% to more than 90.0% of patients registering for PROMS. Hospitals commenced the pilot in a staggered manner which may account for some of the variability between hospitals.

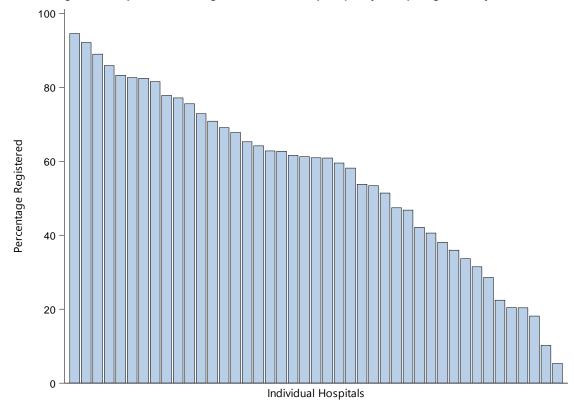


Figure 4 Percentage of Primary Procedures Registered for PROMs by Hospital (Primary Diagnosis OA)

When investigating the variability in registration rates between hospitals, it was noted that over the course of the Pilot study, the rate of PROMs registrations improved (Table 1). After 12 months, 60.2% of procedures undertaken at PROMs Pilot hospitals were registered in the RAPID system.

Table 1 Primary Procedures Registered for PROMs which were matched to Registry Procedures (Primary Diagnosis OA)

Pilot Study Timepoint	N Registry Procedures	N (%) Procedures Registered for PROMs
0 - 3 Months	5275	2366 (44.9)
3 - 6 Months	5008	2516 (50.2)
6 - 9 Months	5052	2706 (53.6)
9 - 12 Months	3631	2175 (59.9)
12+ Months	733	441 (60.2)

# Registration Rates by State/Territory

A State/Territory based breakdown of patient registration for pre and post-operative PROMs collection is shown in Tables 2-4. Patient consent rates varied from 74.3% in South Australia to 90.0% in Victoria (Table 2). The pre-operative PROMs completion rate across States/Territory was consistently close to 100% (Table 3). Post-operative PROMs completion rates across the States/Territory ranged from 69.1% and 85.7% (Table 4). There was an improvement in registration over the duration of the pilot for nearly all States/Territory (Figure 5).

Table 2 Patient Registration by State/Territory

State/Territory	N Patients Registered	N (%) Patients Declined (%)	N (%) Patients Consented
Australian Capital Territory	520	33 (6.3)	438 (84.2)
New South Wales	5973	385 (6.4)	4924 (82.4)
Queensland	2101	128 (6.1)	1760 (83.8)
South Australia	2584	236 (9.1)	1920 (74.3)
Tasmania	1304	75 (5.8)	1092 (83.7)
Victoria	1484	42 (2.8)	1335 (90.0)
Western Australia	924	45 (4.9)	805 (87.1)
TOTAL	14890	944 (6.3)	12274 (82.4)

Table 3 Pre-Op PROMs Completion Rates by State/Territory

State/Territory	N Procedures Initially Registered	N Procedures Currently Registered	N (%) Procedures Consented	N (%) Pre-Op PROMs Complete
Australian Capital Territory	553	520	470 (85.0)	460 (97.9)
New South Wales	6561	6163	5443 (83.0)	5318 (97.7)
Queensland	2242	2111	1882 (84.0)	1846 (98.1)
South Australia	2655	2418	1981 (74.6)	1899 (95.9)
Tasmania	1364	1288	1147 (84.1)	1135 (99.0)
Victoria	1552	1510	1401 (90.3)	1387 (99.0)
Western Australia	961	916	840 (87.4)	826 (98.3)
TOTAL	15888	14926	13164 (82.9)	12871 (97.8)

Table 4 Post-Op PROMs Completion Rates by State/Territory

State/Territory	N 7 Months Post Procedure	N (%) Post Op PROMs Complete
Australian Capital Territory	84	72 (85.7)
New South Wales	2171	1630 (75.1)
Queensland	809	662 (81.8)
South Australia	995	845 (84.9)
Tasmania	539	457 (84.8)
Victoria	415	330 (79.5)
Western Australia	280	188 (67.1)
TOTAL	5293	4184 (79.0)

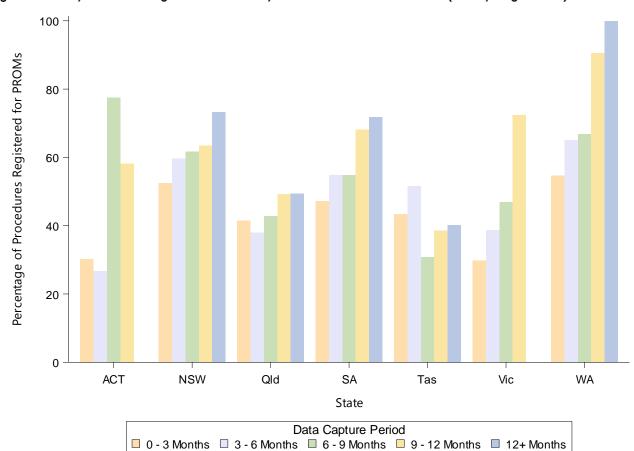


Figure 5 Primary Procedures Registered for PROMs by Data Collection Period and State (Primary Diagnosis OA)

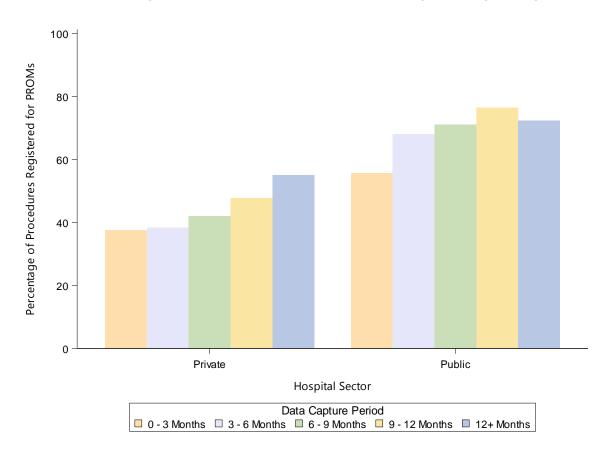
## Registration Rates by Hospital Sector: Public/Private System

There was improvement in registration over the duration of the pilot for both public and private hospital sectors (Table 5 and Figure 6). Registrations were higher in public hospitals (67.3%) compared to private hospitals (41.5%). The registration rates may be affected by differing pre-operative consulting practices of the two sectors. In addition, not all surgeons contributed to the PROMs pilot within the private hospital sector.

Table 5 Primary Procedures Registered for PROMS by Hospital Sector: Public/Private (Primary Diagnosis OA)

	Private Hospitals N		Public Hospitals		
				N .	
Piot Study	N Dogisty / Dysos duyes	Procedures Registered	N Dogisty Propodures	Procedures	
Timepoint 0 - 3 Months	Registry Procedures 3171	for PROMs 1193 (37.6)	Registry Procedures 2104	Registered for PROMs 1173 (55.8)	
3 - 6 Months	3009	1156 (38.4)	1999	1360 (68.0)	
6 - 9 Months	3046	1279 (42.0)	2006	, ,	
		,		1427 (71.1)	
9 - 12 Months	2092	997 (47.7)	1539	1178 (76.5)	
12+ Months	519	286 (55.1)	214	155 (72.4)	
TOTAL	11837	4911 (41.5)	7862	5293 (67.3)	

Figure 6 Primary Procedures Registered for PROMs by Hospital Sector: Public/Private (Primary Diagnosis OA)



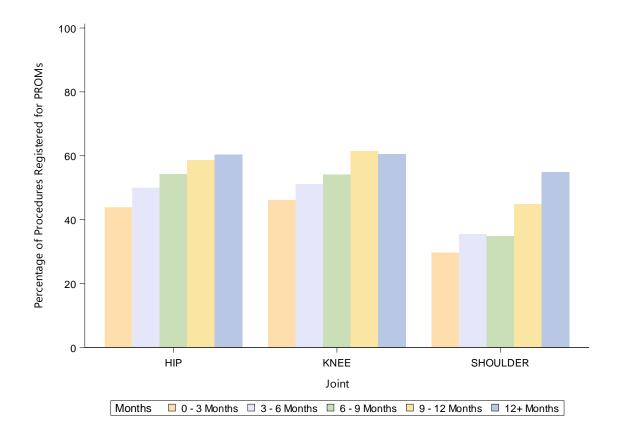
# Registration Rates by Joint Type

There was improvement in patient registration for all joints (hip, knee and shoulder) over the course of the pilot (Table 6 and Figure 7). There was a minor decrease in registration rates for shoulder joints between 6-9 months (n = 53, 34.9%) and 9-12 months (n = 52, 44.8%).

Table 6 Primary Procedures Registered for PROMs by Joint (Primary Diagnosis OA)

	Hi	ps N (%)	Kı	nees	Sho	ulders
Pilot Study Timepoint	N Registry Procedures	N (%) Procedures Registered for PROMs	N Registry Procedures	N (%) Procedures Registered for PROMs	N Registry Procedures	N (%) Procedures Registered for PROMs
0 - 3 Months	1995	876 (43.9)	3142	1449 (46.1)	138	41 (29.7)
3 - 6 Months	1834	917 (50.0)	3019	1544 (51.1)	155	55 (35.5)
6 - 9 Months	1930	1046 (54.2)	2970	1607 (54.1)	152	53 (34.9)
9 - 12 Months	1300	762 (58.6)	2215	1361 (61.4)	116	52 (44.8)
12+ Months	237	143 (60.3)	465	281 (60.4)	31	17 (54.8)
TOTAL	7296	3744 (51.3)	11811	6242 (52.8)	592	218 (36.8)

Figure 7 Percentage of Primary Procedures Registered for PROMs by Joint (Primary Diagnosis OA)



# **Patient Self Registration**

There was variation in registration methods between hospitals (Figure 8). The highest proportion of patients registered by staff was 89.0%. Patient self-registration ranged from 0% up to 82.4% of procedures undertaken.

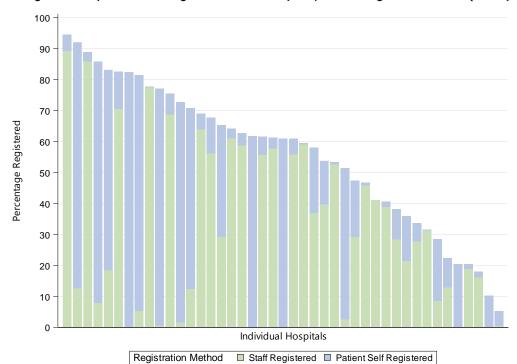


Figure 8 Percentage of Primary Procedures Registered for PROMs by Hospital and Registration Method (Primary Diagnosis OA)

# Phone cohort versus online responses

Despite potentially being cost prohibitive in a national program, phone call follow-up was included in the pilot so that a determination could be made to see if the cohort who required a phone call were different to those who responded to automated reminders. The Arthroplasty Clinical Outcomes Registry National (ACORN) group were contracted to provide follow-up phone calls where patients did not respond to the automated reminders.

Phone call follow-up was provided as a prompt for patients to complete their questions online. Alternatively, patients were able to complete the questions with assistance during the call.

Assistance to complete PROMs was provided via other support (help from a family member) in 23.0% of cases compared with ACORN calling the patient (10.3%). This provided the PROMs Working Group with the data to evaluate the effectiveness and value of phone call follow-up. The Working Group determined the response rate did not indicate value and phone call follow-up ended for preoperative PROMs on 27th May 2019.

Post-operative phone call follow-up continued until the end of the pilot. The cost of phone call follow-up for the duration of the pilot was almost \$65,000. Approximately 15% of AOANJRR hospitals participated in the pilot therefore the cost of phone call follow-up in a national rollout is estimated to be at least \$450,000 annually. Consequently, the Working Group determined that this expense was not sustainable in a national program and other strategies would be implemented to maintain and increase completion rates.

Outcome data for phone-call assistance vs no assistance is available in Appendix 1. Completion rates for phone call assistance versus no call are available in Table 7.

Table 7 Completion rates for phone call assistance versus no call

Pre-operative N (%)		Post-operative N (%)	
No call	With call	No call	With call
10543 (81.9)	2328 (18.1)	3067 (64.2)	1712 (35.8)

# 9. Stakeholder Survey

#### Introduction

Stakeholders were encouraged to informally provide feedback on the electronic collection of PROMs throughout the pilot study. However, specific feedback was sought from surgeons and site administrators who were responsible for PROMs recruitment, engagement and education to understand potential barriers to collecting PROMs data and identify practices that promoted participation. These key stakeholders from each hospital were invited to respond to a survey to determine the important factors for a successful national roll-out of PROMs collection.

For the purposes of this report, 'site administrators' refers to the collective group of nursing, administration and research staff, engaged to recruit, register and educate PROMs patients across a variety of clinical settings, for the PROMs Pilot.

#### Method

Separate surveys were developed for surgeons and site administrators based on stakeholder feedback collated at the commencement of the Pilot that was further clarified and refined during subsequent working group meetings. The surveys were finalised through consultation with an experienced mixed-methods researcher, an orthopaedic clinician and AOANJRR project staff.

Invitations to complete the survey were circulated via email to all active registered users in both stakeholder groups (304 surgeons and 264 hospital administrators) across the 44 pilot sites. The surveys were voluntary and were conducted using a web-based portal (SurveyMonkey) from the 22/11/2019 to the 13/12/2019. Stakeholders could respond anonymously.

Participants were asked questions regarding:

- their respective role in implementing the PROMs Pilot
- functionality of the RAPID system for their requirements
- the perceived value of the collection of PROMs in the wider healthcare context

Copies of the surveys are attached as Appendix 2.

Formal patient stakeholder feedback was not undertaken at this time; however, a comprehensive engagement and analysis process is planned with consumers following completion of the Pilot. Patient engagement was informally ascertained by the volume of patients who successfully registered and recorded PROMs in RAPID (as detailed in Section 8 – Assessment of Recruitment).

# **Findings**

#### Response rates

304 surgeons were invited to participate in the survey:

- 70 (23.0%) surgeons completed the survey
- From 7 Australian states and territories

264 hospital administrators were invited to participate in the survey:

- 50 (18.9%) completed the survey
- From 7 Australian states and territories

# Surgeon specific questions

The majority of surgeons indicated their PROMs patients were registered in a private hospital/clinic setting (54.3%). Surgeons had heard about the PROMs pilot directly from the Registry (n=47, 71.2%) or from other colleagues (n=14, 21.2%). Only 10 (15.9%) surgeons explained PROMs data collection to their patients, with 44 (69.8%) surgeons indicating that it was 'someone else's role' to communicate the details of the project.

Table 8 Surgeons were asked if they advised their patients to complete the PROMs survey

N (%)	N (%)	N (%)	
Always	Sometimes	Never	
19 (29.2)	25 (38.5)	21 (32.3)	

For a national rollout of PROMs data collection, it may be helpful to have more surgeons advising their patients about PROMs. This advice could be incorporated into the initial information package sent to sites and surgeons.

A key study objective was the development of dashboard reporting, in order to deliver the results to stakeholders (surgeons, patients, participating institutions and project sponsors) in real time. The stakeholder survey results indicate that only 46.0% of surgeons who responded had accessed their dashboard; a further 16% were unaware that they had a dashboard. Of those who had accessed their dashboard, only 27.5% indicated that they reviewed individual patient results, while 96.5% reviewed aggregated results for their patient group. None of the surgeons who responded had discussed the responses provided with their patients.

Throughout the pilot study, site investigators were provided with reports on the registration of patients into RAPID from their site. The reports included the number of patients registered, patient completion of PROMs (pre and post-operative completion rates) and data on patient registration rates (after being matched with Registry operative forms). Only 41.3% of surgeons indicated that they had seen these reports. A 10-point Likert Scale was used to determine how useful the reports were (1 = 'not helpful' to 10 = 'very helpful'). The average response from surgeons who had seen the reports was 7 out of 10.

## Administrator specific questions

To gain a better understanding of the patient registration process, administrators were asked about the setting in which patients were registered and the hospital role of the person who coordinated the PROMs registration process.

- The majority who responded worked in public hospitals (60%)
- Pre-admission clinic was the most common site for registration for both site administrators (59.6%) and surgeons (63.4%). A further 25% were registered in a mix of preadmission clinic and surgeon rooms
- Registration was usually undertaken using a combination of nurse, administrator, surgeon and patient self-registration. Administrators were most often involved in registering patients (74.5%), followed by nurses (46.8%) and patients (40.4%). Surgeons were rarely involved in registering patients

Of those hospital administrators responding to the survey, 71.7% reported being responsible for educating patients regarding the PROMs project, 13.0% indicated that they only provided the education cards to patients. These results clearly indicate that site administrator involvement is critical to patient registration.

To aid in the collection of PROMs data iPads were offered to all sites. It was anticipated that this would mitigate any potential barriers to patients accessing the internet and encourage participation. A total of 39 (86.7%) sites accepted this offer. Site staff were asked three optional questions related to the use of iPads (26).

#### Table 9 iPads were provided to patients for self-registration

N (%)	N (%)	N (%)	
Always	Some of the time	Never	
13 (28.2)	15 (32.6)	11 (23.9)	

#### Table 10 Patients were provided with an iPad to complete their survey questions

N (%)	N (%)	N (%)
All of the time	Sometimes	Never
9 (20.9)	19 (44.2)	8 (18.6)

Table 11 What proportion of patients required assistance to complete their PROMs using iPads?

N (%)	N (%)	N (%)	N (%)
Between 76% and 100%	Between 26% and 75%	Less than 25%	No assistance
6 (14.3)	15 (35.7)	15 (11.9)	5 (11.9)

When site administrators were asked how much time per week was spent registering PROMs patients, 80% reported spending less than 1 hour per week, 20% reported less than 15 minutes, 17.5% spent between 1 and 4 hours, and 2.5% spent more than 4 hours per week. The size of the hospital, staff availability and number of procedures performed were potential factors which influenced the time required to register patients. However, these factors were not explored in the survey.

Approximately 74% of site administrators had at least one patient decline to participate prior to being registered. Site administrators identified that the two main concerns expressed by patients when declining to participate were not having access to a phone or computer and patients not seeing the value of PROMs. To a lesser degree concerns about security and the lack of assistance to complete the survey were indicated.

The survey indicated that just over 50% of site administrators had taken over the role registering patients during the pilot due to staff changes. Of these, 62.5% indicated their staff induction included education about PROMs, while 30.0% were not sure and 7.5% indicated that induction processes did not include PROMs information.

## Sample responses from the Administrator survey

What changes could the registry implement to make it easier?

I think either the movement of the survey to the Surgeon's rooms to complete or must be a part of the pre-admission process for their rooms. Need for support staff/person for individual practices/surgeons' rooms as limited access to patients at preadmissions clinics. Need for Registry to contact surgeons personally regarding their involvement and assisting their staff and finding options to allow easier implementation in their practice.

There needs to be .... a refusal box as at present there isn't, and it implies staff are not registering patients.

One of the nurses registers every patient who is booked into preadmission. This is to make sure that all patients are registered. If we left it up to the patients to register, you would get a lower response rate

Completion of the survey was initially assigned to the Pre-Admission Clinic. However due to patient and clinic non-compliance results, the Admissions Office changed the process and became responsible to the collection of data.

No big changes but I do find my more elderly patients like to sit near my desk and do the survey so they can ask some questions.

## Do you have any additional feedback?

Even though we collect our own PROMs data, I find the export process to the AOANJRR useful in ensuring our own data quality Funding would be beneficial

This is an additional burden on clinicians and admin staff to collect this data. It is repetitive and time consuming and does not give information about how to improve our service so does not benefit our service. It only gives information about whether the surgery had made a difference.

I have had many patients comment that when they receive the text from the Registry, they are afraid it's a scam. Also, as with any survey, sometimes the answers the patients wish to give are more complex than the response options.

# Questions common to surgeons and site administrators

Participating surgeons and site administrators were asked if they saw value in the collection of PROMs data. It was clear that both site administrators and surgeons saw the value of collecting this data, 97.5% of site administrators and 95.0% of surgeons indicated they thought collecting PROMs for joint replacement was important.

When asked the intended purpose of PROMs data by their hospital or practice, the surgeon and site administrator responses were similar.

Table 12 Surgeon and Site Administrator use of PROMs data

Responses	Surgeon	Site Administrator
Monitor patient outcomes	85.2%	92.5%
Quality improvement	67.2%	72.5%
Benchmarking against other national data	55.7%	67.5%
Research	45.7%	50%
Patient education	36.0%	47.5%
Staff education	Not asked	47.5%

Over 50% of site administrators and 38.1% surgeons thought that patients understood the value of collecting PROMs. Site administrators and surgeons were both able to add comments to explain why they thought patients valued PROMs collection. These comments centred around patients wanting improved outcomes, to help others in the future, wanting their surgeons to see their results and that patients were generally very happy to assist.

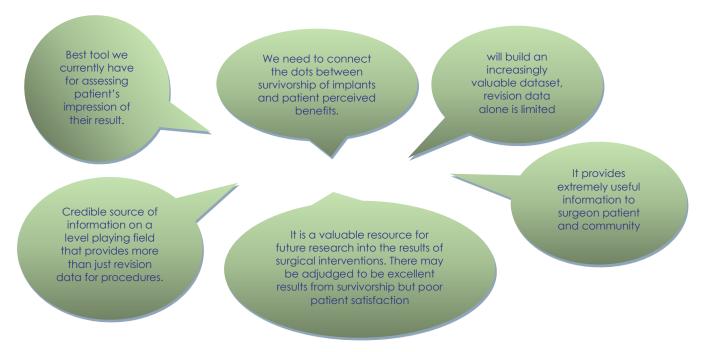
When site administrators and surgeons were asked if they thought that the collection of PROMs data should continue, there was a positive response with more than 95.0% of site administrators and 65.9% of surgeons indicating that PROMs data collection should continue.

# Why should the AOANJRR PROMs continue?

#### Site Administrators:



#### Surgeons:



# **Summary**

The results of the survey have established where and how patients are registered and have demonstrated that the use of technology improves registration and data collection efficiency. The responses indicate clear support from surgeons and administrators for its continuance, and that iPads were useful in improving registration and data collection efficiency.

As financial resources were not provided to support participating sites an objective was to ensure there was a low resource burden on staff. Despite not being funded site staff were critical to the success of this project; to maintain ongoing engagement, dedicated training and support initiatives will be an important feature of the national rollout.

# 10. Data Outcomes

The PROMs pilot project was designed to collect outcome data from primary joint replacement procedures for hip, knee and shoulder. The majority of procedures (90.4%) were for a primary procedure with a main diagnosis of osteoarthritis (OA) (Table 13 and Table 14). Hospitals were advised that PROMs collection was also available for other diagnoses as well as revision procedures. The remaining 9.6% of procedures collected were diagnoses including (but not restricted) to osteonecrosis, rheumatoid/inflammatory arthritis, shoulder rotator cuff arthropathy, developmental dysplasia and fractured neck of femur.

The capacity to register patients into the *RAPID* system and collect pre-operative PROMs is not always possible in an emergency/trauma situation. For consistency, the outcome data presented in this report will only include primary procedures with a main diagnosis of OA.

Table 13 Initial Diagnosis of Patients Registered into the RAPID System

	Н	lip	Kn	ee	Shou	lder	TOT	AL
Procedure Type	N	%	N	%	N	%	N	%
Primary OA	3766	88.4	6287	93.8	218	55.2	10271	90.4
Primary Other Diagnosis	301	7.1	126	1.9	149	37.7	576	5.1
Revision	195	4.6	286	4.3	28	7.1	509	4.5
TOTAL	4262	100.0	6699	100.0	395	100.0	11356	100.0

As established earlier, PROMs are defined as standardised, validated questionnaires (or instruments) completed by patients. Table 14 and 15 outline the instruments that were available for patient completion through the *RAPID* system. In addition to these instruments, patients were asked questions about pain, satisfaction, change and expectations. The instruments and questions were available for patient completion pre-operatively (ideally within 1 month of surgery) and at 6 months (between 5 and 7 months) post-operatively.

The results of the PROMs instruments (except for those regarding back and neck pain) are available in the following three sections by joint type: Hip: Total Conventional Hip Replacement; Knee: Total Knee Replacement, and; Shoulder: Total Reverse Shoulder Replacement.

Table 14 Instruments collected at the PROMs collection time points

PROMs Instruments				
Hip	Knee	Shoulder		
EQ-5D-5L (including VAS)	EQ-5D-5L (including VAS)	EQ-5D-5L (including VAS)		
Oxford Hip Score	Oxford Knee Score	Oxford Shoulder Score		
HOOS-12 (optional completion)	KOOS-12 (optional completion)			

Table 15 Questions asked at the PROMs

Question	Answers/Options		
Pain Questions			
All Joints -Joint specific pain (over the last 7 days)	scale 0 (no pain at all) -10 (worst pain imaginable)		
Hip and Knee - Lower back pain (over the last 7 days)	scale 0 (no pain at all) -10 (worst pain imaginable)		
Shoulder – Neck pain (over the last 7 days)	scale 0 -10 (no pain at all) -10 (worst pain imaginable)		
Satisfaction Questions			
All Joints			
Patients selected one option which best described their satisfaction with their procedure	5 option Likert scale from 'very dissatisfied' to 'very satisfied'		
Joint Change Questions			
All Joints			
Patients selected one option which best described their perceived change with their knee since their joint replacement operation	5 option Likert scale from 'much better' to 'much worse'		
Expectation Questions			
All Joints			
For pain, mobility and health, patients were asked their expectations in 6 months' time at the preoperative collection point. At the post-operative collection, patients rated their perceptions based on that day.	Pain: scale 0 -10 (no pain at all) -10 (worst pain imaginable) Mobility: 5 option Likert scale from 'no problems' to 'severe problems' Health: scale 0 (worst imaginable health – 100 (best imaginable health)		

# **Total Conventional Hip Replacement Outcomes**

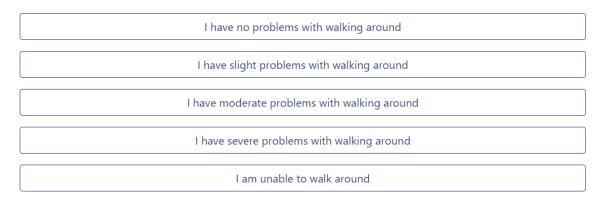
## **EQ-5D-5L & VAS**

The EQ-5D-5L is a standardised instrument for measuring overall health status. The descriptive system is comprised of 5 dimensions: mobility, personal care, usual activities, pain/discomfort and anxiety/depression. VAS is a validated measure on a scale from 0 (the worst health you can imagine) to 100 (the best health you can imagine).

#### **EQ-5D-5L** mobility

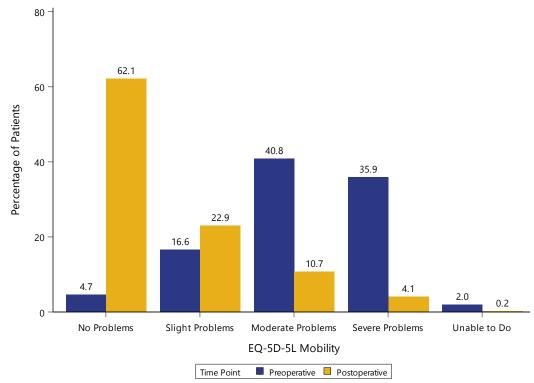
For the EQ-5D-5L mobility dimension, patients were asked to choose the statement most relevant to their current experience of mobility:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 4.7% of patients reported that they had 'no problems' with mobility compared to 62.1% of patients post-operatively (Figure 9).

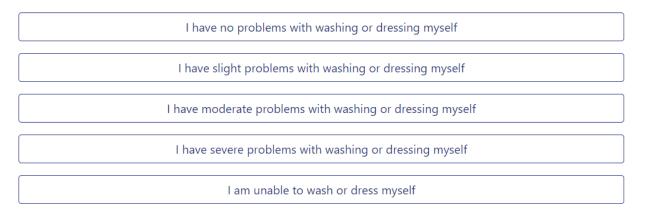
Figure 9 Mobility of Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



#### **EQ-5D-5L** personal care

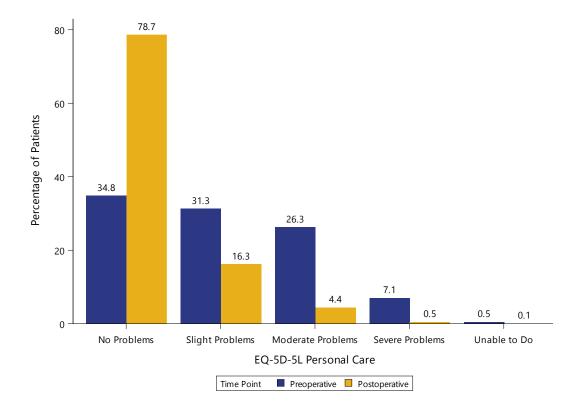
For this dimension, patients were asked to select the statement most relevant to their current experience of personal care:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 34.8% of patients reported that they had 'no problems' with personal care, compared with 78.7% of patients post-operatively (Figure 10).

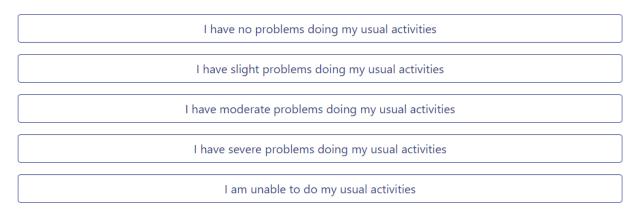
Figure 10 Personal Care of Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



## **EQ-5D-5L** usual activities

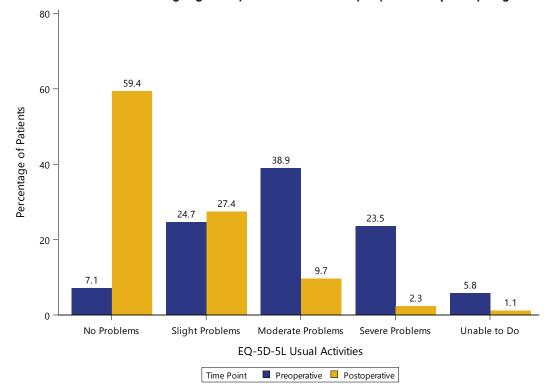
For the EQ-5D-5L usual activities dimension, patients were asked to select the statement most relevant to their current ability to undertake their usual activities:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 7.1% of patient reported that they had 'no problems' with usual activities, compared with 59.4% of patients post-operatively (Figure 11).

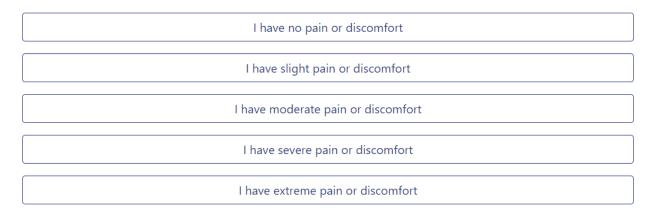
Figure 11 Usual Activities of Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



## EQ-5D-5L pain/discomfort

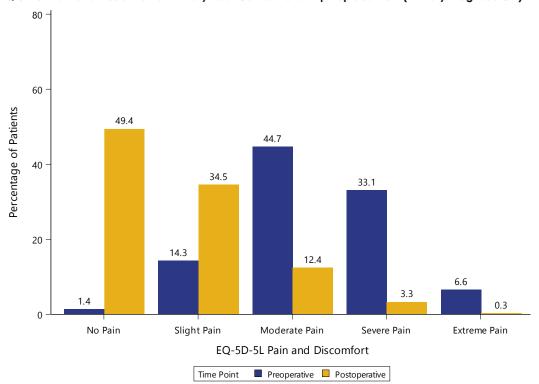
For the EQ-5D-5L pain/discomfort dimension, patients were asked to select the statement most relevant to their current experience of pain/discomfort:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 1.4% of patient reported that they had 'no pain' compared with 49.4% of patients post-operatively (Figure 12).

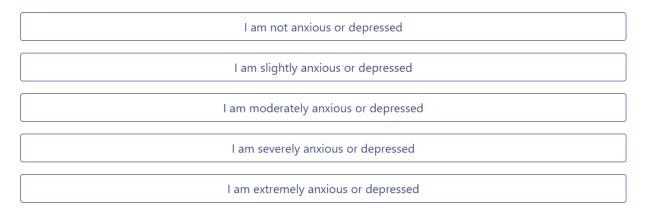
Figure 12 EQ-5D-5L Pain and Discomfort of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



#### EQ-5D-5L anxiety/depression

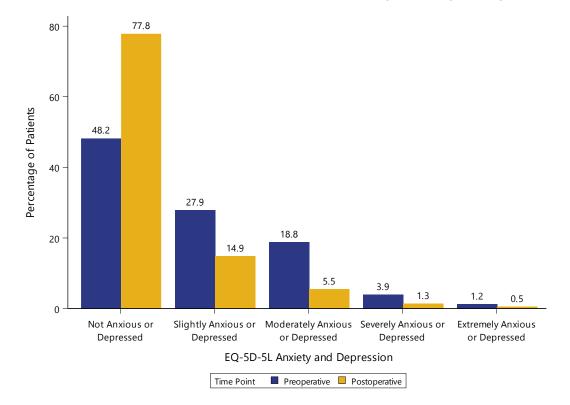
For the EQ-5D-5L anxiety/depression dimension, patients were asked to select the statement most relevant to their current experience of anxiety/depression:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 48.2% of patients reported that they were 'not anxious or depressed' compared with 77.8% of patients post-operatively (Figure 13).

Figure 13 Anxiety and Depression of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

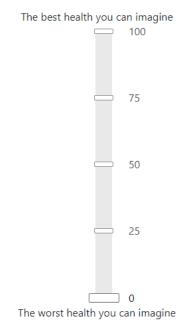


### **EQ VAS**

For the EQ VAS self-rated health instrument, patients were asked to indicate their current health status:

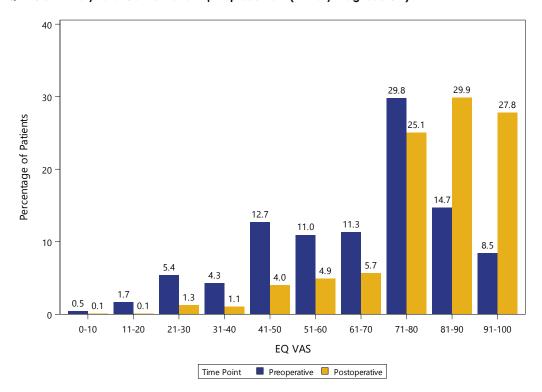
- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
   0 means the <u>worst</u> health you can imagine.
- Please use the slider to indicate how your health is TODAY.

### YOUR HEALTH TODAY:



Pre-operatively, 23.2% of patients had a VAS of 81 or more (out of 100) compared with 57.7% of patients post-operatively (Figure 14).

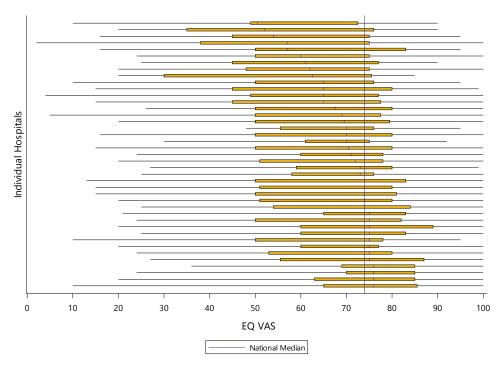
Figure 14 EQ VAS of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



Analyses were performed to determine pre-operative variation by hospital for the EQ VAS. There was variation between hospitals for the pre-operative outcome measures (Figure 15).

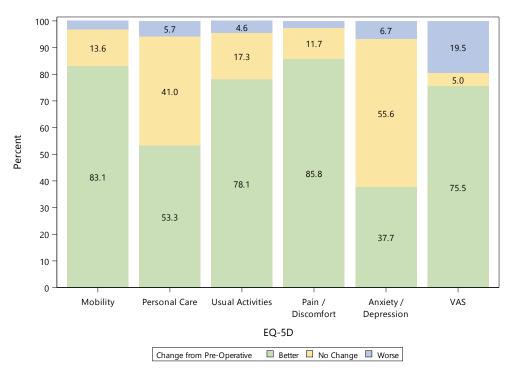
The median VAS was 74.0 as indicated by the vertical line in Figure 15.

Figure 15 Pre-Operative VAS by Hospital for Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



The percentage change in pre to post-operative scores for all EQ-5D-5L and VAS were analysed further according to the extent of change experienced ('better', 'no change', or 'worse') (Figure 16). Most patients had improvement post-operatively with mobility (n=1262, 83.1%), pain/discomfort (n=1296, 85.8), usual activities (n=1184, 78.1%) and for EQ VAS (n=1126, 75.5%).

Figure 16 Percent Change in EQ-5D-5L Scores from Pre-Operative to Post-Operative for Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



## **Oxford Hip Score**

The Oxford Hip Score (OHS) is a standardised and validated PROMs instrument developed to assess function and pain in patients undergoing total hip replacement surgery. The OHS provides a single summed score; the lower the score, the higher the severity of the patient's problems. Patients were asked to select one response for each of the following questions:

	Question	Options / Response	Score
		None	4
	During the past 4 weeks	Very Mild	3
1		Mild	2
	How would you describe the pain you <u>usually</u> have	Moderate	1
	from your hip?	Severe	0
		No trouble at all	4
2	During the past 4 weeks	Very little trouble	3
		Moderate trouble	2
	Have you had any trouble with washing and drying	Extreme difficulty	1
	yourself (all over) because of your hip?	Impossible to do	0
	During the past 4 weeks	No trouble at all	4
	Boning mo pasi 4 weeks	Very little trouble	3
3	Have you had any trouble getting in and out of a car	Moderate trouble	2
Ü	or using public transport because of your hip?	Extreme difficulty	1
	(whichever you tend to use)	Impossible to do	0
	(milenerel yearend to essy	Yes, easily	4
	During the past 4 weeks	With little difficulty	3
4		With moderate difficulty	2
4	Have you been able to put on a pair of socks,	<del>-</del>	
	stockings or tights?	With extreme difficulty	1
		No, impossible	0
		Yes, easily	4
_	During the past 4 weeks	With little difficulty	3
5		With moderate difficulty	2
	Could you do the household shopping on your own?	With extreme difficulty	1
		No, impossible	0
	During the past 4 weeks	No pain/More than 30 minutes	4
		16 to 30 minutes	3
6	For how long have you been able to walk before	5 to 15 minutes	2
	pain from your hip becomes severe? (with or without	Around the house only	1
	a stick)	Not at all/pain severe when walking	0
		Yes, easily	4
	During the past 4 weeks	With little difficulty	3
7		With moderate difficulty	2
	Have you been able to climb a flight of stairs?	With extreme difficulty	1
		No, impossible	0
	During the past 4 weeks	Not at all painful	4
		Slightly painful	3
8	After a meal (sitting at a table), how painful has it been for you to stand up from a chair because of	Moderately painful	2
		Very painful	1
	your hip?	Unbearable	0
		Rarely/never	4
	During the past 4 weeks	Sometimes, or just at first	3
9		Often, not just at first	2
•	Have you been limping when walking, <u>because of</u>	Most of the time	1
	your hip?	All of the time	0
		No days	4
	During the past 4 weeks	Only 1 or 2 days	3
0		Some days	2
0	Have you had any sudden, severe pain - 'shooting',	Most days	1
	'stabbing' or 'spasms' - <u>from the affected hip</u>	Every day	0
		Not at all	4
	During the past 4 weeks		
1	· ·	A little bit	3
1	How much has <u>pain from your hip</u> interfered with your	Moderately	2
	usual work (including housework)?	Greatly	1
	,	Totally	0
	During the past 4 weeks	No nights	4
	259 9	Only 1 or 2 nights	3
2	Have you been troubled by pain from your hip in bed	Some nights	2
	at night?	Most nights	1
	_ ~· ···ສ····	Every night	0

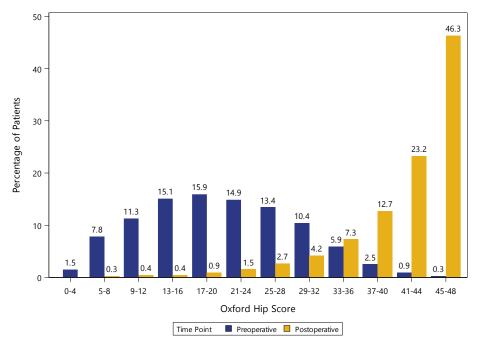
Score 0 to 19 May indicate severe arthritis
Score 20 to 29 May indicate moderate to severe arthritis

Score 30 to 39 May indicate mild to moderate arthritis

Score 40 to 48 May indicate satisfactory joint function

Pre-operatively, 1.2% of patients had an Oxford Hip Score of 41 or more out of 48 compared with 69.5% of patients post-operatively (Figure 17).

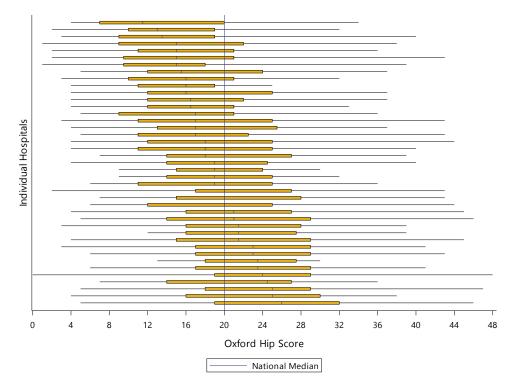
Figure 17 Oxford Hip Score of Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



Analyses were performed to determine pre-operative variation by hospital for the Oxford Knee Summary Score. There was variation between hospitals for the pre-operative outcome measures (Figure 18).

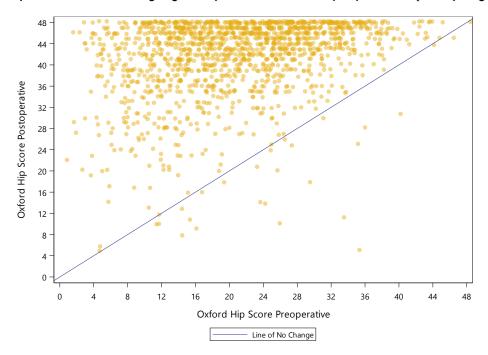
The median Oxford Hip Score was 20.0 as indicated by the vertical line in Figure 18.

Figure 18 Pre-Operative Oxford Hip Score by Hospital for Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



A scatterplot of pre versus post-operative Oxford Hip Score for each patient is presented in Figure 19. Most patients (n=1443, 98.0%) had a higher post-operative score compared with their pre-operative score meaning an improvement following their surgery as indicated by the yellow dots that fall above the 'line of no change'. A small number of patients experienced no change (n=6, 0.4%) or were worse post operatively (n=24, 1.6%).

Figure 19 Oxford Hip Score of Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



#### **HOOS-12**

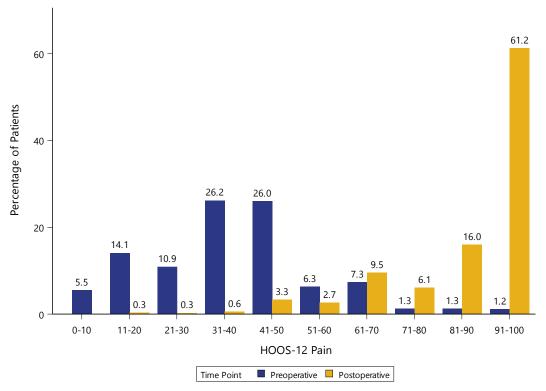
The HOOS-12 instrument is a 12-item measure derived from the original Hip disability and Osteoarthritis Outcome Score (HOOS). HOOS-12 contains 4 HOOS Pain items, 4 HOOS Function (activities of daily living and sport/recreation) items, and 4 HOOS Quality of Life (QOL) items. HOOS-12 reduces respondent burden by 70% from the original HOOS while providing scaled scores for hip-specific Pain, Function and QOL, along with a summary measure of overall hip impact.<sup>5</sup> To interpret HOOS scoring, the outcome measure is a scale from worst to best from 0 to 100, with 100 indicating no symptoms and 0 indicating extreme symptoms.

The HOOS-12 instrument was optional for patients enrolled in the RAPID system. Patients were asked the following questions:

portant that you answer all que d be if you attempted to do the	e activity.						
▶ How often do you experience	pain in your surgical hip?						
Never	Monthly	Weekly		Daily		Alway	/S
0	0	0		0		0	
▶ What amount of <b>pain</b> have y	ou experienced the last week	in your surgical hip during the	e following ac	tivities?			
The state of the s			None	Mild	Moderate	Severe	Extreme
Walking on a flat surface			0	0	0	0	0
Going up or down stairs			0	0	0	0	0
Sitting or lying			0	0	0	0	0
Rising from sitting			None	Mild	Moderate		Extreme
following activities please ind	ern your physical <b>function</b> . By icate the degree of difficulty you y not seem relevant to you. If you if	ou have experienced in the la	st week due	to your su	rgical hip. I	t is important	you answ
to do the activity.			None	Mild	Moderate	Severe	Extreme
Rising from sitting			0	0	0	0	0
Ch = 1:					1,000		1,000
Standing			0	0	0	0	0
Getting in/out of car			0	0	0	0	0
Getting in/out of car  The following question conce degree of difficulty you have	erns your physical <b>function</b> who experienced during the <b>last w</b> were not able to do an activity	eek due to your surgical hip.	evel. The que	stions shou	uld be answ	ered thinking stions even if the activity.	of what
Getting in/out of car  The following question conce degree of difficulty you have	experienced during the last w	eek due to your surgical hip.	evel. The que It is importa	stions shou nt you ans you attem	ald be answ wer all ques	ered thinking stions even if the activity.	of what
Getting in/out of car  The following question conce degree of difficulty you have seem relevant to you. If you Walking on uneven surface following questions concern you how often are you aware of	experienced during the last we were not able to do an activity of life.  your hip problem?	eek due to your surgical hip y listed, tell us how difficult	evel. The que It is importa t would be if	stions shou nt you ans you attem Mild	uld be answ wer all ques oted to do	ered thinking stions even if the activity.	of what they may
Getting in/out of car  The following question conce degree of difficulty you have seem relevant to you. If you Walking on uneven surface  Following questions concern you how often are you aware of Never	experienced during the last we were not able to do an activity are quality of life.  Your hip problem?	eek due to your surgical hip y listed, tell us how difficult	evel. The que It is importa t would be if	stions shount you ansyou attem	uld be answ wer all ques oted to do	ered thinking titions even if the activity.  e Severe	of what they may
Getting in/out of car  The following question conce degree of difficulty you have seem relevant to you. If you Walking on uneven surface following questions concern you how often are you aware of	experienced during the last we were not able to do an activity of life.  your hip problem?	eek due to your surgical hip y listed, tell us how difficult	evel. The que It is importa t would be if	stions shou nt you ans you attem Mild	uld be answ wer all ques oted to do	ered thinking stions even if the activity.	of what they may
Getting in/out of car  The following question conce degree of difficulty you have seem relevant to you. If you Walking on uneven surface  Following questions concern you how often are you aware of Never	experienced during the last we were not able to do an activity are quality of life.  Your hip problem?	eek due to your surgical hip y listed, tell us how difficult	evel. The que It is importa t would be if None	stions shou nt you ans you attemp Mild	uld be answ wer all ques oted to do Moderat	ered thinking stions even if the activity.  e Severe	of what they may
Getting in/out of car  The following question conce degree of difficulty you have seem relevant to you. If you  Walking on uneven surface  Following questions concern you  How often are you aware of the seem relevant to you.	experienced during the last we were not able to do an activity of life.  your hip problem?  Monthly	eek due to your surgical hip y listed, tell us how difficult weekly	evel. The quee It is importa t would be if None	stions shou nt you ans you attem Mild  Daily  Mildly	Ild be answer all questoted to do  Moderate	ered thinking stions even if the activity.  e Severe	of what they may
Getting in/out of car  The following question conce degree of difficulty you have seem relevant to you. If you Walking on uneven surface  Tollowing questions concern you how often are you aware of Never	experienced during the last we were not able to do an activity are quality of life.  Your hip problem?	eek due to your surgical hip y listed, tell us how difficult in the work of th	evel. The que It is importa t would be if None	stions shou nt you ans you attemp Mild	uld be answ wer all ques oted to do Moderat	ered thinking stions even if the activity.  e Severe	of what they may
Getting in/out of car  The following question conce degree of difficulty you have seem relevant to you. If you Walking on uneven surface  Walking on uneven surface  Tollowing questions concern you have of the seem relevant to you aware of the y	experienced during the last we were not able to do an activity ar quality of life.  your hip problem?  Monthly  Style to avoid activities potenti with lack of confidence in your	week due to your surgical hip y listed, tell us how difficult is weekly  Weekly  ially damaging to your hip?	evel. The que It is importa t would be if  None	stions shount you ansyou attem  Mild  Daily  Mildly	Idd be answ wer all ques oted to do Moderat	ered thinking stions even if the activity.  e Severe  Consta	of what they may
Getting in/out of car  The following question conce degree of difficulty you have seem relevant to you. If you Walking on uneven surface  Walking on uneven surface  Tollowing questions concern you have of the seem relevant to you aware of the y	experienced during the last we were not able to do an activity ar quality of life.  your hip problem?  Monthly  Style to avoid activities potential	week due to your surgical hip y listed, tell us how difficult is weekly  Weekly  ially damaging to your hip?	evel. The que It is importa t would be if  None	stions shount you ansyou attem  Mild  Daily  Mildly	Idd be answ wer all ques oted to do Moderat	ered thinking stions even if the activity.  e Severe  Consta	of what they may  Extrem  Extrem  C

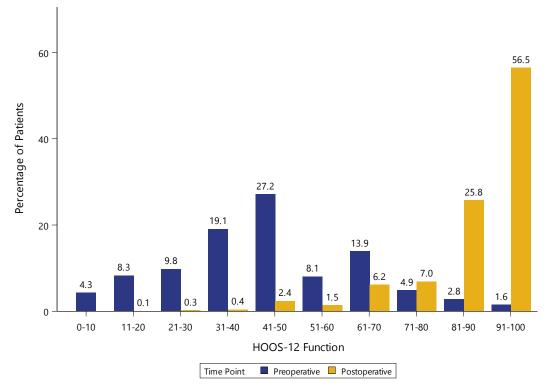
Pre-operatively, 2.5% of patients had a HOOS-12 Pain Score of 81 or more (0 to 100, worst to best) compared with 77.2% of patients post-operatively (Figure 20).

Figure 20 HOOS-12 Pain Score of Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



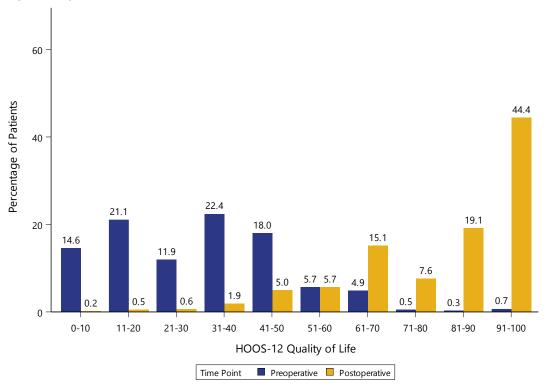
Pre-operatively, 4.4% of patients had a HOOS-12 Function Score of 81 or more (out of 100) compared with 82.3% of patients post-operatively (Figure 21).

Figure 21 HOOS-12 Function Score of Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



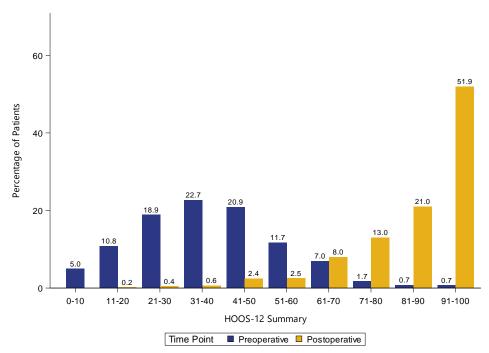
Pre-operatively, 1.0% of patients had a HOOS-12 Quality of Life Score of 81 or more (out of 100) compared with 63.5% of patients post-operatively (Figure 22).

Figure 22 HOOS-12 Quality of Life Score of Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



Pre-operatively, 1.4% of patients had a HOOS-12 Summary Score of 81 or more (out of 100) compared with 72.9% of patients post-operatively (Figure 23).

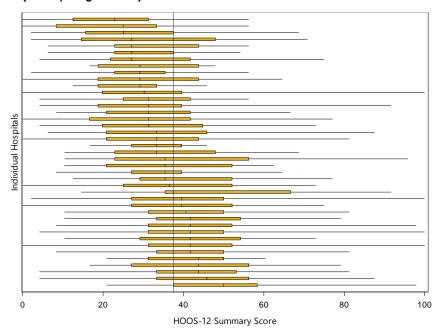
Figure 23 HOOS-12 Summary Score of Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



Analyses were performed to determine pre-operative variation by hospital for the VAS, Oxford Knee and HOOS-12 Summary Scores. There was variation between hospitals for the pre-operative outcome measures (Figure 24).

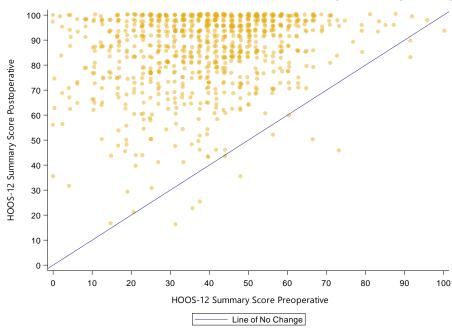
The median HOOS Summary Score was 37.5 as indicated by the vertical line in Figure 24.

Figure 24 Pre-Operative HOOS-12 Summary Score by Hospital for Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



A scatterplot of pre versus post-operative HOOS-12 Summary Score for each patient is presented in Figure 25. Most patients (n=862, 98.5%,) had a higher post-operative score compared with their pre-operative score as indicated by the yellow dots that fall above the 'line of no change'. A small number of patients experienced no change (n=3, 0.3%) or were worse (n=10, 1.1%) post-operatively.

Figure 25 HOOS-12 Summary Score of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



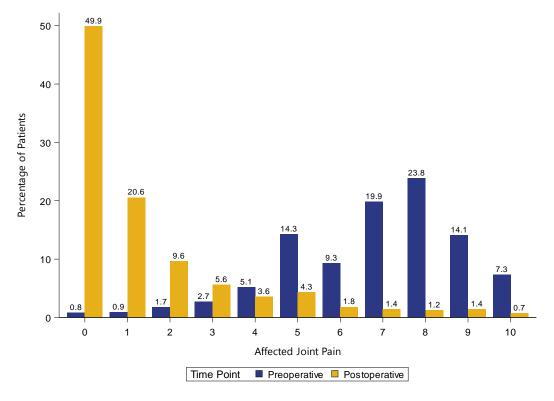
# **Average Pain for the Affected Joint**

Pre and post-operatively, patients used a sliding scale to indicate the average joint pain they had experienced over the last 7 days (from 0: no pain at all to 10: the worst pain imaginable):



Pre-operatively, 45.2% of patients had an affected joint pain score of 8 or more (out of 10) and 80.1% of patients had a score of 2 or less (out of 10) post-operatively (Figure 26).

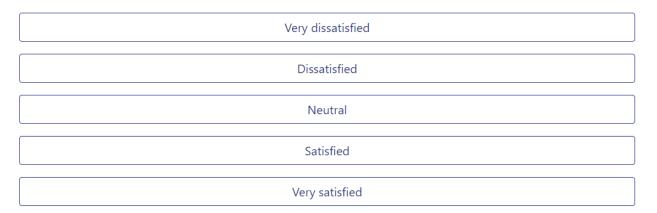
Figure 26 Affected Joint Pain of Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



## Satisfaction

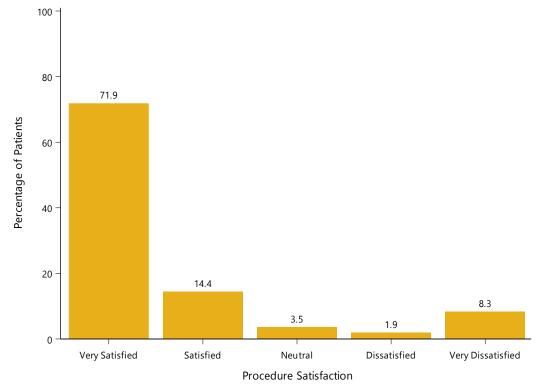
At the 6-month post-operative PROMs collection timepoint, patients were asked to select the statement which best described how satisfied they were with the results of their procedure:

Please select ONE box which best describes how satisfied you are with the results of your left hip replacement?



The majority of patients were either 'very satisfied' or 'satisfied' with their procedure (86.3%) (Figure 27).

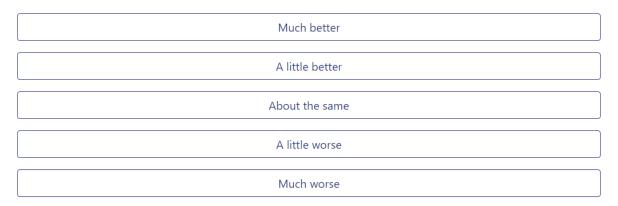
Figure 27 Procedure Satisfaction After Total Conventional Hip Replacement (Primary Diagnosis OA)



# **Joint Change**

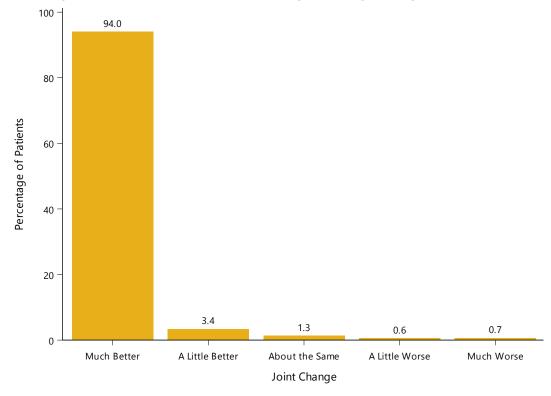
After their procedure, patients were asked to select the statement which best described their perceived change in the problems associated with their joint:

Please select ONE box which describes overall, how the problems are now with your hip on which you had surgery, compared to before you had your operation?



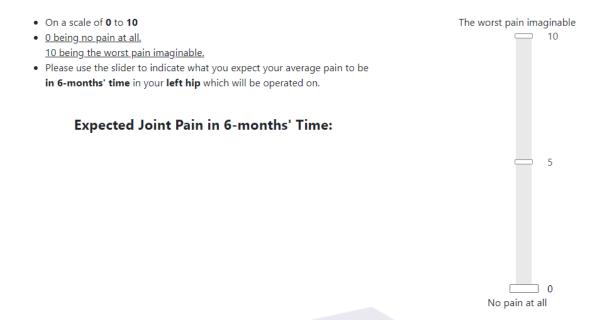
The majority of patients (94.0%) described their perceived problems with their joint as 'much better' (Figure 28).

Figure 28 Joint Change After Total Conventional Hip Replacement (Primary Diagnosis OA)

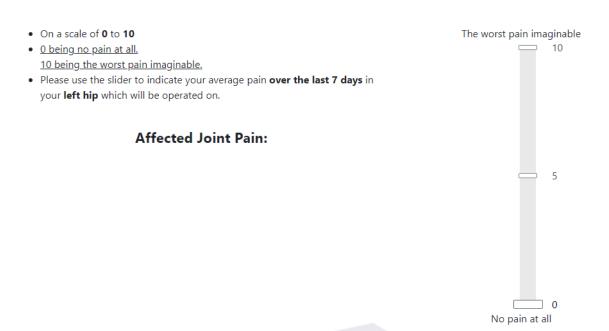


# **Pain Expectation**

Before their procedure, patients were asked to use a sliding scale to indicate their expected joint pain in 6-months' time (from 0: no pain at all to 10: the worst pain imaginable):

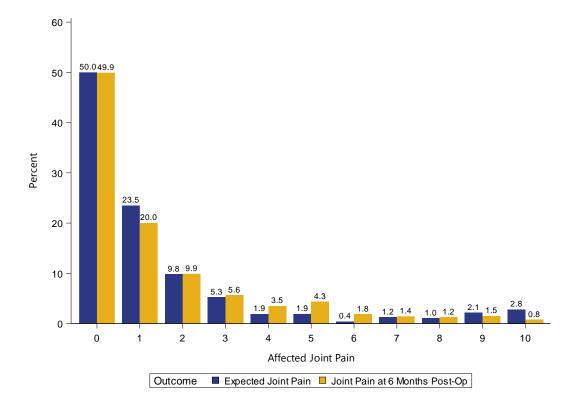


At the 6-month post-operative collection point, patients were provided with the same sliding scale and asked to indicate their average joint pain experienced over the last 7 days:



Of the patients who opted to complete the expected joint pain question, 50.0% reported that they expected no joint pain post-operatively, and at the 6-month post-operative PROMs collection timepoint 49.9% reported experiencing no joint pain (Figure 29).

Figure 29 Expected Joint Pain vs Actual Joint Pain for Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



When comparing patients' expected joint pain (recorded pre-operatively) with the actual joint pain experienced (recorded post-operatively at 6-months), 68.2% of patients reported that their pain was as expected or better than expected (Table 16).

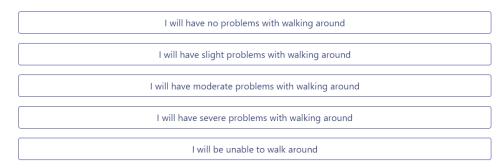
Table 16 Expected Joint Pain vs Actual Joint Pain for Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

Expectation Compared to Actual	N	%
Worse than Expected	466	31.8
As Expected	552	37.7
Better than Expected	446	30.5
TOTAL	1464	100.0

## **Mobility Expectation**

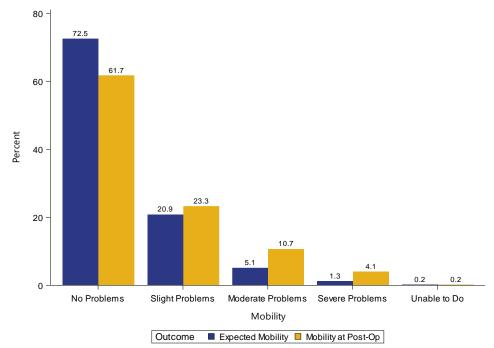
Before their procedure, patients were asked to select the statement that best described their expected mobility following their operation:

Please select ONE box that best describes how you think your health will be in 6-months' Time.



Of the patients who opted to complete the mobility expectation question, 72.5% did not expect to experience problems with mobility post-operatively, and at the 6-month post-operative PROMs collection timepoint 61.7% of patients reporting experiencing no problems with mobility (Figure 30).

Figure 30 Expected Mobility vs Actual Mobility for Patients Undergoing Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



When comparing patients' expected mobility at 6-months pre-operatively to their actual post-operative experience of mobility, 72% of patients reported that their mobility was as expected or better than expected (Table 17).

Table 17 Expected Mobility Compared to Actual Mobility for Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

Expectation Compared to Actual	N	%
Worse than Expected	420	28.0
As Expected	885	59.0
Better than Expected	195	13.0
TOTAL	1500	100.0

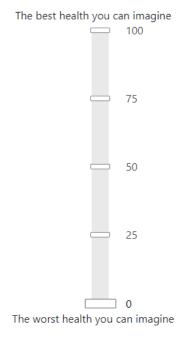
## **Health Expectation**

Before their procedure, patients used a sliding scale to indicate what they expected their health would be in 6-months' time (from 0: worst health you can imagine to 100: best health you can imagine):

- We would like to know how good or bad you expect your health to be in 6-months' time.
  This scale is numbered from 0 to 100.
  100 means the best health you can imagine.
- Please use the slider to indicate how you think your health will be in
   6-months' time.

0 means the worst health you can imagine.

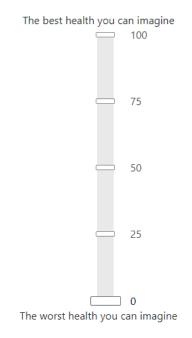
## **Expected Health in 6-months' Time:**



At the 6-months PROMs collection time point, patients used the same sliding scale to indicate their current health status:

- We would like to know how good or bad your health is **TODAY**.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
   0 means the <u>worst</u> health you can imagine.
- Please use the slider to indicate how your health is **TODAY**.

#### YOUR HEALTH TODAY:



Of the patients who opted to complete the health expectation question, 48.0% expected their health to be 91 or more (out of 100) post-operatively, and at the 6-month post-operative PROMs collection time point 27.8% of patients reported their actual experience of health as 91 or more (out of 100) (Figure 31).

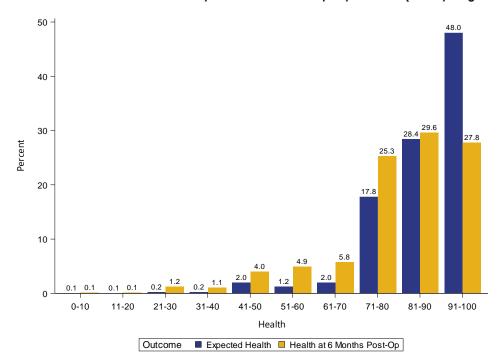


Figure 31 Expected Health vs Actual Health for Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

A scatterplot of pre versus post-operative expected health versus actual health for each patient is presented in Figure 32. Almost two thirds of patients (n=956, 64.5%) had a lower post-operative score compared with their pre-operative score as indicated by the yellow dots that fall below the 'line of no change'. Just over a third of patients reported their actual experience of health was better (n=385, 26.0%) or as expected (n=142, 9.6%).

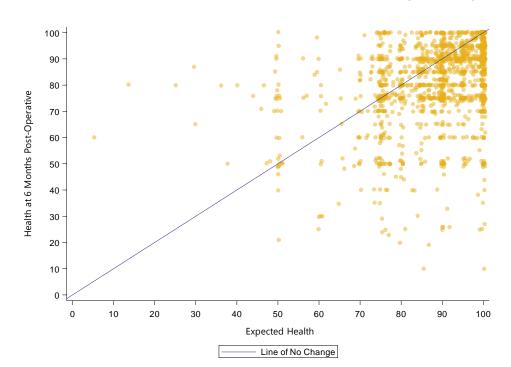


Figure 32 Expected Health vs Actual Health of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

## **Total Knee Replacement Outcomes**

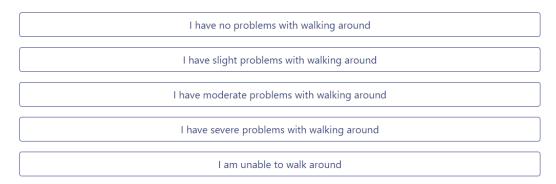
#### EQ-5D-5L & VAS

The EQ-5D-5L is a standardised instrument for measuring overall health status. The descriptive system is comprised of 5 dimensions: mobility, personal care, usual activities, pain/discomfort and anxiety/depression. VAS is a validated measure on a scale from 0 (the worst health you can imagine) to 100 (the best health you can imagine).

#### **EQ-5D-5L** mobility

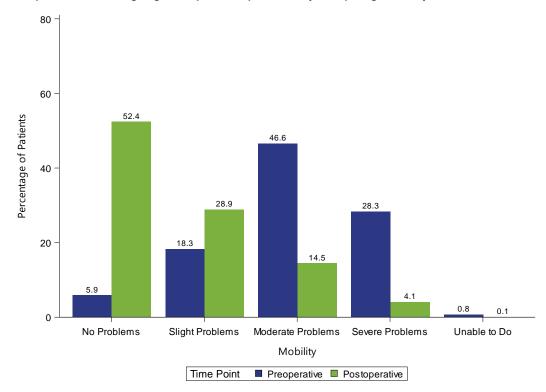
For the EQ-5D-5L mobility dimension, patients were asked to choose the statement most relevant to their current experience of mobility:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 5.9% of patients reported that they had 'no problems' with mobility, compared with 52.4% of patients post-operatively (Figure 33).

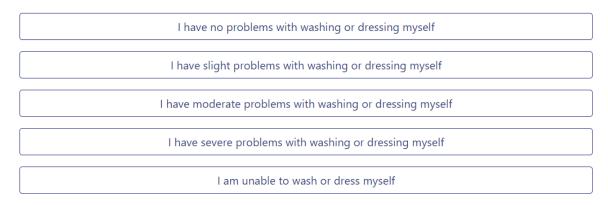
Figure 33 Mobility of Patients Undergoing Primary Knee Replacement (Primary Diagnosis OA)



### **EQ-5D-5L** personal care

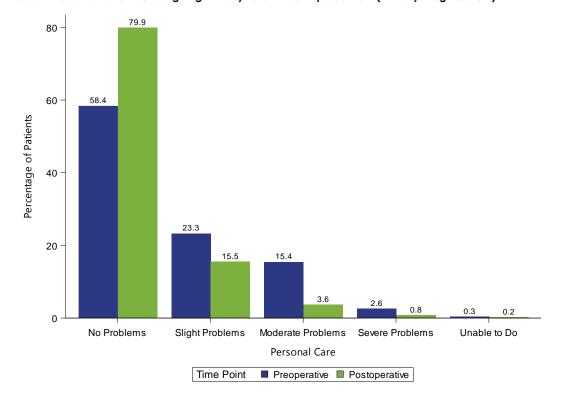
For the EQ-5D-5L personal care dimension, patients were asked to select the statement most relevant to their current experience of personal care:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 58.4% of patients reported that they had 'no problems' with personal care, compared with 79.9% of patients post-operatively (Figure 34).

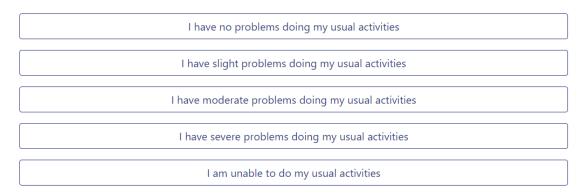
Figure 34 Personal Care of Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)



#### **EQ-5D-5L** usual activities

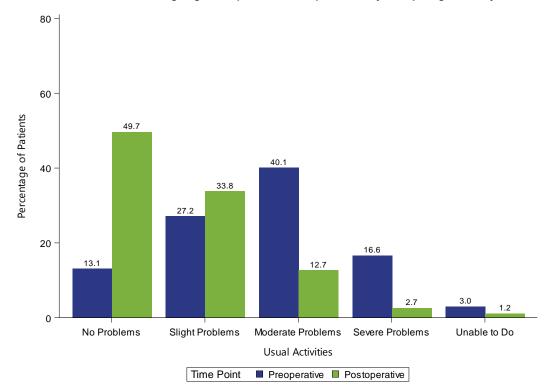
For the EQ-5D-5L usual activities dimension, patients were asked to select the statement most relevant to their current ability to undertake their usual activities:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 13.1% of patients reported that they had 'no problems' with usual activities, compared with 49.7% of patients post-operatively (Figure 35).

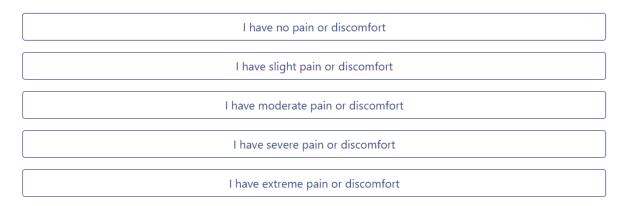
Figure 35 Usual Activities of Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)



### EQ-5D-5L pain/discomfort

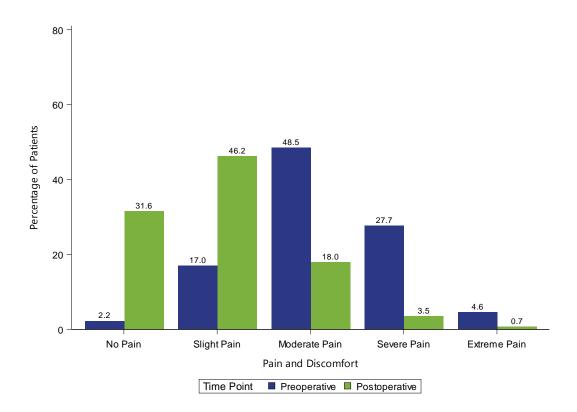
For the EQ-5D-5L pain/discomfort dimension, patients were asked to select the statement most relevant to their current experience of pain/discomfort:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 2.2% of patients reported that they had 'no pain', compared with 31.6% of patients post-operatively (Figure 36).

Figure 36 Pain and Discomfort of Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)



### EQ-5D-5L anxiety/depression

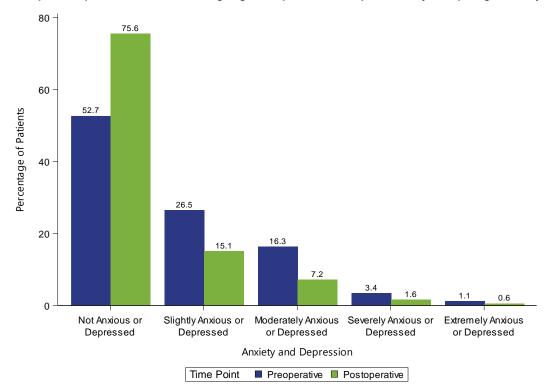
For the EQ-5D-5L anxiety/depression dimension, patients were asked to select the statement most relevant to their current experience of anxiety/depression:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 52.7% of patients reported that they were 'not anxious or depressed', compared with 75.6% of patients post-operatively (Figure 37).

Figure 37 Anxiety and Depression of Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)

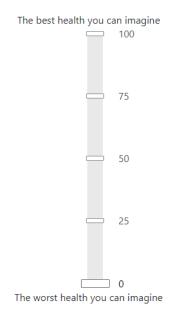


#### **EQ VAS**

For the EQ VAS self-rated health instrument, patients were asked to indicate their current health status:

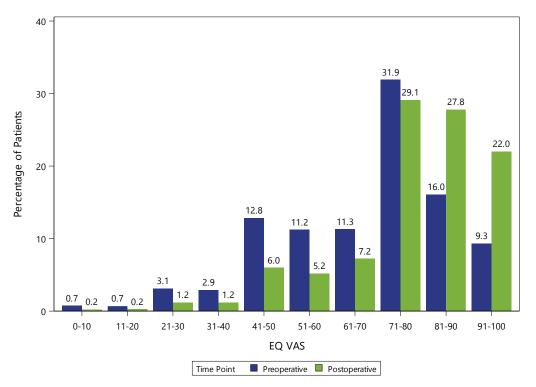
- We would like to know how good or bad your health is **TODAY**.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
   0 means the <u>worst</u> health you can imagine.
- Please use the slider to indicate how your health is **TODAY**.

#### YOUR HEALTH TODAY:



Pre-operatively, 25.3% of patients had a VAS of 81 or more (out of 100), compared with 49.8% of patients post-operatively (Figure 38).

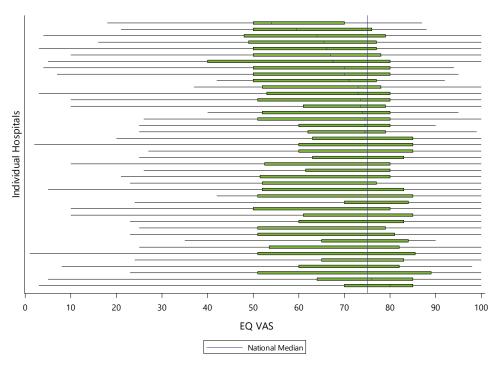
Figure 38 EQ VAS of Primary Total Knee Replacement (Primary Diagnosis OA)



Analyses were performed to determine pre-operative variation by hospital for the EQ VAS. There was variation between hospitals for the pre-operative outcome measures (Figure 39).

The median VAS was 75.0 as indicated by the vertical line in Figure 39.

Figure 39 Pre-Operative VAS by Hospital for Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)



The percentage change in pre to post-operative scores for all EQ-5D-5L and VAS were analysed further according to the extent of change experienced ('better', 'no change', or 'worse') (Figure 40). Most patients had improvement post-operatively, with mobility (n=1798, 75.4%), pain/discomfort (n=1754, 74.0%), usual activities (n=1568, 66.0%%) and for EQ VAS (n=1598, 68.2%).

Figure 40 Percent Change in EQ-5D-5L Scores from Pre-Operative to Post-Operative for Primary Total Knee Replacement (Primary Diagnosis OA)



### **Oxford Knee Score**

The Oxford Knee Score (OKS) is a standardised and validated PROMs instrument developed to assess function and pain in patients undergoing knee replacement surgery. The OKS provides a single summed score; the lower the scoring, the higher the severity of the patient's problems. Patients were asked to select one response for each of the following questions:

	Question	Options / Response	Score
	During the past 4 weeks	None	4
	During the past 4 weeks	Very Mild	3
1	How would you describe the pain you <u>usually</u> have from	Mild	2
	your knee?	Moderate	1
	you knoo!	Severe	0
	During the past 4 weeks	No trouble at all	4
2		Very little trouble	3
	Have you had any trouble with washing and drying	Moderate trouble	2
	yourself	Extreme difficulty	1
	(all over) because of your knee?	Impossible to do	0
3	During the past 4 weeks	No trouble at all	4
	Doing the past 4 weeks	Very little trouble	3
	Have you had any trouble getting in and out of a car or	Moderate trouble	2
	using public transport because of your knee? (whichever	Extreme difficulty	1
	you tend to use)	Impossible to do	0
		No pain/More than 30 minutes	4
	During the past 4 weeks	16 to 30 minutes	3
4	For how long have you been able to walk before pain	5 to 15 minutes	2
	from your knee becomes <b>severe</b> ? (with or without a stick)		
	HOTH YOU KIND DOCOTTICS SEFERY (WILLI OF WILLIOU & SIICK)	Around the house only	1 4
	During the past 4 weeks	Not at all painful	
		Slightly painful	3
5	After a meal (sitting at a table), how painful has it been	Moderately painful	2
	for you to stand up from a chair <u>because of your knee?</u>	Very painful	1
		Unbearable	0
	During the part 1 weeks	Rarely/never	4
	During the past 4 weeks  Have you been limping when walking, because of your knee?	Sometimes, or just at first	3
6		Often, not just at first	2
		Most of the time	1
	Miles.	All of the time	0
		Yes, easily	4
	During the past 4 weeks	With little difficulty	3
7		With moderate difficulty	2
	Could you kneel down and get up again afterwards?	With extreme difficulty	1
		No, impossible	0
		No nights	4
	During the past 4 weeks	Only 1 or 2 nights	3
8	Have you been troubled by pain from your knee in bed	Some nights	2
•		Most nights	1
	at night?	Every night	0
		Not at all	4
	During the past 4 weeks	A little bit	3
9			2
7	How much has <u>pain from your knee</u> interfered with your	Moderately	1
	usual work (including housework)?	Greatly	
		Totally	0
	During the past 4 weeks	Rarely/never	4
		Sometimes, or just at first	3
10	Have you felt that your knee might suddenly 'give way	Often, not just at first	2
	'or let you down?	Most of the time	1
	· ·	All of the time	0
		Yes, easily	4
	During the past 4 weeks	With little difficulty	3
11		With moderate difficulty	2
	Could you do the household shopping on your own?	With extreme difficulty	1
		No, impossible	0
		Yes, easily	4
	During the past 4 weeks	With little difficulty	3
12		With moderate difficulty	2
_	Could you walk down one flight of stairs	With extreme difficulty	1
	,	No, impossible	0
		110, 111100331010	U

Score 0 to 19 May indicate severe arthritis Score 20 to 29 May indicate moderate to severe arthritis Score 30 to 39 May indicate mild to moderate arthritis Score 40 to 48 May indicate satisfactory joint function Pre-operatively, 1.3% of patients had an Oxford Knee Score of 41 or more out of 48, compared with 44.3% of patients post-operatively (Figure 41).

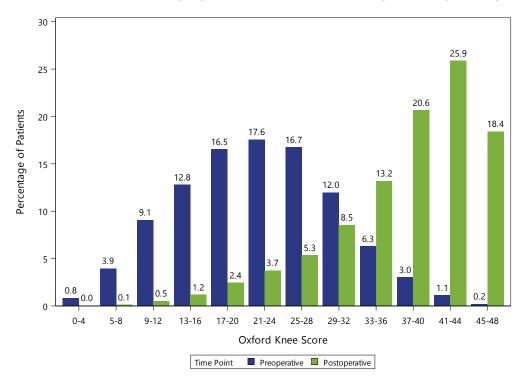
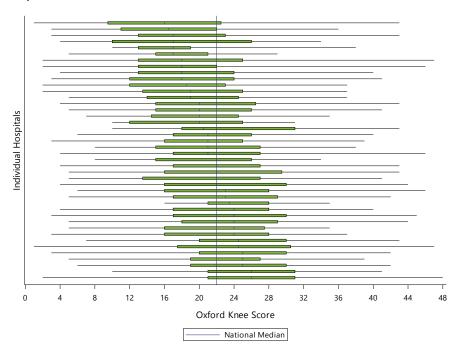


Figure 41 Oxford Knee Score of Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)

Analyses were performed to determine pre-operative variation by hospital for the Oxford Knee Summary Score. There was variation between hospitals for the pre-operative outcome measure (Figure 39 and Figure 42).

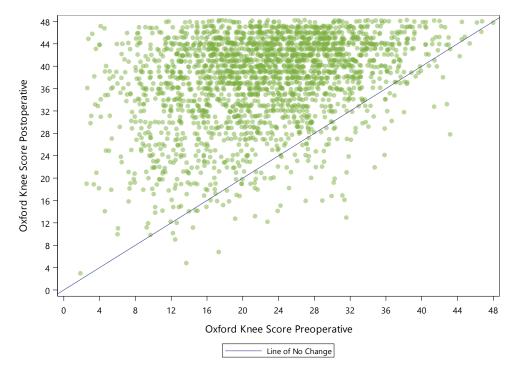
The median Oxford Knee Score was 22.0 as indicated by the vertical line in Figure 42.

Figure 42 Pre-Operative Oxford Knee Score by Hospital for Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)



A scatterplot of pre versus post-operative Oxford Knee Score for each patient is depicted in Figure 43. Most patients (n=2169, 94.3%) had a higher post-operative score compared to their pre-operative score meaning an improvement in their knee following their surgery as indicated by the green dots that fall above the 'line of no change'. A small number of patients experienced no change (n=28, 1.2%) or were worse (n=103, 4.5%) post-operatively.

Figure 43 Oxford Knee Score of Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)



### **KOOS-12**

The KOOS-12 instrument is a 12-item measure derived from the original Knee Injury and Osteoarthritis Outcome Score (KOOS). KOOS-12 contains 4 KOOS Pain items, 4 KOOS Function (Activities of Daily Living and Sport/Recreation) items, and 4 KOOS Quality of Life (QOL) items. KOOS-12 reduces respondent burden by 70% from the original KOOS while providing scale scores for knee-specific Pain, Function and QOL, along with a summary measure of overall knee impact. 6 To interpret KOOS scoring, the outcome measure is a scale from worst to best from 0 to 100, with 100 indicating no symptoms and 0 indicating extreme symptoms

The KOOS-12 instrument was optional for patients enrolled in the RAPID system. Patients were asked

OS-1	owing questions:								
. It is		view about your SURGICAL KNE all questions even if they may ne activity.							
P Ho	ow often do you experience	pain in your surgical knee?							
	Never Monthly Weekly				Daily		Alwa	ys	
	0		0		0				
ø ▶ WI	hat amount of <b>pain</b> have you experienced the <b>last week</b> in your surgical knee during the following activities?								
٦, ۲			, , ,	None	Mild	Moderate	Severe	Extreme	
W	Valking on a flat surface			0	0	0	0	0	
G	oing up or down stairs			0	0	0	0	0	
S	itting or lying			0	0	0	0	0	
Ri	ising from sitting			None	Mild	Moderate	Severe		
				None	Mild	Moderate	Severe	Extreme	
	0.000 = 0.000 0.000 0.000 = 0.000 = 0.000 0.000 = 0.000 0.00			0	0	0	0	0	
100	tanding			0	0	0	0	0	
G	setting in/out of car			0	0	0	0	0	
de	gree of difficulty you have e	ns your <b>physical function</b> who experienced during the <b>last we</b> you were not able to do an acti	ek due to your surgical knee	e. It is import ult it would b	tant you an be if you att	swer all ques tempted to de	tions even if the activity	they may	
				None	Mild	Moderate	Severe	Extreme	
Т	wisting/pivoting on your sur	gical knee		0	0	0	0	0	
_	wing questions concern your ow often are you aware of yo Never		Weekly		Daily		Consta	ntly	
	0	0	0		0		0		
No.						·			
0					************				
				Not at all	Mildly	Moderately	Severely	Extremel	
	ave you modified your life st urgical knee?	tyle to avoid activities potentia	ally damaging to your	Not at all	Mildly	Moderately	Severely	Extremel	
SI	urgical knee?	tyle to avoid activities potentia				The second secon			
H	urgical knee? low much are you troubled w		surgical knee?	0	0	0	0	0	
H	urgical knee? low much are you troubled w	with lack of confidence in your	surgical knee?	0	0	0	0	0	

Pre-operatively, 2.0% of patients had a KOOS-12 Pain Score of 81 or more (out of 100), compared with 50.7% of patients post-operatively (Figure 44).

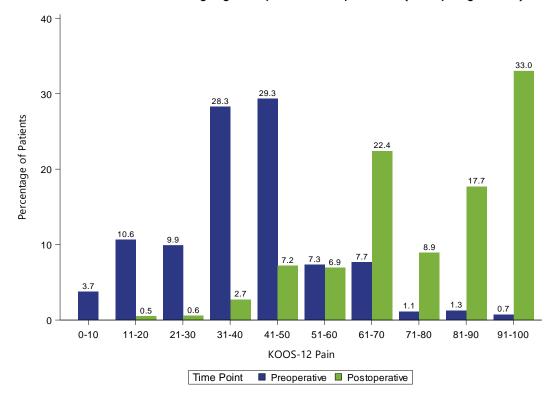


Figure 44 KOOS-12 Pain Score of Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)

Pre-operatively, 4.1% of patients had a KOOS-12 Function Score of 81 or more (out of 100), compared with 61.7% of patients post-operatively (Figure 45).

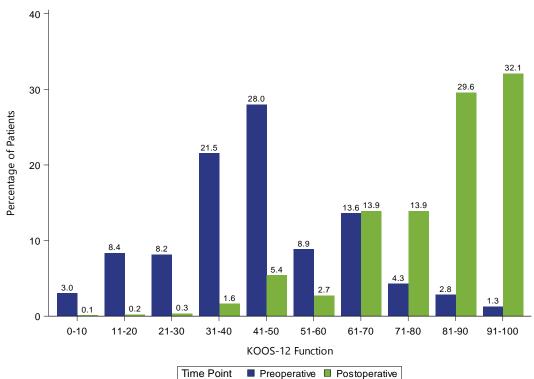


Figure 45 KOOS-12 Function Score of Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)

Pre-operatively, 0.6% of patients had a KOOS-12 Quality of Life Score of 81 or more (out of 100), compared with 38.2% of patients post-operatively (Figure 46).

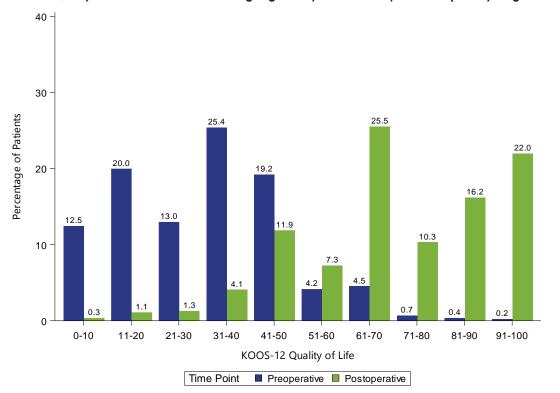


Figure 46 KOOS-12 Quality of Life Score of Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)

Pre-operatively, 1.0% of patients had a KOOS-12 Summary Score of 81 or more (out of 100) pre-operatively compared with 44.9% of patients post-operatively (Figure 47).

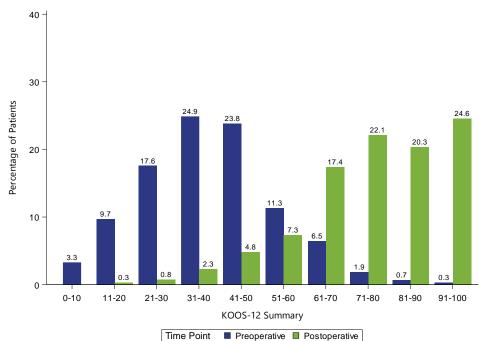
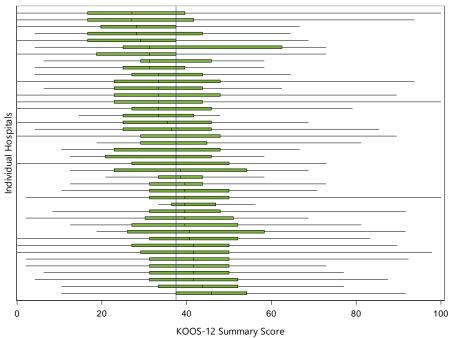


Figure 47 KOOS-12 Summary Score of Patients Undergoing Primary Knee Replacement (Primary Diagnosis OA)

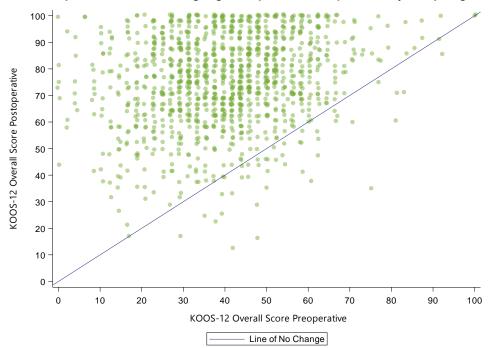
Analyses were performed to determine pre-operative variation by hospital for the KOOS-12 Summary Score. There was variation between hospitals for the pre-operative outcome measure (Figure 48). The median KOOS Summary Score was 37.5 as indicated by the vertical line in Figure 48.

Figure 48 Pre-Operative KOOS-12 Summary Score by Hospital for Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)



A scatterplot of pre versus post-operative KOOS-12 Summary Score for each patient is shown in Figure 49. Most patients (n=1171, 95.8%) had a higher post-operative score compared with their pre-operative score as indicated by the green dots that fall above the 'line of no change'. A small number of patients experienced no change (n=10, 0.8%) or were worse (n=41, 3.4%) post-operatively.

Figure 49 KOOS-12 Summary Score of Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)



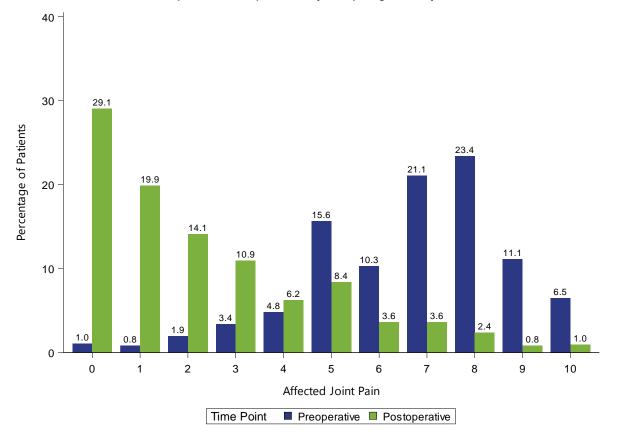
## Average pain for the affected joint

Pre and post-operatively, patients used a sliding scale to indicate the average joint pain they had experienced over the last 7 days (from 0: no pain at all to 10: the worst pain imaginable):



Pre-operatively, 41.0% of patients had an affected joint pain score of 8 or more (out of 10) and 63.1% of patients had a score of 2 or less (out of 10) post-operatively (Figure 50).

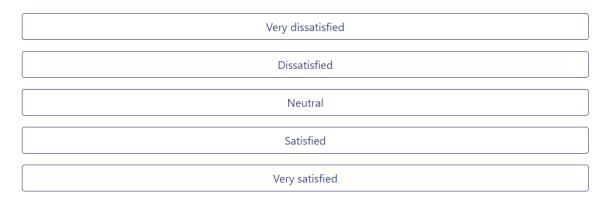
Figure 50 Affected Joint Pain of Primary Total Knee Replacement (Primary Diagnosis OA)



### Satisfaction

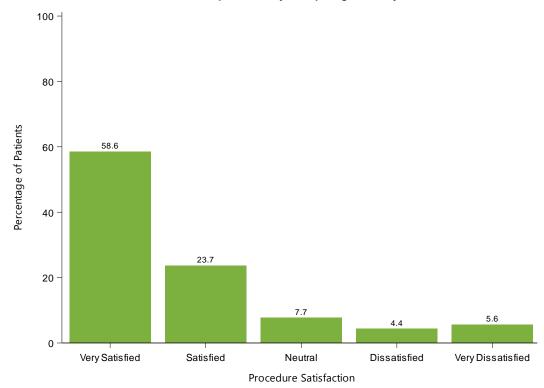
At the 6-month post-operative timepoint, patients were asked to select the statement which best described how satisfied they were with the results of their procedure:

Please select ONE box which best describes how satisfied you are with the results of your left knee replacement?



The majority of patients (82.3%) were either 'very satisfied' or 'satisfied' with their procedure (Figure 51).

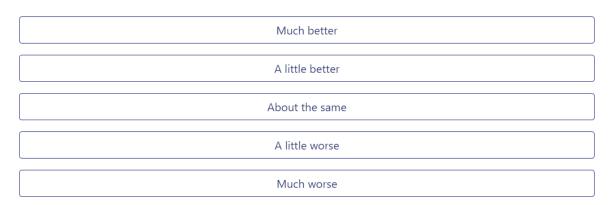
Figure 51 Procedure Satisfaction After Total Knee Replacement (Primary Diagnosis OA)



## **Joint Change**

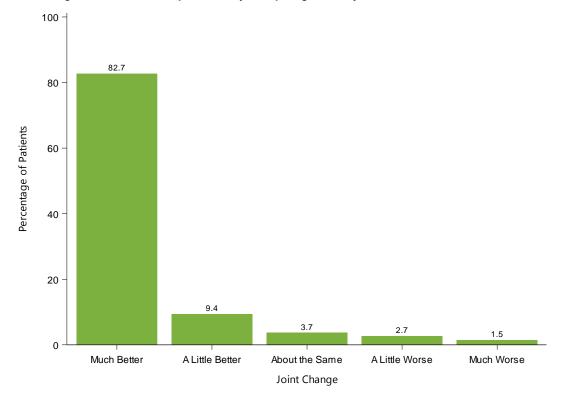
After their procedure, patients selected one option which best described their perceived change in the problems associated with their joint:

Please select ONE box which describes overall, how the problems are now with your knee on which you had surgery, compared to before you had your operation?



The majority of patients (82.7%) described their perceived change with their procedure as 'much better' (Figure 52).

Figure 52 Joint Change After Total Knee Replacement (Primary Diagnosis OA)



# **Pain Expectation**

Before their procedure, patients used a sliding scale to indicate their expected joint pain in 6-months' time (from 0: no pain at all to 10: the worst pain imaginable):

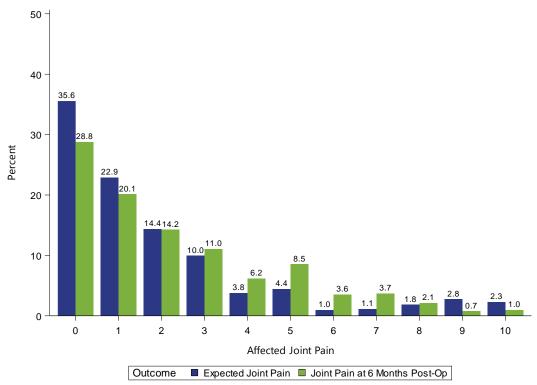


At the 6-month post-operative point, patients were provided with the same sliding scale and asked to rate their pain over the last 7 days:



Of the patients who opted to complete the expected joint pain question, 35.6% expected to experience no pain post-operatively, and at the 6-month post-operative PROMs collection timepoint 28.8% of patients reported experiencing no joint pain (Figure 53).

Figure 53 Expected Joint Pain vs Actual Joint Pain for Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)



When comparing expected joint pain (recorded pre-operatively) with actual joint pain (recorded post-operatively at 6-months), 55.2% of patients reported that their pain was as expected or better than expected (Table 18).

Table 18 Expected Joint Pain Compared to Actual Joint Pain for Primary Total Knee Replacement (Primary Diagnosis OA)

Expectation Compared to Actual	N	%
Worse than Expected	1023	44.8
As Expected	526	23.1
Better than Expected	732	32.1
TOTAL	2281	100.0

## **Mobility Expectation**

Before their procedure, patients were asked to select the statement that best described their expected mobility following their operation:

Please select <b>ONE</b> box that best describes how you think your health will be in <b>6-months' Time</b> .				
	I will have no problems with walking around			
	I will have slight problems with walking around			
	I will have moderate problems with walking around			
	I will have severe problems with walking around			
	I will be unable to walk around			
At the 6-month post-operative collection point, patients were provided with the same mobility tatements and asked to indicate their current experience of mobility:  Please select <b>ONE</b> box that best describes your health <b>TODAY</b> .				
	I have no problems with walking around			
	I have slight problems with walking around			
	I have moderate problems with walking around			

I have severe problems with walking around

I am unable to walk around

Of the patients who opted to complete the mobility expectation question, 58.9% did not expect to experience problems with mobility post-operatively, and at the 6-month post-operative PROMs collection timepoint 52.4% of patients reported experiencing no problems with mobility (Figure 54).

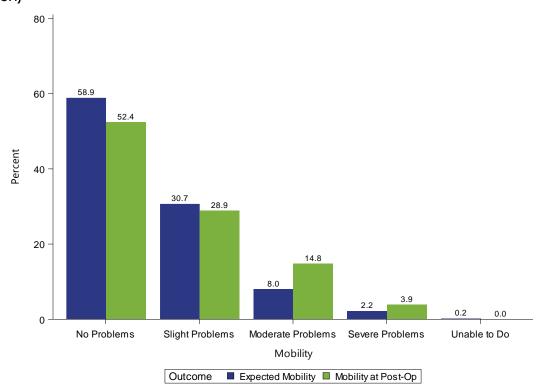


Figure 54 Expected Mobility vs Actual Mobility for Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)

When comparing patients' expected mobility at 6-months pre-operatively to their actual post-operative experience of mobility, 68.7% reported that their mobility was as expected or better than expected (Table 19).

Table 19 Expected Mobility Compared to Actual Mobility for Patients Undergoing Primary Total Knee Replacement (Primary Diagnosis OA)

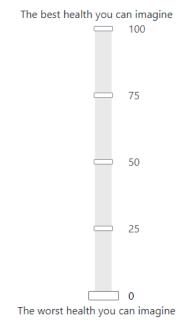
Expectation Compared to Actual	N	%
Worse than Expected	733	31.3
As Expected	1137	48.5
Better than Expected	473	20.2
TOTAL	2343	100.0

## **Health Expectation**

Before their procedure, patients used a sliding scale to indicate how they expected their health would be in 6-months' time (from 0: worst health you can imagine to 100: best health you can imagine):

- We would like to know how good or bad you expect your health to be in **6-months' time**.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
   0 means the <u>worst</u> health you can imagine.
- Please use the slider to indicate how you think your health will be in **6-months' time**.

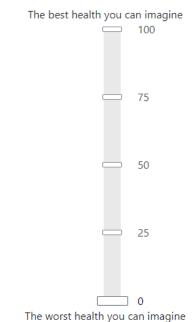
## **Expected Health in 6-months' Time:**



At the 6-months post-operative PROMs collection timepoint, patients used the same sliding scale to indicate their current health status:

- We would like to know how good or bad your health is **TODAY**.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
  0 means the <u>worst</u> health you can imagine.
- Please use the slider to indicate how your health is **TODAY**.

### YOUR HEALTH TODAY:



Of the patients who completed the health expectation question, 40.9% expected their health to be 91 or more (out of 100) post-operatively, at the 6-month post-operative PROMs collection timepoint 22.2% of patients reported their health to be 91 or more (out of 100) (Figure 55).

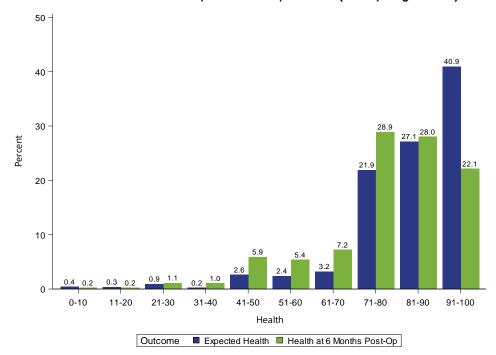


Figure 55 Expected Health vs Actual Health for Primary Total Knee Replacement (Primary Diagnosis OA)

A scatterplot of pre versus post-operative expected health versus actual health for each patient is presented in Figure 56. More than half (n=1503, 64.4%) of patients had a lower post-operative score compared with their pre-operative score as indicated by the yellow dots that fall below the 'line of no change'. More than a third of patients reported that their actual experience of health was better (n=630, 27.0%) or as expected (n=200, 8.6%).

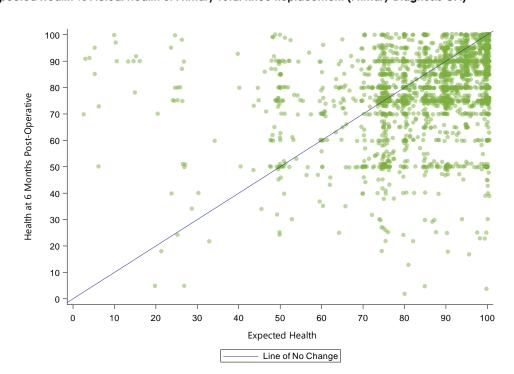


Figure 56 Expected Health vs Actual Health of Primary Total Knee Replacement (Primary Diagnosis OA)

## **Total Reverse Shoulder Replacement Outcomes**

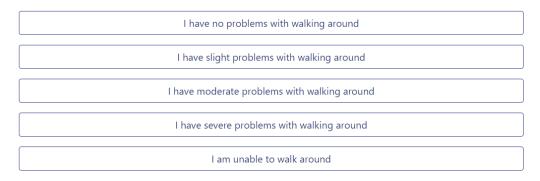
## EQ-5D-5L & VAS

The EQ-5D-5L is a standardised instrument for measuring overall health status. The descriptive system is comprised of 5 dimensions: mobility, personal care, usual activities, pain/discomfort and anxiety/depression. VAS is a validated measure on a scale from 0 (the worst health you can imagine) to 100 (the best health you can imagine).

#### **EQ-5D-5L** mobility

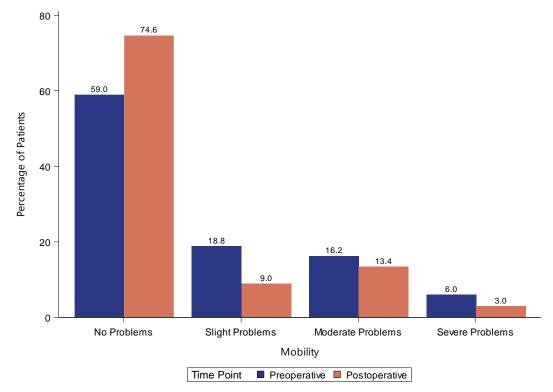
For the EQ-5D-5L mobility dimension, patients were asked to choose the statement most relevant to their current experience of mobility:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 59.0% of patients reported that they had 'no problems' with mobility, compared with 74.6% of patients post-operatively (Figure 57).

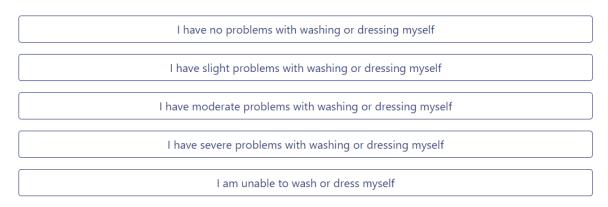
Figure 57 Mobility of Patients Undergoing Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)



## **EQ-5D-5L** personal care

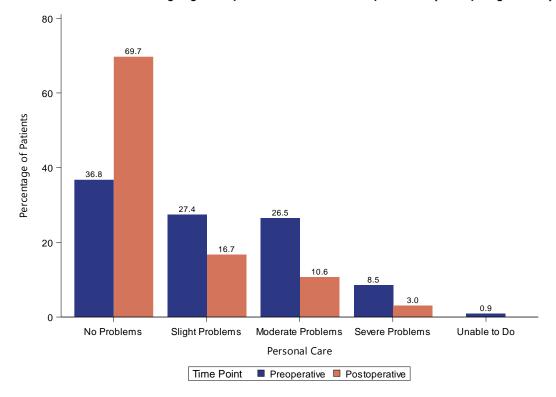
For the EQ-5D-5L personal care dimension, patients were asked to select the statement most relevant to their current experience of personal care:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 36.8% of patients reported that they had 'no problems' with personal care preoperatively, compared with 69.7% of patients post-operatively (Figure 58).

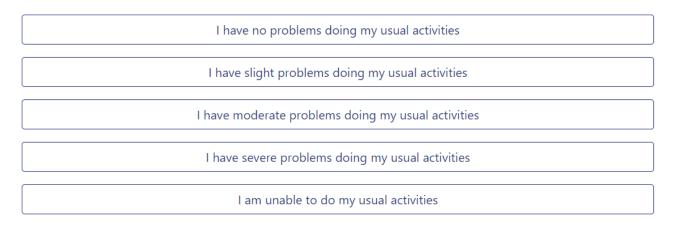
Figure 58 Personal Care of Patients Undergoing Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)



#### **EQ-5D-5L** usual activities

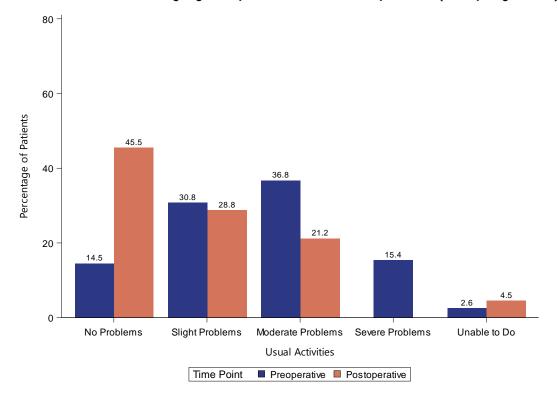
For the EQ-5D-5L usual activities dimension, patients were asked to select the statement most relevant to their current ability to undertake their usual activities:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 14.5% of patients reported that they had 'no problems' with usual activities, compared with 45.5% of patients post-operatively (Figure 59).

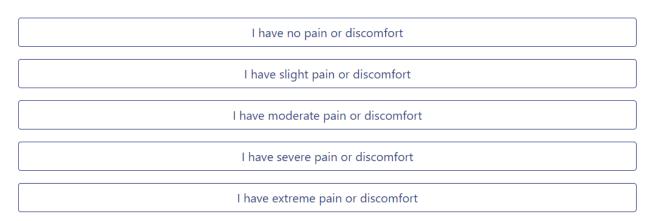
Figure 59 Usual Activities of Patients Undergoing Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)



## EQ-5D-5L pain/discomfort

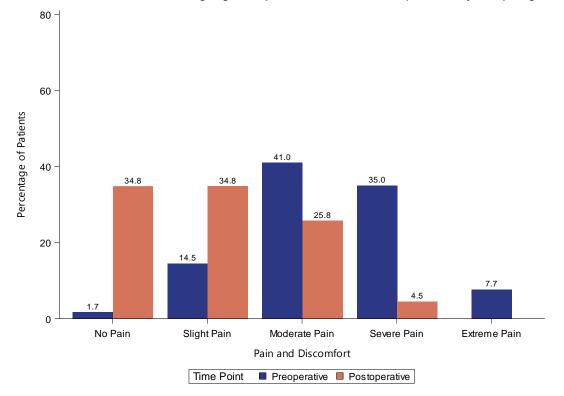
For the EQ-5D-5L pain/discomfort dimension, patients were asked to select the statement most relevant to their current experience of pain/discomfort:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 1.7% of patients reported that they had 'no pain', compared with 34.8% of patients post-operatively (Figure 60).

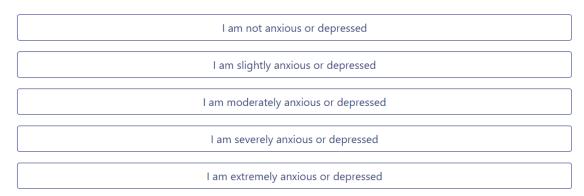
Figure 60 Pain and Discomfort of Patients Undergoing Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)



## EQ-5D-5L anxiety/depression

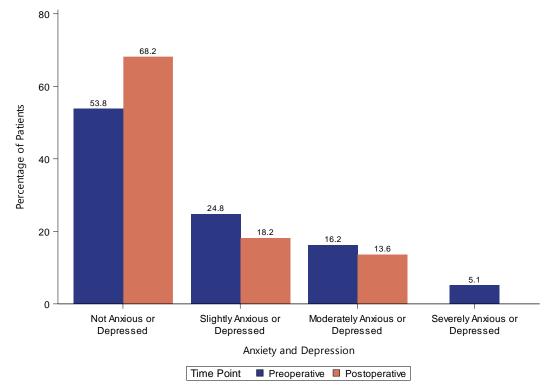
For the EQ-5D-5L anxiety/depression dimension, patients were asked to select the statement most relevant to their current experience of anxiety/depression:

Please select **ONE** box that best describes your health **TODAY**.



Pre-operatively, 53.8% of patients reported that they were 'not anxious or depressed', compared with 68.2% of patients post-operatively (Figure 61).

Figure 61 Anxiety and Depression of Patients Undergoing Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

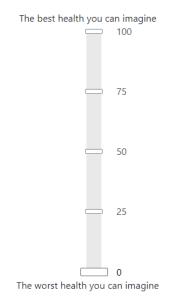


#### **EQ VAS**

For the EQ VAS self-rated health instrument, patients were asked to indicate their current health status:

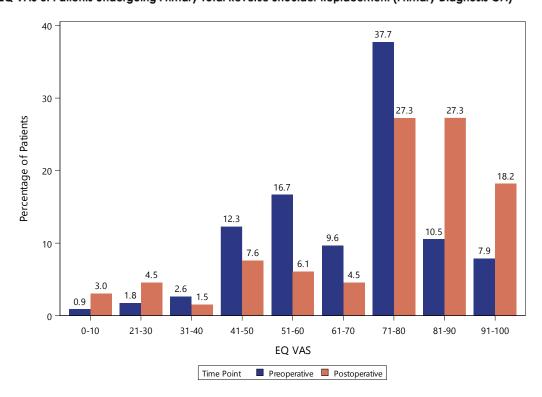
- We would like to know how good or bad your health is **TODAY**.
- This scale is numbered from 0 to 100.
- 100 means the <u>best</u> health you can imagine.
   0 means the <u>worst</u> health you can imagine.
- Please use the slider to indicate how your health is **TODAY**.

### YOUR HEALTH TODAY:



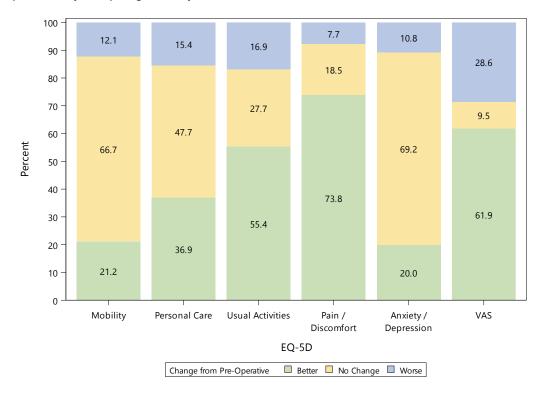
Pre-operatively, 18.4% of patients had a VAS of 81 or more (out of 100), compared with 45.5% of patients post-operatively (Figure 62).

Figure 62 EQ VAS of Patients Undergoing Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)



The percentage change in pre to post-operative scores for all EQ-5D-5L and VAS were analysed further according to the extent of change experienced ('better', 'no change', or 'worse') (Figure 63). Most patients had improvement post-operatively, with pain/discomfort (n=48, 73.8%) and for EQ VAS (n=39, 61.9%).

Figure 63 Percent Change in EQ-5D-5L Scores from Pre-Operative to Post-Operative for Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)



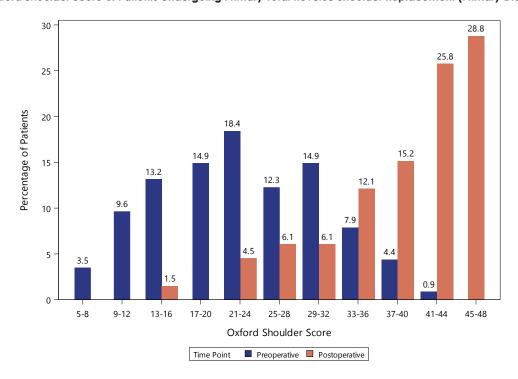
## **Oxford Shoulder Score**

The Oxford Shoulder Score (OSS) is a standardised and validated PROMs instrument developed to assess function and pain in patients undergoing shoulder surgery. The OSS provides a single summed score; the lower the score, the higher the severity of the patient's problems. Patients were asked to select one response for each of the following questions:

	one response for each of the following questions:  Question	Options / Response	Score
	During the post Awards	None	4
	During the past 4 weeks	Very Mild	3
1	How would you describe the <b>worst</b> pain you had from your	Mild	2
	shoulder?	Moderate	1
	2Houldet 6	Severe	0
		No trouble at all	4
	During the past 4 weeks	Very little trouble	3
2	Llave you had any trouble with drawing yourself be equipe of your	Moderate trouble	2
	Have you had any trouble with dressing yourself <u>because of your</u> shoulder?	Extreme difficulty	1
	3100ldel 4	Impossible to do	0
	During the past 4 weeks	No trouble at all	4
		Very little trouble	3
3	Have you had any trouble getting in and out of a car or using public transport <u>because of your shoulder</u> ? (whichever you tend to use)	Moderate trouble	2
		Extreme difficulty	1
		Impossible to do	0
		Yes, easily	4
	During the past 4 weeks	With little difficulty	3
4	Boning into past 4 wooks	With moderate difficulty	2
•	Have you been able to use a knife and fork – at the same time?	With extreme difficulty	1
		No, impossible	0
		Yes, easily	4
	During the past 4 weeks	With little difficulty	3
5	Dolling the past 4 weeks	With moderate difficulty	2
5	Could you do the household shopping on your own?	With extreme difficulty	1
	good year as me necessition and painty on year own.	No, impossible	0
		Yes, easily	4
	During the past 4 weeks	With little difficulty	3
_		With moderate difficulty	2
6	Could you do the carry a tray containing a plate of food across a	With extreme difficulty	1
	room?		0
		No, impossible	
		Yes, easily	4
7	During the past 4 weeks	With little difficulty	3
7		With moderate difficulty	2
	Could you brush/comb your hair with the affected arm?	With extreme difficulty	1
		No, impossible	0
	During the past 4 weeks	None	4
	Boning the past 4 weeks	Very Mild	3
8	How would you describe the pain you <u>usually</u> had from your	Mild	2
	shoulder?	Moderate	1
		Severe	0
	During the past 4 weeks	Yes, easily	4
	During the past 4 weeks	With little difficulty	3
9	Could you hang your clothes in a wardrobe, using the affected	With moderate difficulty	2
	arm?	With extreme difficulty	1
	<u></u>	No, impossible	0
		Yes, easily	4
	During the past 4 weeks	With little difficulty	3
10		With moderate difficulty	2
	Have you been able to wash and dry yourself under both arms?	With extreme difficulty	1
		No, impossible	0
		Not at all	4
	During the past 4 weeks	A little bit	3
11	How much has pain from your know interfered with your usual works	Moderately	2
	How much has <u>pain from your knee</u> interfered with your usual work	Greatly	1
	(including housework)?	Totally	0
		Yes, easily	4
	During the past 4 weeks	With little difficulty	3
12	Have you been troubled by <u>pain from your snoulder</u> in bed at	With moderate difficulty	2
-		With extreme difficulty	1
	night?	No, impossible	0
	1		<u> </u>

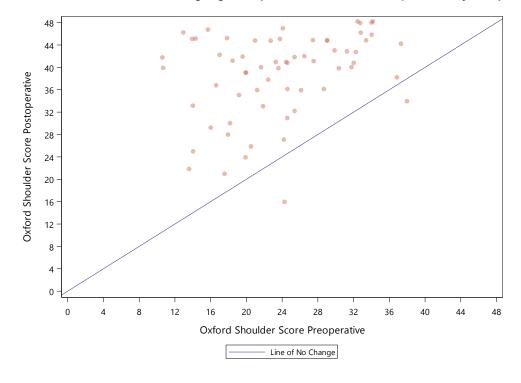
Score 0 to 19 May indicate severe arthritis Score 20 to 29 May indicate moderate to severe arthritis Score 30 to 39 May indicate mild to moderate arthritis Score 40 to 48 May indicate satisfactory joint function Pre-operatively, 0.9% of patients had an Oxford Shoulder Score of 41 or more out of 48, compared with 54.5% of patients post-operatively (Figure 64).

Figure 64 Oxford Shoulder Score of Patients Undergoing Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)



A scatterplot of pre versus post-operative Oxford Shoulder Score for each patient is shown in Figure 65. Most patients (n=62, 96.9%) had a higher post-operative score compared with their pre-operative score as indicated by the pink dots that fall above the 'line of no change'. There were only two patients who were worse post-operatively (n=2, 3.1%).

Figure 65 Oxford Shoulder Score of Patients Undergoing Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)



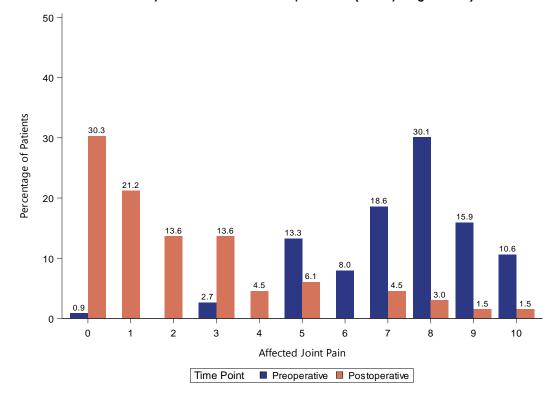
## **Average Pain for the Affected Joint**

Pre and post-operatively, patients used a sliding scale to indicate the average joint pain they had experienced over the last 7 days (from 0: no pain at all to 10: the worst pain imaginable):



Pre-operatively, 56.6% of patients had an affected joint pain score of 8 or more (out of 10), and 65.1% of patients had a score of 2 or less (out of 10) post-operatively (Figure 66).

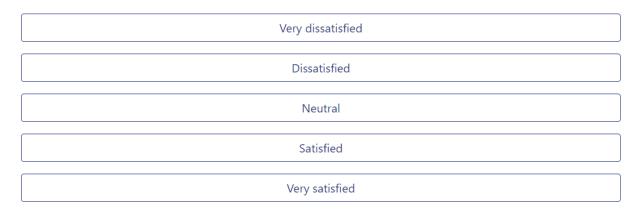
Figure 66 Affected Joint Pain of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)



### Satisfaction

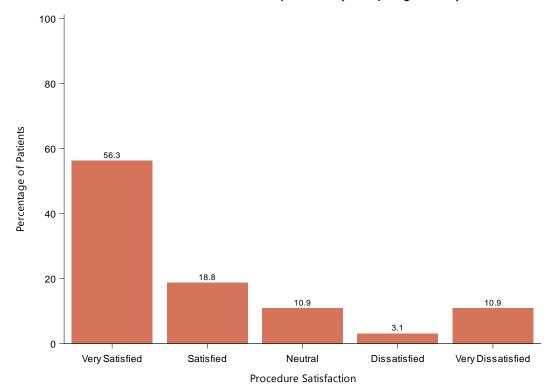
At the 6-month post-operative collection timepoint, patients were asked to select the statement which best described how satisfied they were with the results of their procedure:

Please select ONE box which best describes how satisfied you are with the results of your left shoulder replacement?



The majority of patients (75.1%) were either 'very satisfied' or 'satisfied' with their procedure (Figure 67).

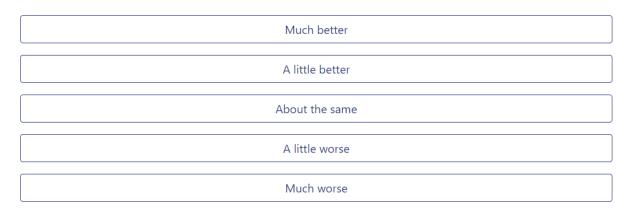
Figure 67 Procedure Satisfaction After Total Reverse Shoulder Replacement (Primary Diagnosis OA)



## **Joint Change**

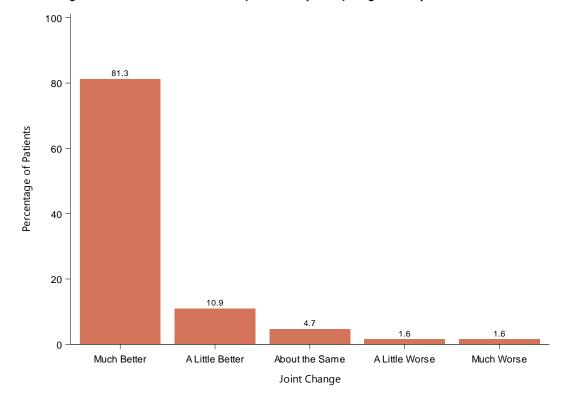
After their procedure, patients selected one option which best described their perceived change in problems associated with their joint:

Please select ONE box which describes overall, how the problems are now with your shoulder on which you had surgery, compared to before you had your operation?



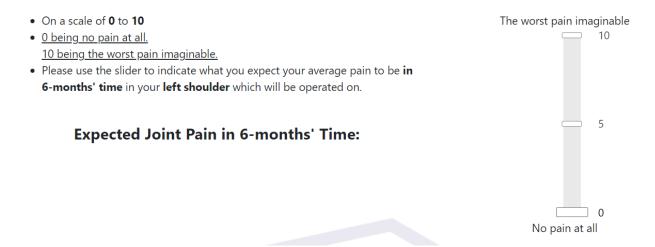
The majority of patients (81.3%) described their perceived change with their procedure as 'much better' (Figure 68).

Figure 68 Joint Change After Total Reverse Shoulder Replacement (Primary Diagnosis OA)



## **Pain Expectation**

Before their procedure, patients were asked to use a sliding scale to indicate their expected joint pain in 6-months' time (from 0: no pain at all to 10: the worst pain imaginable):



At the 6-month post-operative PROMs collection point, patients were provided with the same sliding scale and asked to indicate their current joint pain:

On a scale of 0 to 10

O being no pain at all.
10 being the worst pain imaginable.

Please use the slider to indicate your average pain over the last 7 days in your left shoulder which will be operated on.

Affected Joint Pain:

The worst pain imaginable

10

No pain at all

No pain at all

No pain at all

No pain at all

O

Of the patients who opted to complete the pain expectation question, 31.7% of patients expected no pain post-operatively, and at the 6-month post-operative PROMs collection timepoint 28.6% of patients reported no pain (Figure 69).

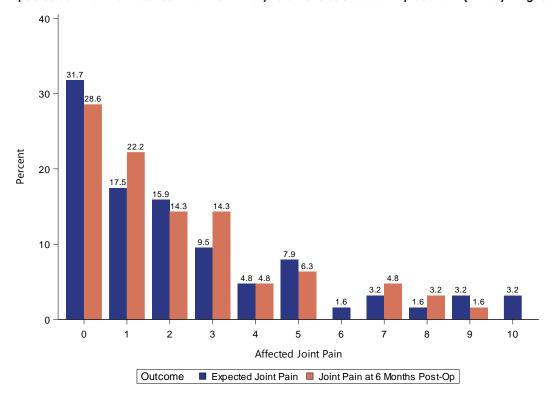


Figure 69 Expected Joint Pain vs Actual Joint Pain for Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

When comparing expected joint pain (recorded pre-operatively) with actual joint pain (recorded at 6 months), 57.2% of patients reported that their pain was as expected or better than expected (Table 20).

Table 20 Expected Joint Pain Compared to Actual Joint Pain for Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

Expectation Compared to Actual	N	%
Worse than Expected	27	42.9
As Expected	9	14.3
Better than Expected	27	42.9
TOTAL	63	100.0

## **Mobility Expectation**

Before their procedure, patients were asked to select the statement that best described their expected mobility following their operation:

Please select **ONE** box that best describes how you think your health will be in **6-months' Time**.

I will have no problems with walking around		
I will have slight problems with walking around		
I will have moderate problems with walking around		
I will have severe problems with walking around		
I will be unable to walk around		

At the 6-month post-operative collection point, patients were provided with the same task and asked to select the statement that best described their current experience of mobility:

Please select **ONE** box that best describes your health **TODAY**.

I have no problems with walking around
I have slight problems with walking around
I have moderate problems with walking around
I have severe problems with walking around
I am unable to walk around

Of the patients that opted to complete the mobility expectation question, 64.6% of patients expected no problems post operatively, and 73.8% of patients reported no problems with mobility at the 6-month post-operative PROMs collection timepoint (Figure 70).

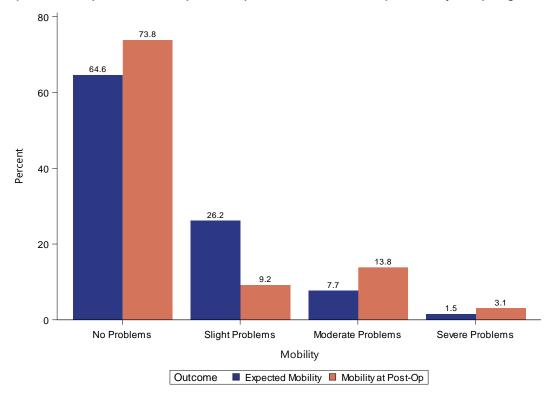


Figure 70 Expected Mobility vs Actual Mobility for Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

When comparing patients' expected mobility at 6-months (pre-operatively to their actual post-operative experience of mobility, 84.6% of patients reported that their mobility was as expected or better than expected (Table 21).

Table 21 Expected Mobility vs Actual Mobility for Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

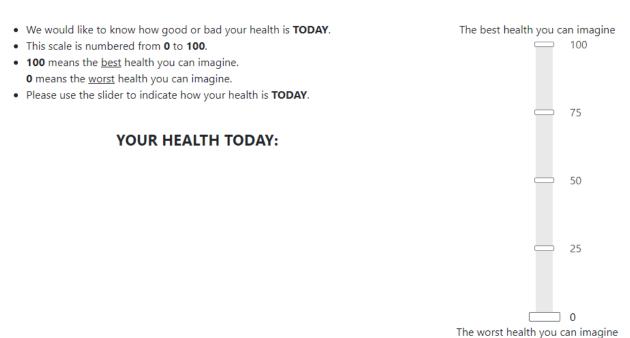
Expectation Compared to Actual	N	%
Worse than Expected	10	15.4
As Expected	42	64.6
Better than Expected	13	20.0
TOTAL	65	100.0

## **Health Expectation**

Before their procedure, patients used a sliding scale to indicate what they expected their health would be in 6-months' time (from 0: worst health you can imagine to 100: best health you can imagine):



At the 6-months PROMs collection timepoint, patients used the same sliding scale to indicate their current health status:



Of the patients who opted to complete the health expectation question, 29.7% expected their health to be 91 or more (out of 100) pre-operatively, and at the 6-month post-operative PROMs collection timepoint 18.8% of patients recorded their actual health to be 91 or more (out of 100) (Figure 71).

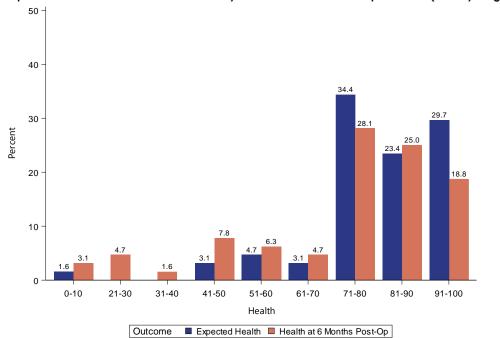


Figure 71 Expected Health vs Actual Health for Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

A scatterplot of pre versus post-operative expected health versus actual health for each patient is presented in Figure 72. More than half of patients (n=35, 54.7%) had a lower post-operative score compared with their pre-operative score as indicated by the yellow dots that fall below the 'line of no change'. Just under half of patients reported their actual health to be better (n=23, 35.9%) or as expected (n=6, 9.4%).

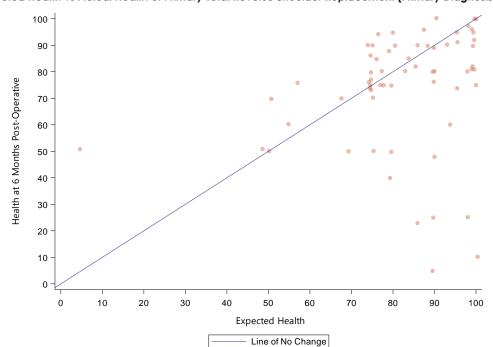


Figure 72 Expected Health vs Actual Health of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

## 11. Overview of Pilot Objectives

## Did the Pilot meet the aims/objectives?

There were eight objectives set during the planning stage of the PROMs Pilot. The following section aims to provide an overview of the strategies used to achieve these objectives, to consider whether the objectives were met and to recommend strategies for a national rollout of PROMs collection.

# Objective 1 - Understand barriers and enablers for PROMs data collection with a view to informing a broader implementation plan.

The pilot project has provided information on a variety of factors that will inform the national rollout of PROMs data collection. Many barriers identified during the pilot were addressed at the time, others may continue to be important throughout the national rollout.

Overall, during the 12-month data collection period of the Pilot, PROMs were collected on 51.3% of primary hip procedures, 52.8% of primary knee procedures and 36.8% of primary shoulder procedures (all with an initial primary diagnosis of osteoarthritis).

## Identified barriers and approaches to mitigating these

## Non-elective surgery

Patients undergoing joint replacement as a result of an emergency procedure or trauma can contribute PROMs data. This group of patients included (but not restricted to) fractured neck of femur patients, and those with a diagnosis of tumour. These patients were not the primary target group for PROMs collection as the ability of hospitals to collect PROMs data via emergency/specialty departments was always expected to be challenging and not a priority for patients or staff in these circumstances.

### Availability of pre-admission clinic

Private hospitals were less likely to have structured face to face pre-admission processes for patients. Initial recruitment and patient registration in RAPID are dependent on individual practice staff. Effective registration processes were still possible when patients did not attend a pre-admission clinic but in general, optimal registration levels were dependent on the commitment and resourcing of the personnel involved. To overcome this barrier, liaison and communication between the PROMs Project staff, clinical staff and the surgeon was critical to success.

## **Joint Type**

Many participating sites were unable to recruit patients undergoing shoulder arthroplasty as these patients are often not part of a pre-admission clinic cohort. To overcome this, targeted communication with shoulder surgeons and admission staff was critical to develop a feasible process that worked for each site.

### Procedure type

- Partial versus Total Joint Replacement The Registry received multiple queries from sites throughout the Pilot questioning whether partial joint replacements were included in the pilot. Although it was communicated prior to implementation that all joint replacement procedures were eligible, the uncertainty maybe a reason for the low patient registration rate for partial joint replacement procedures. For example, patients undergoing partial knee replacement were less likely to be registered, 15.1% compared to 46.1% for total knee replacement. To overcome this, in a national rollout education needs to emphasise that all joint replacement procedures are included.
- Revision hip and knee replacements were not excluded from the pilot project. However, only a small number of revision procedures were registered in the system. Trauma patients are not the intended group for PROMs collection but general encouragement in the national rollout could see valuable data collected.

#### Limited resources

One of the main considerations for this project was to develop a system which would not overburden hospital and administrative staff. *RAPID* was designed to be flexible and work within multiple environments. Patients self-register or an administrator can register patients. Administrators reported registration took approximately 20 seconds per patient. When the pilot first commenced, it was assumed that most patients would self-register. Throughout the pilot, some sites changed their process to a bulk pre-registration of patients prior to their pre-admission clinic and found this very effective in increasing patient registration rates at their site. This process would be recommended in a national rollout depending on the individual site practices. In addition, staff feedback early in the pilot identified that patients in pre-admission clinics are required to attend a variety of appointments. This meant it became difficult to complete the survey on the supplied iPad in one sitting. Following this feedback, a system adjustment was made to implement a 'resume' function in *RAPID*. This allowed patients to leave part way through the survey and come back within 14 days and complete the survey in their own time on an alternative device. Feedback from hospital staff to the AOANJRR indicated this was an extremely effective system improvement.

### **Staff changes**

Staff changes were identified as a barrier to PROMs collection in many hospitals. The Registry relied on hospital staff as well as surgeon administrative staff to identify patients preoperatively and then register patients into RAPID. When staff changes occurred, there was inconsistency in handover processes between sites. Throughout the pilot, patient registration rates were tracked closely, and the AOANJRR staff worked closely with site staff to keep them engaged and provide appropriate training and information resources. For a national rollout, collaboration and communication with hospital staff and project staff will continue to be important to maintain and improve patient registration.

## Language barriers

The Registry found that the most feedback regarding patients' inability to successfully use the electronic system was from public sites with a large proportion of non-English (or English as a second language) speaking patients. The PROMs questions/instruments were not translated as not all instruments are not validated for use in multiple languages.

In discussion with hospitals it was also clear that, although translated materials were often available to staff, they did not use them as literacy levels for many patients were varied. Staff also emphasised that some of these patients were from an older cohort and that patients generally had a family member (or when this was not possible, a translator) present. The AOANJRR communicated with sites that patients could nominate a family member or friend to assist completing the PROMs and to receive the reminders on their behalf. Sites reported that this alleviated the situation for many non-English (or English as a second language) speaking patients.

## Minimal contact details available

RAPID allows for three contact methods to be recorded – email, mobile and landline. When only one contact was provided, the ability to follow up a patient to complete their PROMs was reduced (especially if the only contact was a landline). Consideration for a national rollout to having either a mobile number or email address as a compulsory field may be worthwhile. For patients who do not have their own mobile, a family member's number could be provided. Of the procedures registered 1,148 (7.7%) have a landline only (no email, no mobile contact). See Appendix 1 Table A

#### Over burdening patients

Several sites already collect PROMs from patients for other ongoing or short-term projects and research trials. In all situations, effort was made to ensure patients were not asked to complete the same or similar data. RAPID was designed to be flexible, accept data from external sources and to export and provide data to external sites. This proved to be an important function for some hospitals. In some instances, certain sites no longer need to collect the data on paper forms and collate it themselves as it was then provided them to via a secure download site. In other instances, sites continued their current collection processes and provided the data to the Registry via the secure upload process. For these sites, having their data included in RAPID meant that they could have their data compared to national data,

when previously this option was not available. Whilst all hospitals will be encouraged to use RAPID the flexibility of the current approach will continue to be offered to hospitals where relevant in the national rollout to ensure collection is possible at all sites. If a large number of sites in the national rollout chose not to enter the data directly into RAPID, there would be resource implications and potentially data quality implications.

#### Potential Barrier to PROMs collection at a national level

The multiple ethics and governance approvals required for the pilot project was a resource-intensive process. This process will be challenging to implement and maintain (annual progress reports) for over 300 hospitals nationally as part of a national rollout. Although significant work has been undertaken to try and streamline the ethics and governance processes for research projects in Australia, this is still a difficult process to navigate especially when implementing a project nationally.

Multiple ethics approvals are required to cover public as well as private hospitals in states where they have not agreed to the National Mutual Acceptance Scheme. States use a mixture of online systems and manual processes to review and approve applications and requirements of the different committees are constantly changing. Whilst some governance offices have streamlined processes, others may take longer to review applications and submit feedback. This can cause delays to a site being able to start registering patients for PROMs. Many sites requested site specific patient information sheets with very slight variations to preapproved versions creating significantly increased requirements to provide these in the RAPID system. Unfortunately, most delays caused by ethics and governance reviews are unavoidable.

Approval as a Federal Quality Assurance Activity for PROMs collection would alleviate some of this duplication and encouragement of approval under this method would be worthwhile for a national project.

#### **Enablers**

### Training for site staff

Where possible, undertaking face-to-face training was an effective tool for engaging site personnel. Utilising web conference software was also a useful tool. A training test site which would allow site users to trial the system and setup test patients prior to data collection commencing would be worthwhile consideration for a national project.

### Flexibility to modify the RAPID system

The ability to adapt the functionality of *RAPID* following user feedback and respond quickly to address any identified issues was a critical enabler to improve engagement with sites and subsequent patient registration rates.

#### User-friendly efficient interface

This ensured reduced burden to patient data collection and as above, the ability to be flexible with existing data collection processes at sites further reduced the burden of collection on patients.

### **Custom built system**

RAPID is fit for purpose and designed to meet the requirements of PROMs collection.

### Inhouse software development expertise

Expertise was built and retained within the internal staffing team at SAHMRI. Modifications to the RAPID system were designed, tested, prioritised and delivered quickly and efficiently.

### Access to clinical expertise

Weekly access to clinical expertise including practicing orthopaedic surgeons throughout the development of the pilot was extremely important in enabling the project team to meet deadlines in the system build, design and implementation. Clinical expertise to liaise with surgeons and clinicians directly at sites often assisted with approval for hospitals to participate and was critical to reassuring surgeons if there were any doubts in relation to process or security of data.

## Project management resources

Sufficiently skilled and resourced AOANJRR/SAHMRI project team was also critical to ensure the project remained on schedule and was delivered with maximum efficiency.

#### Clinician contact point at each site

At each site there was a clinician/champion, who acted as the liaison person between the site and the AOANJRR ensuring queries and concerns were responded to promptly. This meant that sites were supported during implementation and ongoing data collection. This strategy will be critical to the success of a national rollout.

## Registry infrastructure and expertise

Having access to the existing expertise within the Registry (AOANJRR/SAHMRI) and infrastructure provided in-house access to knowledge, advice, prompt response to problems and queries, and a forum for problem solving based on previous experience.

### Existing connections, relationships and reputation

The connections and network of the AOA and AOANJRR both locally and internationally were highly beneficial and increased access to expert knowledge. A good example of this was the formation of the expert working group for the selection of PROMs instruments. This group provided global expertise to consider available information on psychometric properties, instrument scoring and clinical and research utility and advised which instruments would be most appropriate for collection.

**Fully met** – Early in the pilot a process was implemented to ensure all challenges, issues, requests and feedback along with any mitigation strategies and recommendations for change were recorded. In addition, formal feedback surveys were provided to all surgeons and site administrators. Feedback from funders and stakeholders via the Steering Committee was also recorded. Feedback from project staff and the Working Group has also been collated over the life of the project. This has provided a comprehensive understanding of the barriers and enablers to collecting this data which will inform the implementation of a national rollout.

## Recommendations - Objective 1

- 1. Continue to have flexible recruitment arrangements with sites to cater for variability of preadmission processes. Acknowledging that communication and relationship building with the person responsible for registration of patients is critical to success.
- 2. Increase communication with all surgeons and specifically shoulder surgeons to ensure the maximum number of patients are registered both in and out of pre-admission clinics.
- 3. Encourage sites to pre-register patients en masse prior to pre-admission clinics (dependent on the site) to minimise the resource burden on hospital/clinic staff.
- 4. Continue to match PROMs registrations to data already collected by the AOANJRR or other resources and use data linkage to other government datasets where practicable to ensure the burden of data collection is minimised.
- 5. Continue to enhance the RAPID system based on feedback from site staff and patients to increase efficiency and maximise ease of use.
- 6. Review site training, educational material and induction documentation to ensure these meet the needs of new site staff to address staff turnover and leave requirements and provide opportunity for successful site to share their learnings.
- 7. Continue to record the need for support to complete PROMs for patients for ongoing monitoring purposes.
- 8. Remove the option for landline contact only, as phone call follow-up will not be sustainable in a national rollout.
- 9. Ensure adequate project resources are in place within the AOANJRR to establish and maintain the required support and to communicate with sites during the implementation of a national rollout.
- 10. Ensure new sites have a clinician contact point within the site as part of a national rollout.
- 11. Continue a governance structure that provides expert clinical input and access to the networks of the AOANJRR throughout the national rollout.

12. Continue to allow patients undergoing non-elective joint replacement to contribute PROMs whilst acknowledging that the process of collecting these in emergency departments is challenging.

# Objective 2 - Develop infrastructure to facilitate data collection e.g. a web-based portal to enable direct data entry.

The AOANJRR subcontracted SAHMRI to assist in designing and developing an ICT platform which would enable the electronic capture of PROMs directly from patients. In designing the system, it was imperative that the AOANJRR remained flexible about how data could be collected and develop solutions for multiple data collection modalities. *RAPID* design commenced in October 2017 and a functional specification document was finalised by the AOANJRR and SAHMRI in early 2018. Multiple groups contributed to the functional specification document including the PROMs Project Working Group, the PROMs Steering Committee, the Registry Working Group as well as participating surgeons, hospitals, and national and international experts in PROMs collection.

Key requirements to be met included:

#### Scalability

Ability for expansion/rollout at a national level should the pilot be successful. It was felt necessary that any approach used in the pilot must be scalable.

**Fully met -** *RAPID* can be scaled for national implementation.

#### **Ownership**

Licensing and flexibility to redesign and further develop the system as required needed to remain with the AOANJRR.

**Fully met –** Ownership and Intellectual Property of *RAPID* sits with the AOANJRR providing full control over development, design and reporting functionality. Including an in-house test site environment available for further design. *RAPID* has the ability to customise and adapt as the need arises and provides a solid foundation for future trials and studies.

## Integration

The ability to integrate data and reporting with current AOANJRR data and the core business of the Registry was considered critically important.

**Fully met** – Whilst the data collected via *RAPID* is located on a separate server, the data of PROMs collection is able to be matched to the existing Registry data. This enables patient outcome data to be matched with procedure data. In future, PROMs data can be included in data linkage projects with MBS and PBS data. These data linkage projects greatly expand the capability of the Registry to undertake nested clinical trials and population-level data linkage studies that may improve patient outcomes.

#### **Engagement**

Dashboard options to enable stakeholders to access data in real time was considered integral to ensure ongoing engagement of stakeholders with the project.

**Fully met** – in the early stages of the pilot the AOANJRR was successful in securing a Medical Research Futures Fund (MRFF) Applied Research Translation grant. This meant development of the dashboards to enable stakeholder access to PROMs data in real time was fast-tracked and achieved in the first year of the pilot. The content of the dashboards will undergo continual refinement as part of the national project.

#### Branding

The AOA and AOANJRR reputation is critically important to the successful collection of PROMs data. It was determined that appropriate branding had the potential to reassure and encourage involvement not only of surgeons but also patients and other stakeholders. This branding was required to be visible on the system and stakeholder facing dashboards.

**Fully met** – Full ownership and control over design and in-house development has meant *RAPID* is branded in line with AOA branding and marketing guidelines.

#### Security

Implementing a system that could securely store patient and other sensitive data was a critical requirement of the PROMs Pilot.

**Fully met** – Access to the highly skilled software development team within SAHMRI who are fully aware of the security requirements of highly sensitive data was critical. *RAPID* meets SAHMRI's internal standards for secure software development and all security requirements requested by the AOA. An external security review was also conducted prior to the commencement of data collection. SAHMRI has policies, procedures and access controls, to protect personal information. Additionally, SAHMRI has physical security systems in place to limit facility access to authorised personnel.

## Recommendations – Objective 2

- 13. Maintain adequate ICT support within the SAHMRI ICT Team to ensure that enhancements can be made quickly, and efficiently as new functions are required.
- 14. Continue ongoing development of dashboard displays of real-time data to meet the needs of all stakeholders.
- 15. Maintain stakeholder confidence in the system by continued use of Australian Orthopaedic Association (AOA)/AOANJRR branding, high level ICT security and stability of the online platform.

## Objective 3 - Develop a system that is user-friendly, easy for patients and hospital staff to access.

The electronic data collection system RAPID was designed with the arthroplasty patient demographic in mind. The majority (63.8%) of patients participating in the pilot were aged 65 years or older. The system was required to:

- Operate on multiple devices: smart phone, tablet or computer, utilising Android or iOS platforms
- Provide clear graphics and instructions
- Not over burden patients in either complexity or time to complete
- Not over burden hospital staff
- Provide full question text on one screen
- Provide one touch question response
- Provide minimal scrolling
- Provide simple registration
- Provide multiple options for reminders i.e. text message, email and phone call follow-up
- Allow assistance from family/friend/staff and record when this was used
- Provide patients online dashboards with graphical data via displays appropriate to the patients' level of data comprehension

One of the main considerations when designing and implementing the system was not to overburden patients. The system was designed to minimise the amount of time required to complete the questions at each time point. Registration of a patient into the system took 20-30 seconds and completion of the surveys took 10-12 minutes.

The flexibility within the system meant that when feedback was received it could be responded to in a timely manner. A change was made to RAPID to enable patients to read each consent question component, expand the information if desired and to confirm their consent only once. Response to the change was positive.

RAPID is designed for patients to be able to enter survey answers with assistance. A question was asked at the end of the survey for patients to indicate if they received any assistance from a family member or healthcare professional to complete the survey. This was felt to be important for patients who may not be confident with technology or have literacy or language difficulties. Therefore, it will be possible to undertake analysis to determine if the cohort who required assistance was different to those who did not and to determine if their outcomes were different. Approximately 36% of PROMs responses both pre and post-operatively were completed with assistance Refer to Appendix 1.

There was not the resourcing capacity within the pilot project to undertake a structured approach for collecting and analysing patient feedback on the RAPID platform. The project team utilised informal methods and collected feedback via site administrators and ad hoc patient feedback (patient phone calls and emails directly to the Registry).

Anecdotal feedback from patients and site administrators indicated that the system was user friendly, quick and easy for patients to navigate.

#### **Dashboards**

Throughout the design phase mock-ups were sent to site coordinators to obtain patient feedback on the dashboards. Feedback provided by patients to site coordinators included:

- A preference for brighter colours and bigger/bolder statistics for impaired vision
- Some patients indicated they would be happy to participate but were not really interested in knowing how they compared to other patients.

The Registry was also contacted by patients who accessed their real time dashboards to provide feedback. No negative feedback was received regarding the patient dashboards.

**Fully met** - In consultation with consumers the PROMs working group worked together to try and ensure that the functionality of the system would be user friendly and easy for all users (patients, hospital staff and surgeons) to navigate. Throughout the pilot, modifications were made to *RAPID* based on feedback from hospital staff and patients. A number of these modifications have made the system simpler for patients and hospital staff to use. All the above requirements were met in the design of the system. As stated above, for the pilot study there was insufficient resourcing available for a full patient feedback focus group. A consumer representative was on the Steering Committee and hospital staff provided feedback from their patients in the Stakeholder Survey (section 9). Consumer Engagement is an important component of the Registry's four-year Strategic Plan and it is the view of the Registry that a more fulsome engagement with consumers in the future would provide further valuable input.

## Recommendations – Objective 3

- 16. Ensure all future modifications to RAPID maintain the usability and do not increase the burden for all participants for all users.
- 17. Review patient feedback regularly in a more structured process to ensure a broad range of views are captured.
- 18. Continue to monitor the proportion of patients who require assistance to complete their PROMs.

## Objective 4 - Test patient registration rates and identify optimum data collection methods for PROMs.

Patient registration rates have been outlined extensively in Section 8: Assessment of Recruitment. In summary, almost 15,000 patients were initially registered into the RAPID system. Of the patients who consented, pre-operative PROMs collection was obtained for 97.8% of procedures. At the end of the pilot period, there were 5,293 post-operative PROMs collections due, of which 79.0% were completed.

Patient response rates indicate that once a patient is registered into RAPID, the system is a highly effective method for PROMs data collection. Registration in RAPID is undertaken by two methods i.e. patient self-registration or registration by hospital/practice staff. There is significant variation in the rates of registration by hospital. Registration processes at hospitals not performing as well as expected will require further support as part of the national rollout. Refer to Section 8: Assessment of Recruitment for more detailed analysis of recruitment and registration.

**Fully met** – patient response rates have been analysed and modifications to both *RAPID* and hospital processes throughout the pilot improved both recruitment and registration. An understanding of patient response rates has been obtained and strategies developed for further work required in the national rollout to continue to improve registration rates.

## Recommendations – Objective 4

- 19. Ensure the system remains flexible to adapt to different sites' pre-admission processes.
- 20. Implement close monitoring of registration rates for each site as they join the national rollout.
- 21. Ensure adequate resources are in place to provide the required support for new sites to become familiar with the PROMs and RAPID.

## Objective 5 - Trial data matching between currently collected AOANJRR procedure data and PROMs data.

Throughout the PROMs project AOANJRR procedure data was matched with the PROMs data to identify when a procedure occurred in order to determine when the 6-month post-operative follow-up was due. A matching algorithm was developed using patient and procedure identifiers recorded in the electronic data capture system. The identifiers used for matching included:

- First name
- Middle name
- Last name
- DOB
- Postcode
- Hospital
- Surgeon
- Joint type e.g. Left Knee

The ability to match AOANJRR procedure data to the *RAPID* patient allows targeted analyses based on prosthesis information such as model name, type of prosthesis or catalogue number as well as patient factors including BMI and ASA. This capability greatly enhances the AOANJRR scope for research.

**Fully met** - An effective data matching process was in place and system modifications continue to address data discrepancies in an efficient manner. During the matching process discrepancies between the data recorded in the PROMs system and the AOANJRR database were identified and decisions were made throughout the project on how to address data discrepancies in a manner feasible for a national rollout.

## Recommendations – Objective 5

22. Continue PROMs collection with a minimum dataset to minimise the burden of data collection and utilise data linkage to other government datasets to enhance the value of data collected.

# Objective 6 - Develop reporting models for feedback to stakeholders (surgeons, patients, the public, participating institutions, project sponsors).

As discussed under objective 3 the development of dashboard reporting was fast-tracked and achieved in the first year of the pilot. The content of the dashboards has been undergoing continual refinement. Real-time online dashboards were released for pilot stakeholders including:

- Patients
- Surgeons
- Hospitals
- State Governments
- Project Payers

#### **Patient Dashboard**

Patients were able to review their pre-operative and post-operative responses compared to all other patients recorded in RAPID undergoing the same procedure:

- Type e.g. hip replacement
- Same gender

- Same age group
- Same gender and within the same age group

Patients could also view the change from their pre-operative response to their results post-operatively. Results can be viewed nationally, as well as by age group and gender.

#### Surgeon dashboards

The surgeon dashboard displayed patient recruitment and PROMs completion rates as well as aggregated PROMs results for their patient cohort both pre and post-operatively (when permitted by the patient).

Where PROMs results were displayed, surgeons could review their patient cohort compared to all other surgeons as well as their patient cohort results pre to post-operatively.

- In the reporting section of their dashboard surgeons could view the following:
- Number of procedures registered
- Number of pre and post-operative PROMs completed
- Number of procedures undertaken each month which have been matched to PROMs

This information could be viewed at a national level, for their patient cohort (at all hospitals) and for their patient cohort at each hospital.

Surgeons could review aggregated data and identified responses for their patients when the patient had consented. The 'share with surgeon question' was presented to patients at the end of the survey questions. Pre-operatively, 12236 (95.1%) patients consented for their surgeon to review their responses, 140 (1.1%) did not consent and 495 (3.9%) did not answer the question. Post-operatively 4653 (97.4%) patients consented for their surgeon to review their procedure responses, 51 (1.1%) did not consent and 75 (1.6%) did not answer the question.

#### Hospitals and State governments

The dashboards for hospitals and State Government were similar to surgeons, however, the results were aggregated by hospital or grouped for all hospitals linked to the stakeholder e.g. all public hospitals in a state.

### **Project payers**

Project payers were provided with similar dashboards to surgeons, with the results being aggregated for the pilot. No patient or surgeon could be identified in dashboards provided to these stakeholders.

**Fully met** - The data presented on each stakeholder dashboard was tailored to meet the needs of the stakeholder. The flexibility of *RAPID* allows the dashboards to be modified to meet future needs.

## Recommendations - Objective 6

- 23. Continue to explore new ways to present real-time data via the online dashboards. It is essential that data are provided to stakeholders in a format that could potentially form the foundation for change of practice and improved patient outcomes.
- 24. Ensure patient input and feedback guides future patient reporting developments.

# Objective 7 - Develop a platform for Registry Nested Clinical Trials in joint replacement surgery.

It was always intended that RAPID would also be a platform for Registry Nested Clinical Trials (RNCT). During phase one of the pilot, the AOANJRR was successful in securing a Medical Research Future Fund (MRFF) grant to deliver CRISTAL, a 15,000 patient, cluster randomised trial of aspirin versus low molecular weight heparin for venous thromboembolism prophylaxis in joint replacement surgery, a registry-nested study. The funding for this trial further contributed to the development of RAPID as a platform for clinical trials and enabled many functions of the platform to be fast-tracked.

**Fully met** - RAPID has been developed with the capability to run multiple registry nested clinical trials concurrently. The CRISTAL trial is progressing on track and RAPID is proving highly successful as a platform for such trials. Since the implementation of CRISTAL, a further two industry based RNCTs have been implemented and other trials are under discussion for implementation in 2020.

Studies can be setup utilising the user interface which allows the AOANJRR to customise a range of functions to the trial or study:

- Electronic Consent
- Patient Reported Instruments/questions
- Joint of interest
- Follow-up time points
- Case Report Forms
- Dashboard Reporting

Studies can be linked to specific hospitals and surgeons in *RAPID*. Depending on the type of study, patients will either be automatically linked to the relevant study on registration or an administrator can link the study at registration. All the specific study questions will be presented to the patient and the follow-up time points will automatically be actioned via the system.

A benefit of conducting studies and trials through the Registry for arthroplasty patients is that the patient only needs to complete the relevant questions once, despite having consented to enrolment in more than one study.

## **Recommendations - Objective 7**

- 25. Continue to increase the capability of RAPID to deliver RNCTs.
- 26. Broaden access to the trial capability within *RAPID* to enable a greater number of Australians to electronically access trials across geographical areas that would otherwise not have this opportunity.

## Objective 8 - Test patient and clinician engagement with the data.

Prior to commencement of the pilot the project team developed a communication plan with each site to maximise engagement of clinicians:

- Orthopaedic surgeons at the nominated hospital were contacted to determine their level of interest and agreement to participate
- Once agreement was obtained from the surgeons, contact was made with the hospital executive, inviting the hospital to participate and requesting endorsement of the pilot project
- Web conferences with CEOs
- Communication and information sessions were provided as required
- Attendance at surgeon meetings were provided as required

This process proved highly successful in creating engaged clinicians.

Each hospital had a nominated clinician as the contact person who championed participation at the site. There was some variation between hospitals in the level of engagement at the project level and significant resources were invested in communicating with and supporting hospitals as they became established in the pilot. Where the nominated clinician was engaged and active, this positively impacted on recruitment.

As previously discussed, the AOANJRR joint data collection is approved as a Federal Quality Assurance Activity under the Qualified Privilege scheme and this greatly reduces the burden of individual Ethics approvals and site governance activities and provides significant security and confidence to clinicians.

## Clinician engagement with data

In addition to ensuring hospital and clinician champions were engaged with the project, an analysis of engagement of clinicians and their individual dashboards was undertaken.

- Data collection commenced July 2018
- Online dashboards in RAPID were available in December 2018
- All hospitals were online by December 2018

A total of 391 surgeons are registered in the system, of these 177 (45.3%) logged onto their individual dashboards. Once in the system, surgeons could access various sections as per Table 22.

Table 22 Access to the Surgeon Dashboard

Use of Dashboard	N	%
Number of Surgeons in the system	391	
Surgeons logged into the system	177	45.3
Surgeons Accessed patient responses *	14	3.6
Surgeons Downloaded Responses	19	4.9
Surgeons Reviewed the Reporting *	76	19.4

<sup>\*</sup>Note: not available in the initial design of RAPID

These results and the response from the surgeon stakeholder surveys indicate surgeon engagement with their dashboards could be increased as part of a national program and further exploration of potential strategies would be worthwhile. This would ensure the benefit of real time data is maximised for improved patient outcomes. Refer to Stakeholder Survey Section 9.

## Patient engagement with data

A similar analysis was undertaken to review the engagement of patients with the data. The facility for patients to access individual data via their dashboard was available from December 2018. Each patient was able to log onto RAPID and access their completed survey/s. The dashboard enabled patients to view their data and to also see themselves compared to national data. The analysis showed that 12.9% of patients accessed their data (Table 23). Consideration should be given to further promotion of this function as part of the national rollout.

Table 23 Access to the Patient Dashboard

Use of Dashboard	N	%
Patients logged on	8840	
Patients accessed their own data	1138	12.9

## **Recommendations - Objective 8**

- 27. The communication approach used engaging hospitals via a frequent, open and personal methods was highly effective and should be utilised in the national rollout.
- 28. To ensure the administrative load of the national rollout is manageable, individual hospital agreements and individual ethics approvals should be avoided unless deemed necessary by individual hospitals.
- 29. To ensure high levels of hospital participation in a national rollout, approval for PROMs collection as a Federal Quality Assurance Activity is recommended to ensure the burden of ethics and site approvals is not overwhelming.
- 30. Expand education and promotion of the online dashboard data for all RAPID users to increase engagement with the data.

## 12. Future Analytical Potential

The collection of PROMs data has major benefits for patients and the healthcare system. These data provides the unique and critical important patient perspective on both the impact and severity of end stage joint disease as well as the results of management. At a patient level, PROMs data allows both the patient and clinician to gain important insight into the individual healthcare experience and promotes shared decision making. It is at the population level however where the most important benefits are likely to be gained from the use of these data.

A major focus of the AOANJRR is to assess outcomes variation with respect to patient, prosthesis, technique, surgeon and hospital factors. This information is used to identify both best and less satisfactory practice and determine the factors impacting this. This information is disseminated to stakeholders often in a targeted way to influence practice and policy. The AOANJRR is able to monitor the impact of this and assess how outcomes change over time. This process ensures continuous quality improvement. The collection of PROMs and its linkage to existing Registry and administrative datasets increases both the opportunity and capacity of the AOANJRR to further enhance health outcomes.

The data will enable the AOANJRR to undertake comparative analysis, healthcare delivery assessment and health economic analysis not previously possible. As PROMs data is obtained directly from the patient this information can be used to better understand and enhance the patient experience as well as provide a range of different measures to optimise healthcare delivery and the results of management in a cost-effective manner. It expands the number and type of outcomes that can be assessed and for the first time the AOANJRR is able to consider the impact of preoperative disease severity.

Despite the rapid growth in interest in PROMs in recent years, the full potential of PROMs and PROMs linked to Registry and administrative datasets is yet to be fully realised. An import focus for AOANJRR is to enhance analytics and appropriate use of PROMs and PROMs-linked datasets. AOANJRR will continue to work with national and international experts to optimise the utility and maximise the benefits of this information. This will include assessment of the relative value and importance of the different data elements and develop analytical approaches to ensure this information is used to its full potential. A further important focus is to use predictive analytics to provide patients with quality information on personalised benefit and risk as well as develop point of contact tools to assist clinicians to optimise individual patient management.

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## **Appendices**

# Outcome Data: Telephone Assistance vs No Assistance

A summary of the contact details for each procedure recorded in RAPID is provided in Table A. There were 1,148 (7.7%) procedures registered that had a landline only.

Table A Procedures Contact Details

Contact Details	N	%
Email only	468	3.1
Landline and Email	349	2.3
Landline and Mobile	1166	7.8
Landline only	1148	7.7
Landline, Mobile and Email	3382	22.7
Mobile and Email	5312	35.6
Mobile only	3101	20.8
TOTAL	14926	100.0

The number of pre-operative phone calls made per procedure after 12 June 2019 as shown in Table B (when the calls were first logged in the RAPID system).

Table B Number of Pre-Op Phone calls per Procedure (After 12 June 2019)

Number of Phone Calls	N	%
1	253	41.7
2	134	22.1
3	92	15.2
4	83	13.7
5	28	4.6
6	9	1.5
7	2	0.3
8	6	1.0
TOTAL	607	

\*Note: This table would only be reflective of CRISTAL patients who were also registered to participate in PROMs and were still receiving pre-operative calls.

Of the 12,871 procedures that had a completed pre-operative PROMs, 10,543 (81.9%) did not receive a phone call (Table C).

Table C Phone Call Follow-Up and Completion of Pre-Op PROMs (Procedures)

Received	Not Completed				Completed*			TOTAL		
Phone Call	N	Row%	Col%	N	Row%	Col%	N	Row%	Col%	
No	1198	10.2	58.3	10543	89.8	81.9	11741	100.0	78.7	
Yes	857	26.9	41.7	2328	73.1	18.1	3185	100.0	21.3	
TOTAL	2055	13.8	100.0	12871	86.2	100.0	14926	100.0	100.0	

Of the 4,779 procedures that had a completed post-operative PROMs, 3067 (64.2%) did not receive a phone call (Table D).

Table D Phone Call Follow-Up and Completion of Post-Op PROMs (Procedures)

Received	Not Completed				Completed*			TOTAL		
Phone Call	N	Row%	Col%	N	Row%	Col%	N	Row%	Col%	
No	464	13.1	43.0	3067	86.9	64.2	3531	100.0	60.3	
Yes	615	26.4	57.0	1712	73.6	35.8	2327	100.0	39.7	
TOTAL	1079	18.4	100.0	4779	81.6	100.0	5858	100.0	100.0	

Of the 409 procedures undertaken in patients aged 85 years of age or older, 125 (30.6%) received a phone call for pre-operative PROMs collection. Comparatively, of the 1,560 procedures undertaken in patients under 55 years of age, 271 (17.4%) received a phone call for pre-operative PROMs (Table E)

Table E Phone Call Follow-Up by Age for Pre-Op PROMs (Procedures)

		No			Yes			TOTAL	
Age	N	Row%	Col%	N	Row%	Col%	N	Row%	Col%
<55	1289	82.6	11.0	271	17.4	8.5	1560	100.0	10.5
55-64	3349	81.4	28.5	767	18.6	24.1	4116	100.0	27.6
65-74	4499	78.4	38.3	1240	21.6	38.9	5739	100.0	38.4
75-84	2320	74.8	19.8	782	25.2	24.6	3102	100.0	20.8
≥85	284	69.4	2.4	125	30.6	3.9	409	100.0	2.7
TOTAL	11741	78.7	100.0	3185	21.3	100.0	14926	100.0	100. 0

For procedures where a phone call was made, 2,328 (73.1%) completed at least one question of their pre-operative PROMs. Completion rates ranged from 63.5% in the under 55 years age group to 74.8% in the 65-74 years age group (Table F).

Table F Pre-Op PROMs Completion Status by Age for those who received a phone call (Procedures)

	Not Completed		Comp	leted*	TOTAL		
Age	N	%	N	%	N	%	
<55	99	36.5	172	63.5	271	100.0	
55-64	213	27.8	554	72.2	767	100.0	
65-74	312	25.2	928	74.8	1240	100.0	
75-84	201	25.7	581	74.3	782	100.0	
≥85	32	25.6	93	74.4	125	100.0	
TOTAL	857	26.9	2328	73.1	3185	100.0	

For procedures where a phone call was not made, 10,543 (89.8%) completed at least one preoperative PROMs question. Completion rates ranged from 81.7% in the 85 and over years age group to 91.4% in the under 55 years age group (Table G).

Table G Pre-Op PROMs Completion Status by Age for those who did not receive a phone call (Procedures)

	Not Completed		Comp	leted*	TOTAL		
Age	N	%	N	%	N	%	
<55	111	8.6	1178	91.4	1289	100.0	
55-64	301	9.0	3048	91.0	3349	100.0	
65-74	427	9.5	4072	90.5	4499	100.0	
75-84	307	13.2	2013	86.8	2320	100.0	
≥85	52	18.3	232	81.7	284	100.0	
TOTAL	1198	10.2	10543	89.8	11741	100.0	

There was minimal difference in the percentage of females and males requiring a pre-operative phone call, 23.2% compared to 24.5% respectively (Table H).

Table H Phone Call Follow-Up by Gender for Pre-Op PROMs (Procedures)

		No			Yes			TOTAL	
Gender	N	Row%	Col%	N	Row%	Col%	N	Row%	Col%
Female	4787	76.8	55.3	1443	23.2	53.4	6230	100.0	54.9
Male	3868	75.5	44.7	1258	24.5	46.6	5126	100.0	45.1
TOTAL	8655	76.2	100.0	2701	23.8	100.0	11356	100.0	100.0

The number of pre-operative calls made per procedure after 12 June 2019 (when the calls were first logged in the *RAPID* system) is presented in Table I. Of the 1,436 procedures, 655 procedures received only 1 phone call and 5 procedures received 7 phone calls. Note, this table does not necessarily reflect a successful outcome (i.e. a completed pre-operative survey).

Table I Number of Post-Op Phone calls per Procedure (After 12 June 2019)

Number of Phone Calls	N	%
1	655	45.6
2	312	21.7
3	232	16.2
4	182	12.7
5	34	2.4
6	16	1,1
7	5	0.3
TOTAL	1436	100.0

Of the 138 procedures undertaken in patients aged 85 years or older, 104 (75.4%) received a phone call for post-operative PROMs. Comparatively, of the 1,504 procedures undertaken in patients aged 55-64 years, 574 (38.2%) received a phone call for post-operative PROMs (Table J).

Note that a higher proportion of patients required a phone call post operatively compared to pre operatively (Table B).

Table J Phone Call Follow-Up by Age for Post-Op PROMs (Procedures)

		No			Yes			TOTAL	
Age	N	Row%	Col%	N	Row%	Col%	N	Row%	Col%
<55	293	55.9	9.9	231	44.1	10.0	524	100.0	9.9
55-64	930	61.8	31.3	574	38.2	24.7	1504	100.0	28.4
65-74	1205	59.3	40.5	828	40.7	35.7	2033	100.0	38.4
75-84	510	46.6	17.2	584	53.4	25.2	1094	100.0	20.7
≥85	34	24.6	1.1	104	75.4	4.5	138	100.0	2.6
TOTAL	2972	56.1	100.0	2321	43.9	100.0	5293	100.0	100.0

For procedures where a phone call was made, 1693 (73.4%) completed at least one question of their post-operative PROMs. Completion rates ranged from 58.4% in the under 55 years age group to 76.8% in the 75-84 years age group (Table K).

Table K Post-Op PROMs Completion Status by Age for those who received a phone call (Procedures)

	Not Completed		Comp	leted*	то	TOTAL	
Age	N	%	N	%	N	%	
<55	96	41.6	135	58.4	231	100.0	
55-64	173	30.2	400	69.8	573	100.0	
65-74	187	22.7	636	77.3	823	100.0	
75-84	134	23.2	444	76.8	578	100.0	
≥85	25	24.3	78	75.7	103	100.0	
TOTAL	615	26.6	1693	73.4	2308	100.0	

For procedures where a phone call was not required, 2491 (84.3%) completed at least one post-operative PROMS question. Completion rates ranged from 75.8% in the 85 and over age group to 85.5% in the 55-64 years age group (Table L).

Table L Post-Op PROMs Completion Status by Age for those who did not receive a phone call (Procedures)

	Not Completed		Comple	eted*	TOTAL	
Age	N	%	N	%	N	%
<55	43	14.7	250	85.3	293	100.0
55-64	135	14.5	794	85.5	929	100.0
65-74	178	14.8	1021	85.2	1199	100.0
75-84	100	20.0	401	80.0	501	100.0
≥85	8	24.2	25	75.8	33	100.0
TOTAL	464	15.7	2491	84.3	2955	100.0

There was minimal difference in the percentage of females and males requiring a post-operative phone call, 44.6% compared to 43.0% respectively (Table M).

Table M Phone Call Follow-Up by Gender for Post-Op PROMs (Procedures)

		No			Yes			TOTAL	
Gender	N	Row%	Col%	N	Row%	Col%	N	Row%	Col%
Female	1615	55.4	54.3	1299	44.6	56.0	2914	100.0	55.1
Male	1357	57.0	45.7	1022	43.0	44.0	2379	100.0	44.9
TOTAL	2972	56.1	100.0	2321	43.9	100.0	5293	100.0	100.0

Table N provides detail of the type of assistance received to complete the PROMs at both pre and post-operative timepoints.

Table N Assistance Received to Complete PROMs

	Pre-Op	erative*	Post-Operative		
Assistance Received	N	%	N	%	
N/A	740	9.8	25	0.5	
ACORN	782	10.3	1448	30.6	
No	4292	56.8	3015	63.8	
Yes, a family member	782	10.3	217	4.6	
Yes, a friend	34	0.4	6	0.1	
Yes, a health professional	759	10.0	5	0.1	
Yes, someone else	173	2.3	9	0.2	
TOTAL	7562	100.0	4725	100.0	

<sup>\*</sup>Data prior to 27 May 2019

The Figures below illustrate the distribution of the outcomes for procedures where a phone call was required, compared to procedures where a phone call was not required.

### **Hips**

Figure A Pre-Op EQ-5D Mobility of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

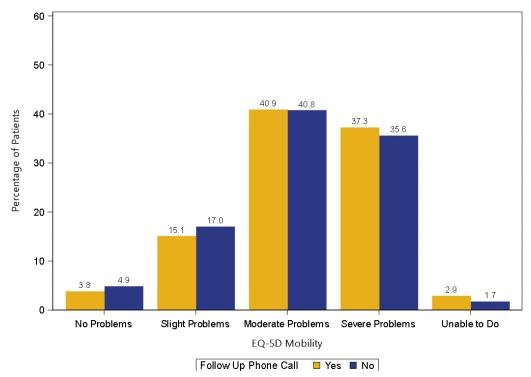


Figure B Post-Op EQ-5D Mobility of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

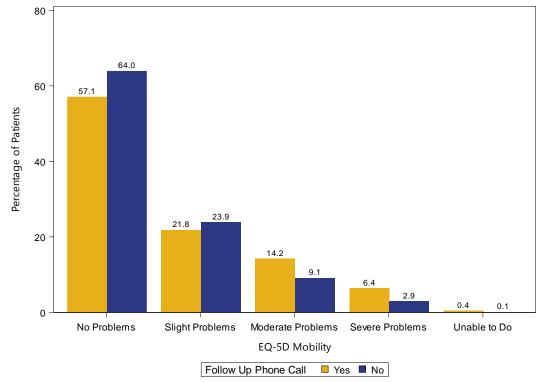


Figure C Pre-Op EQ-5D Personal Care of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

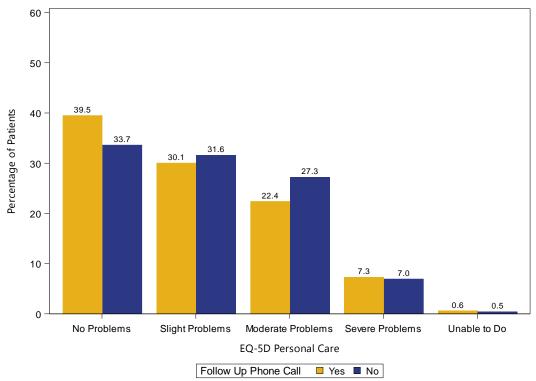


Figure D Post-Op EQ-5D Personal Care of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

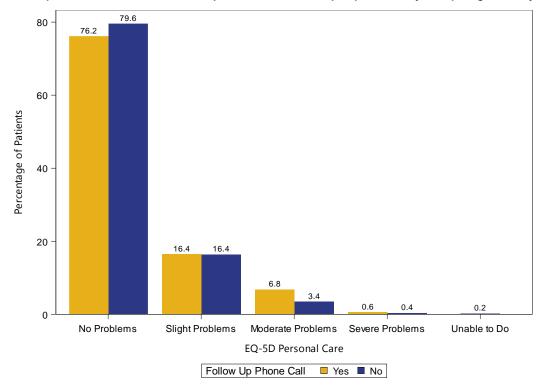


Figure E Pre-Op EQ-5D Usual Activities of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

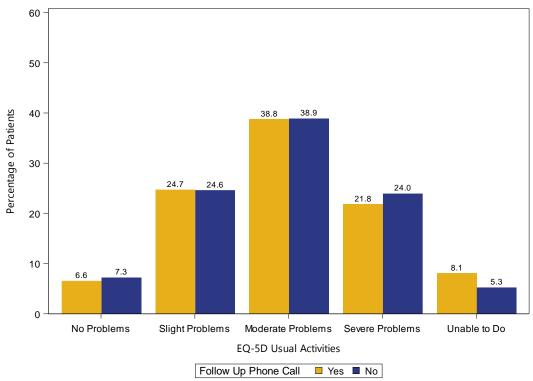


Figure F Post-Op EQ-5D Usual Activities of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

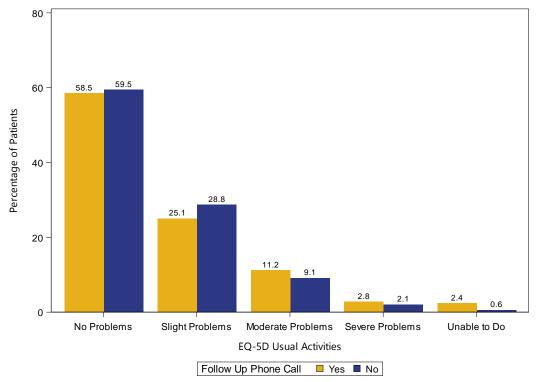


Figure G Pre-Op EQ-5D Pain / Discomfort of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

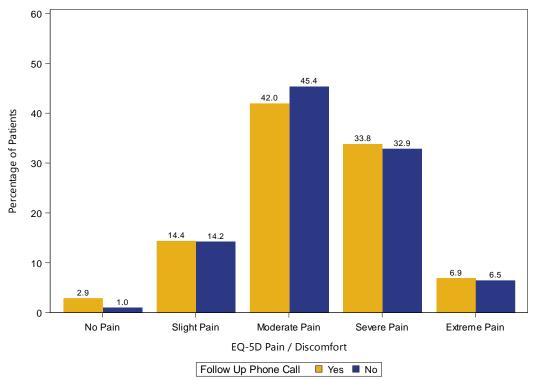


Figure H Post-Op EQ-5D Pain / Discomfort of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

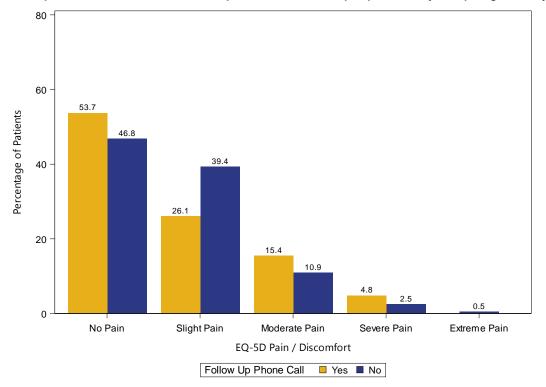


Figure I Pre-Op EQ-5D Depression / Anxiety of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

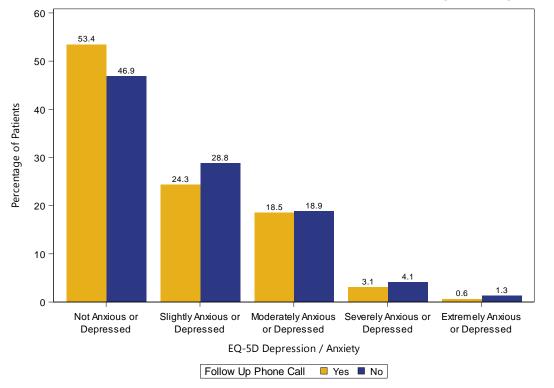


Figure J Post-Op EQ-5D Depression / Anxiety of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

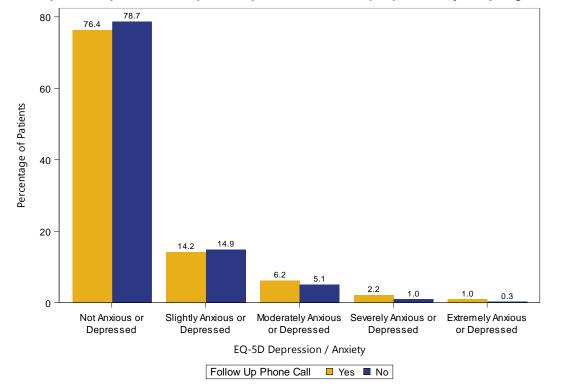


Figure K Pre-Op EQ VAS of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

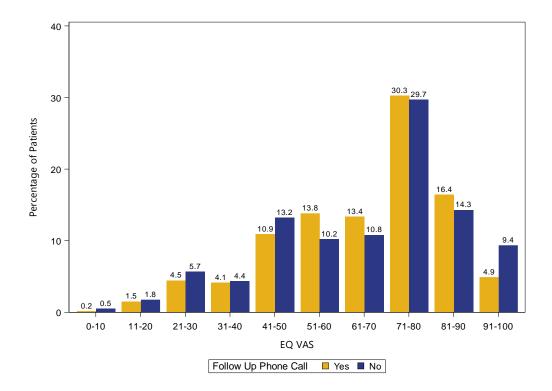


Figure L Post-Op EQ VAS of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

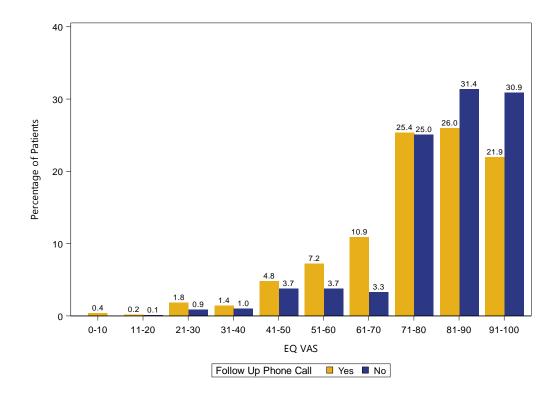


Figure M Pre-Op Oxford Hip Score of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

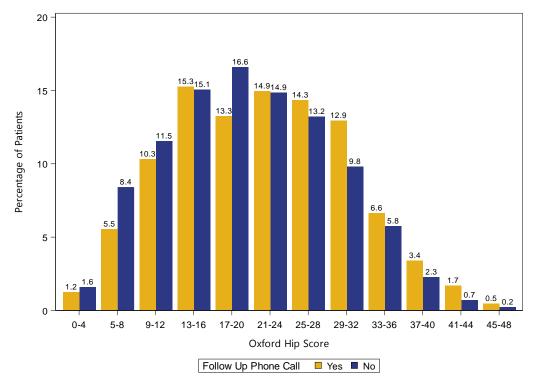


Figure N Post-Op Oxford Hip Score of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

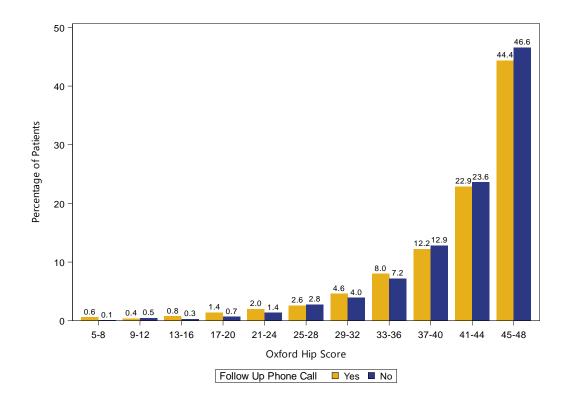


Figure O Pre-Op HOOS-12 Summary Score of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

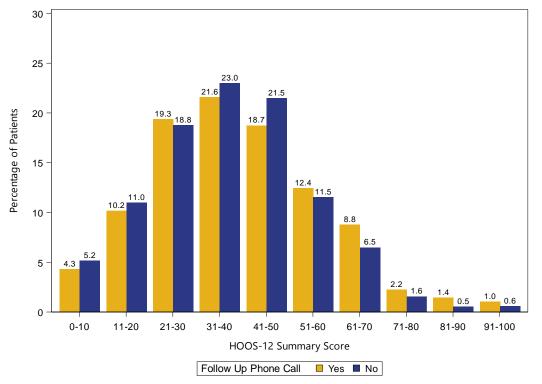


Figure P Post-Op HOOS-12 Summary Score of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

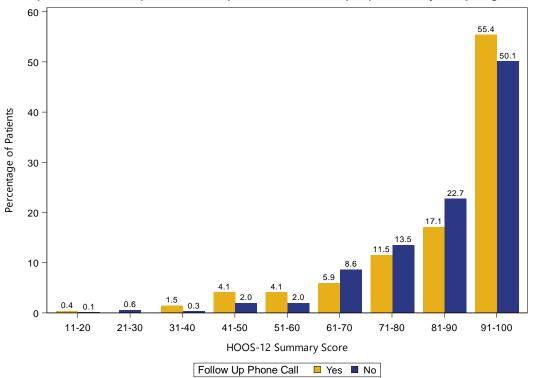


Figure Q Pre-Op Affected Joint Pain of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

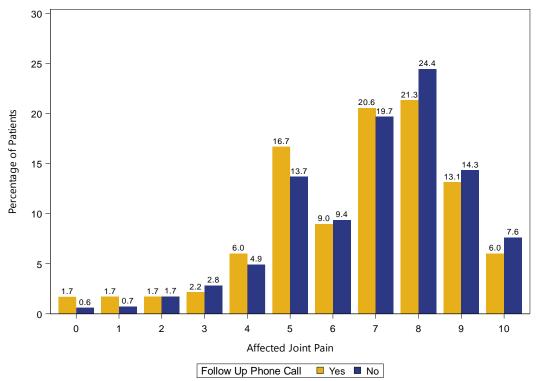
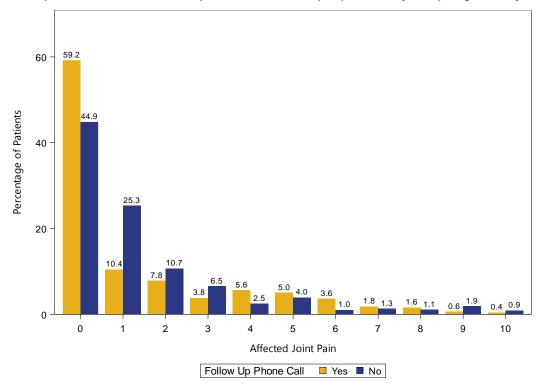


Figure R Post-Op Affected Joint Pain of Primary Total Conventional Hip Replacement (Primary Diagnosis OA)



### Knees

Figure S Pre-Op EQ-5D Mobility of Primary Total Knee Replacement (Primary Diagnosis OA)

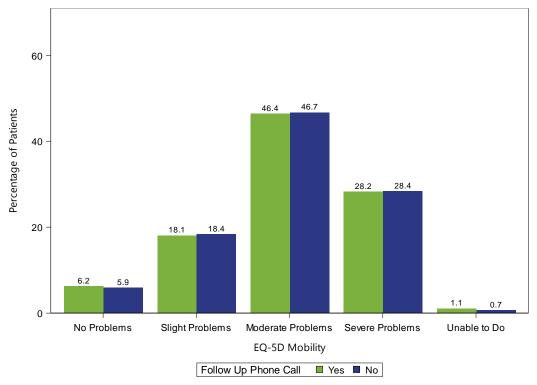


Figure T Post-Op EQ-5D Mobility of Primary Total Knee Replacement (Primary Diagnosis OA)

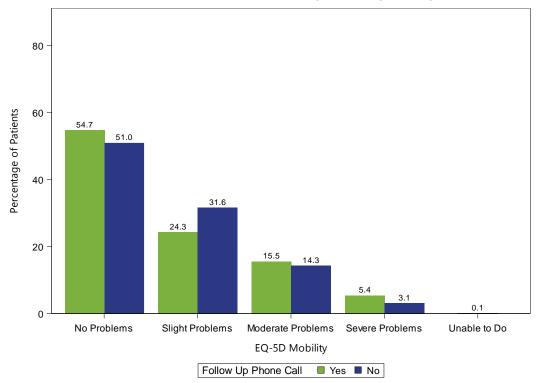


Figure U Pre-Op EQ-5D Personal Care of Primary Total Knee Replacement (Primary Diagnosis OA)

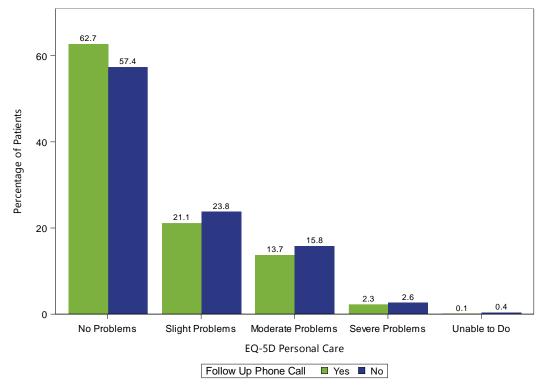


Figure V Post-Op EQ-5D Personal Care of Primary Total Knee Replacement (Primary Diagnosis OA)

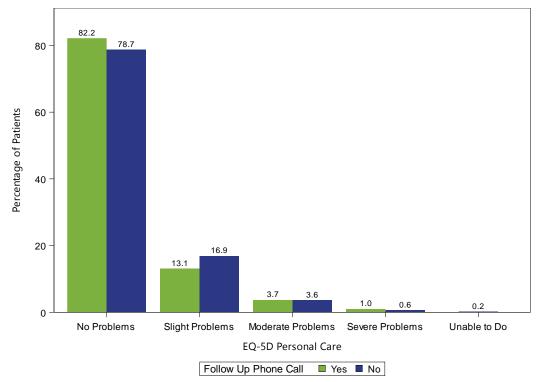


Figure W Pre-Op EQ-5D Usual Activities of Primary Total Knee Replacement (Primary Diagnosis OA)

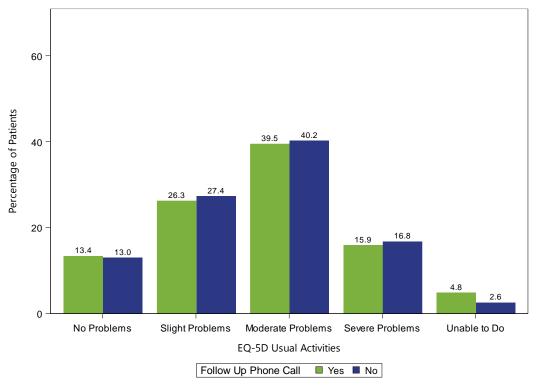


Figure X Post-Op EQ-5D Usual Activities of Primary Total Knee Replacement (Primary Diagnosis OA)

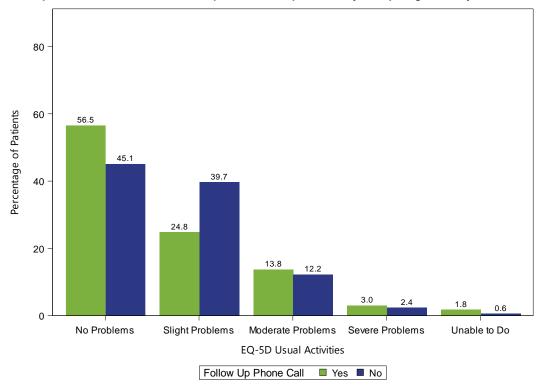


Figure Y Pre-Op EQ-5D Pain / Discomfort of Primary Total Knee Replacement (Primary Diagnosis OA)

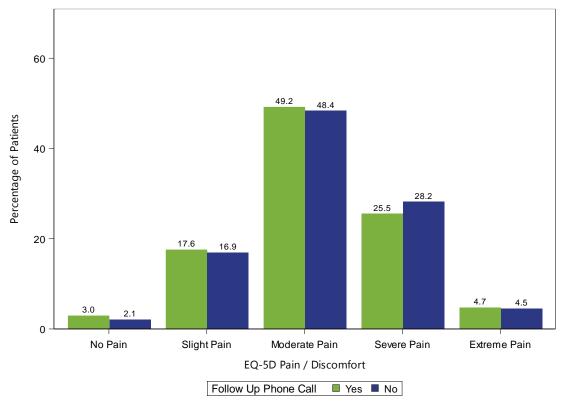


Figure Z Post-Op EQ-5D Pain / Discomfort of Primary Total Knee Replacement (Primary Diagnosis OA)

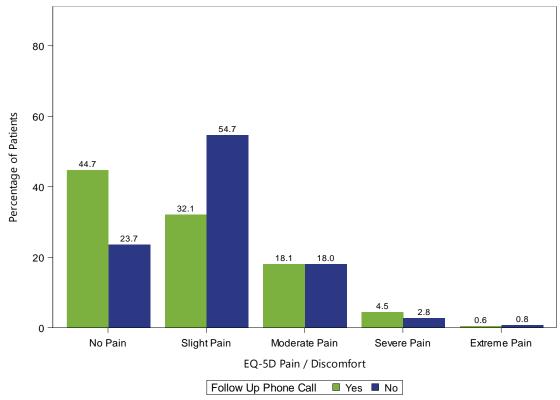


Figure AA Pre-Op EQ-5D Depression / Anxiety of Primary Total Knee Replacement (Primary Diagnosis OA)

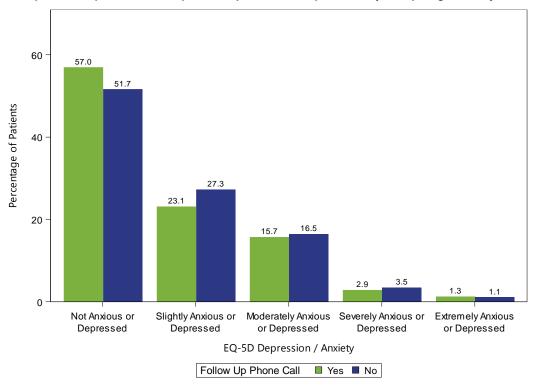


Figure BB Post-Op EQ-5D Depression / Anxiety of Primary Total Knee Replacement (Primary Diagnosis OA)

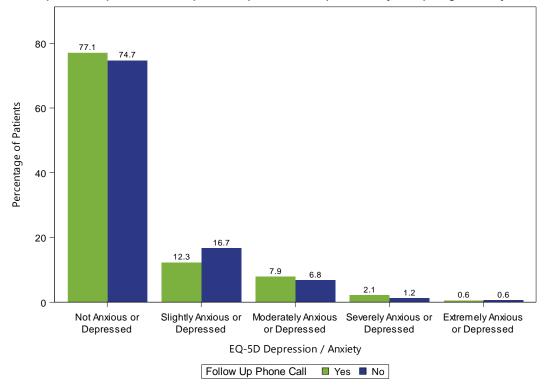


Figure CC Pre-Op EQ VAS of Primary Total Knee Replacement (Primary Diagnosis OA)

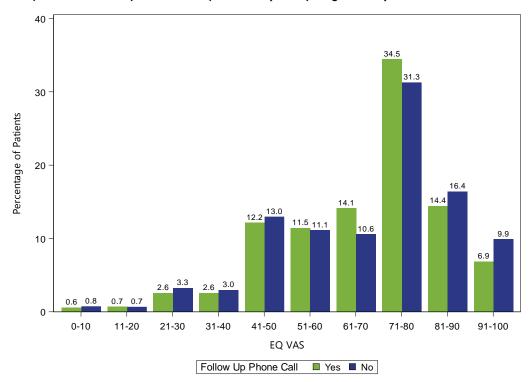


Figure DD Post-Op EQ VAS of Primary Total Knee Replacement (Primary Diagnosis OA)

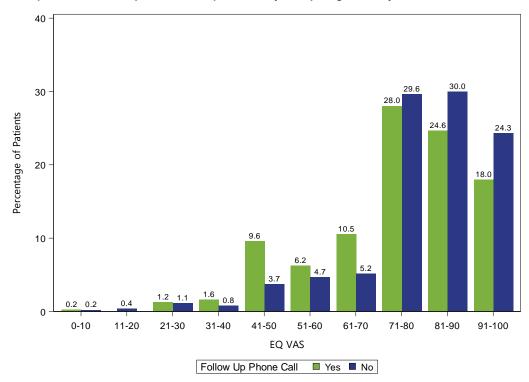


Figure EE Pre-Op Oxford Knee Score of Primary Total Knee Replacement (Primary Diagnosis OA)

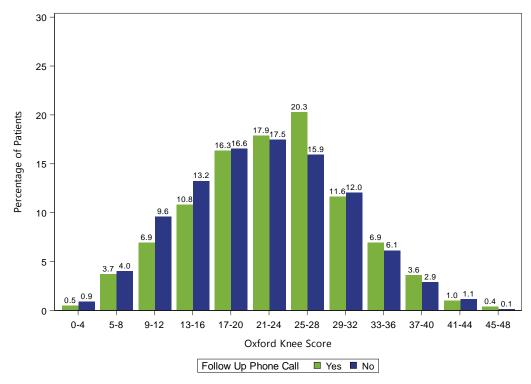


Figure FF Post-Op Oxford Knee Score of Primary Total Knee Replacement (Primary Diagnosis OA)

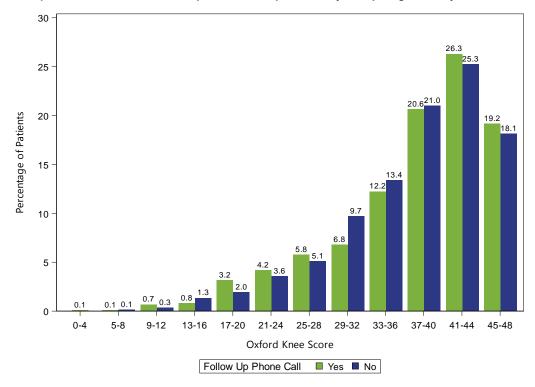


Figure GG Pre-Op KOOS-12 Summary Score of Primary Total Knee Replacement (Primary Diagnosis OA)

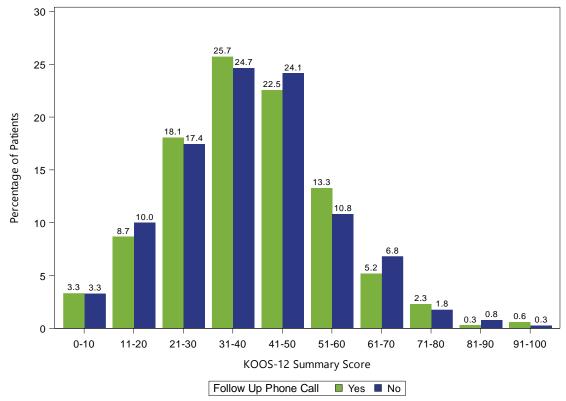


Figure HH Post-Op KOOS-12 Summary Score of Primary Total Knee Replacement (Primary Diagnosis OA)

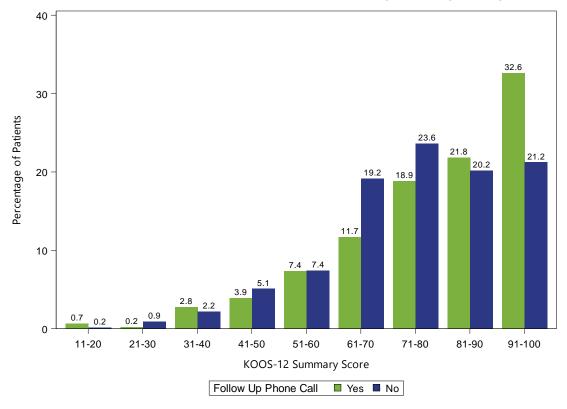


Figure II Pre-Op Affected Joint Pain of Primary Total Knee Replacement (Primary Diagnosis OA)

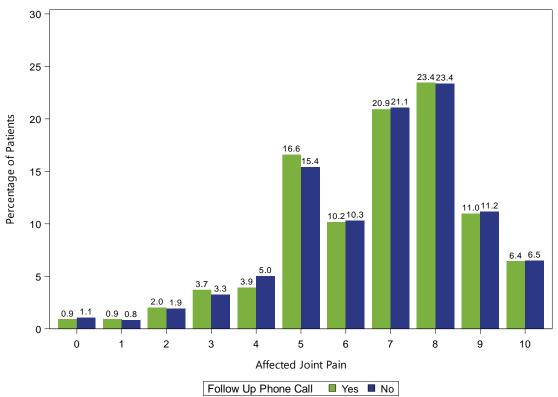
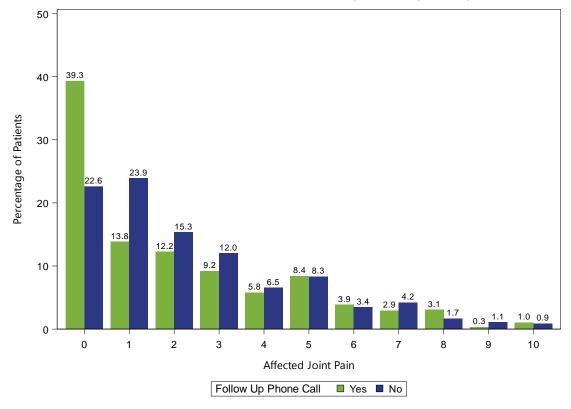


Figure JJ Post-Op Affected Joint Pain of Primary Total Knee Replacement (Primary Diagnosis OA)



### **Shoulders**

Figure KK Pre-Op EQ-5D Mobility of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

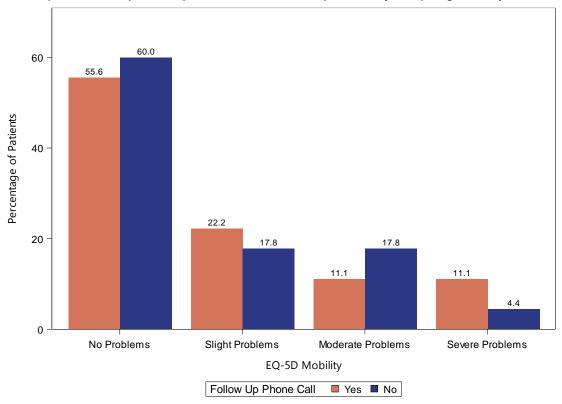


Figure LL Post-Op EQ-5D Mobility of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

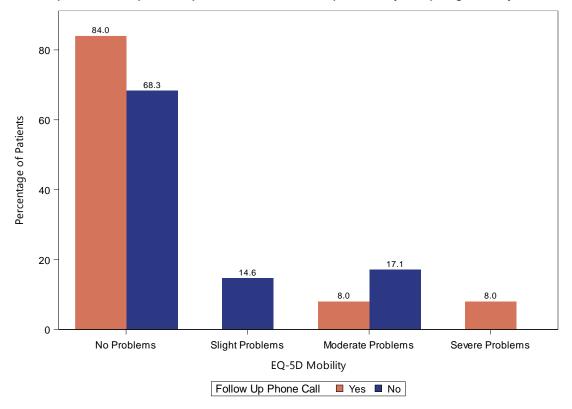


Figure MM Pre-Op EQ-5D Personal Care of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

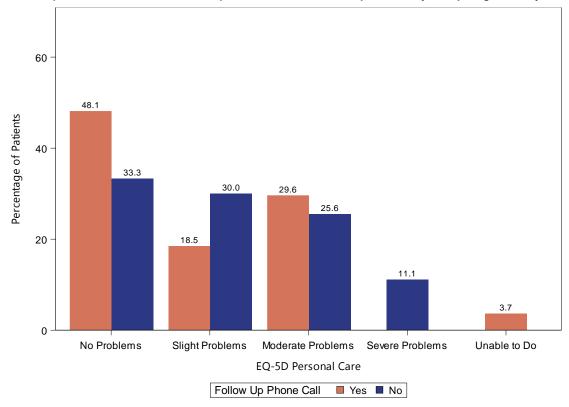


Figure NN Post-Op EQ-5D Personal Care of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

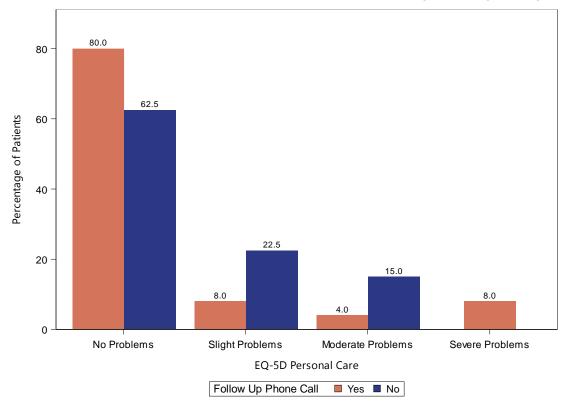


Figure OO Pre-Op EQ-5D Usual Activities of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

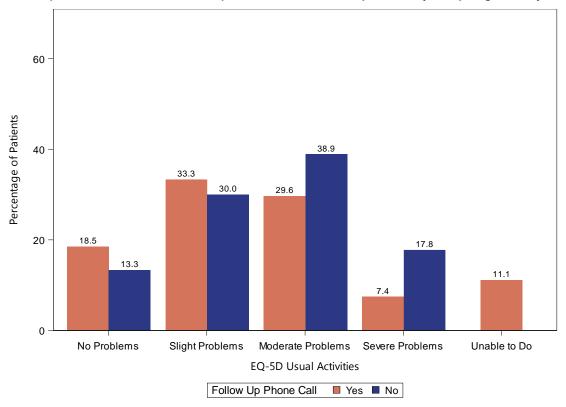


Figure PP Post-Op EQ-5D Usual Activities of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

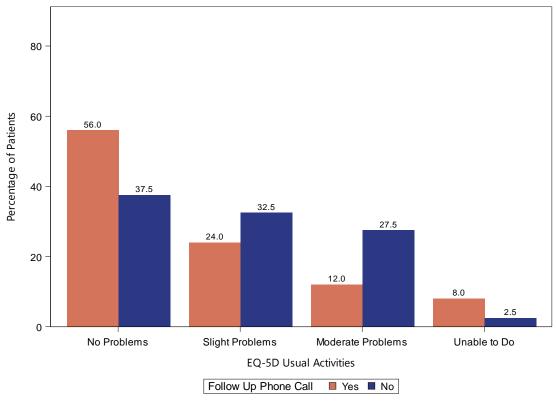


Figure QQ Pre-Op EQ-5D Pain / Discomfort of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

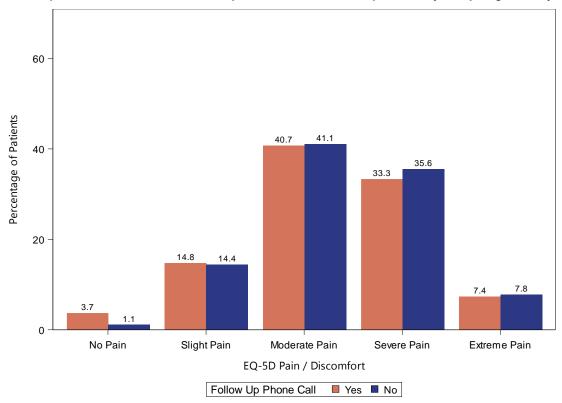


Figure RR Post-Op EQ-5D Pain / Discomfort of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

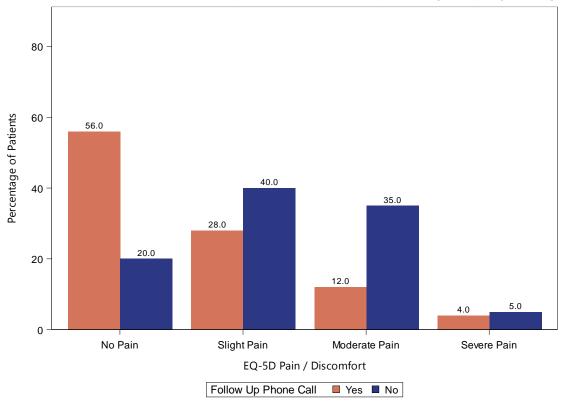


Figure SS Pre-Op EQ-5D Depression / Anxiety of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

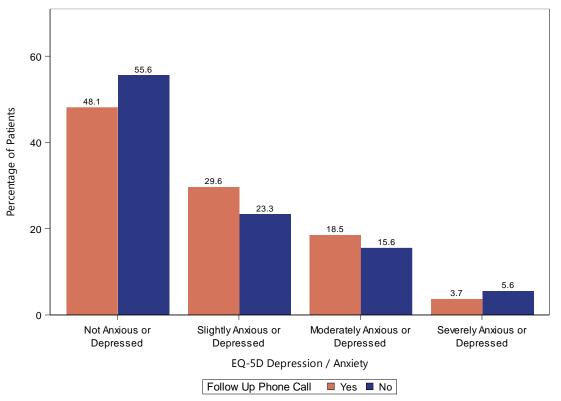


Figure TT Post-Op EQ-5D Depression / Anxiety of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

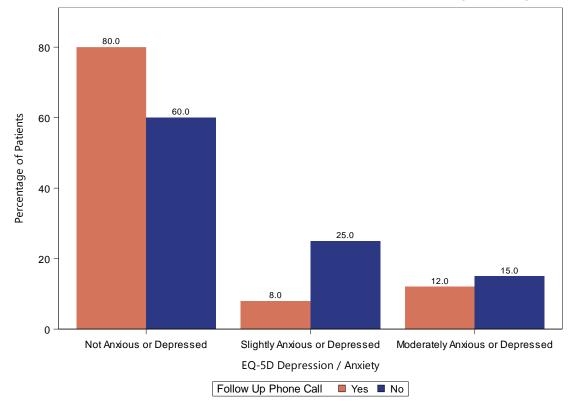


Figure UU Pre-Op EQ VAS of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

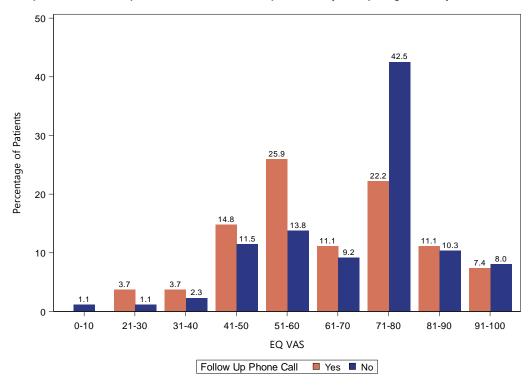


Figure VV Post-Op EQ VAS of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

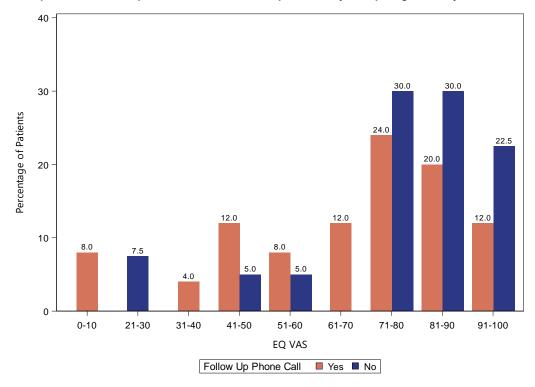
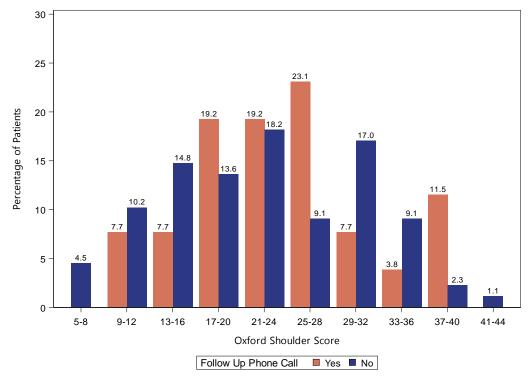


Figure WW Pre-Op Oxford Shoulder Score of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)



<sup>\*</sup>no patients with as score between 45-48

Figure XX Post-Op Oxford Shoulder Score of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

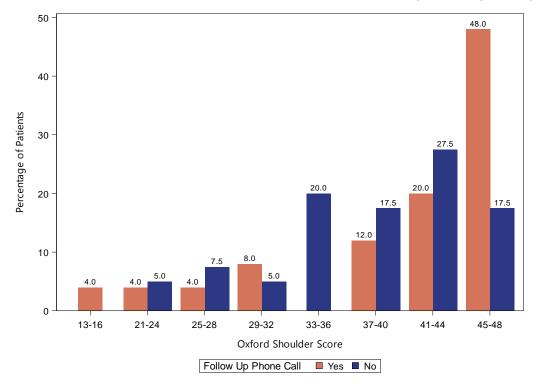


Figure YY Pre-Op Affected Joint Pain of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

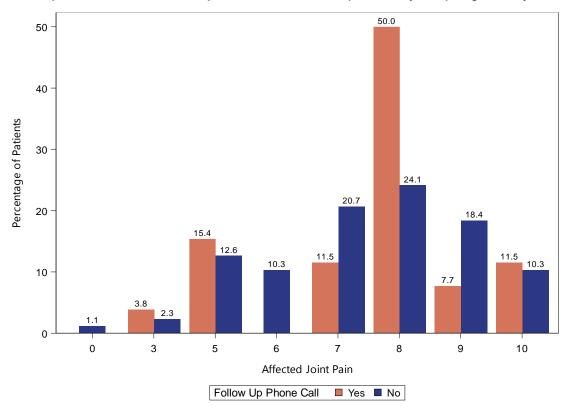
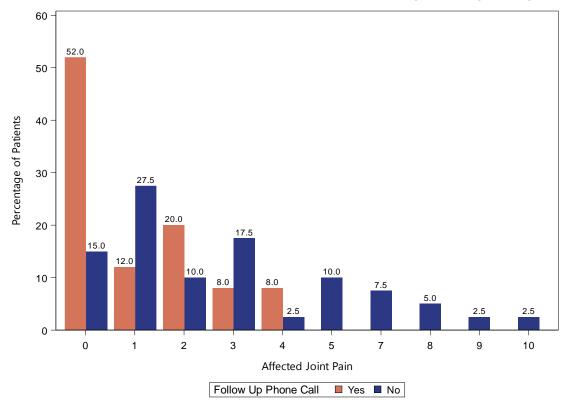


Figure ZZ Post-Op Affected Joint Pain of Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)



### **Surgeon Surveys**

_	Question	Options / Response			
General	Information				
1	Date				
		NSW			
		VIC			
		QLD			
		SA			
2	State	TAS			
		WA			
		ACT			
		NT			
	Hospital Type (in which setting have the majority of your	Public			
3	patients been registered)	Private			
		riivale			
Registrat	ion				
		Hospital Pre-admission Clinic			
4	In what setting are patients registered for the PROMs Pilot? (Select all that apply)	Surgeon Rooms			
-	Thory (select all that apply)	Mix Pre-admission and Surgeon Rooms			
		Patient Self-Register			
		Consultant / Surgeon			
5	Are you a	Registrar			
		Resident / Intern			
		Directly from the Registry			
	How did you hear about the PROMs Pilot? (select all that	Senior Surgeon			
6	apply)	Other Surgical colleagues			
		Conference/Presentation			
		Other source			
	When you see your patients pre-operatively, do you	Always			
7	advise them that you would like them to complete the	Sometimes			
	PROMs Pilot survey questions	Never			
		Yes			
8	Do you explain to the patient what is required of them	No			
	when participating in the PROMs Pilot	Someone else does this			
		No-one does this			
Dashboa	ırd				
	Have you logged onto the AOANJRR PROMs dashboard	Yes			
9	to see your patient results?	No			
		I was unaware that I have a dashboard			
Individud	n Poculte	1 was oriawate trial i flave a dastibodia			
maiviauc	ii results				
10	If yes, do you look at the results for each individual patient	Yes			
		No			
Patient d	iscussion				
	If you look at the individual results, do you discuss this	Yes			
11	information in your consultation process with the patient	No			
Aggrega	ted Results	110			
~991e9u	new results				
12	Do you view the aggregated results for your patients?	Yes			
		No			
Intended	Use				
		Patient education			
	When are your single for independ to be a DDOLLE D'	Monitoring patient outcomes after surgery			
13	What are you using (or intend to) use the PROMs Pilot data for? (select all that apply)	Staff education			
		Benchmarking			
		Research			

### Appendix 2 Stakeholder Feedback Surveys

		Quality Improvement Activities		
1.4	Have balaful da var la diava DDOM a data ia	Not helpful		
14	How helpful do you believe PROMs data is	Very helpful		
ecruitm	nent Data Reports			
15	Have you seen any of the Recruitment Data Reports for	Yes		
15	the PROMs Pilot from the AOANJRR	No		
16	How helpful are these reports	Yes		
10	now helpful die linese reports	No		
17	Do you think collecting PROMs for joint replacement is	Yes		
17	important	No		
atient V	/alue			
	Do you think your patients see value in the collection of	Yes		
18	PROMs?	No		
		Unsure		
19	Why do patients see value?	Free text		
20	Why don't patients see value?	Free text		
ontinu	ation of PROMs			
21	Do you think the collection of PROMs by the AOANJRR for	Yes		
21	joint replacement should continue?	No		
22	Why do you think the AOANJRR PROMs should continue?	Free text		
23	Do you think the collection of PROMs by the AOANJRR for joint replacement should continue?	Free text		
24	Please provide any additional feedback about the AOANJRR PROMs pilot project	Free text		
25	Have you seen any of the Recruitment Data Reports for	Yes		
23	the PROMs Pilot from the AOANJRR?	No		

### **Administrator Group Survey**

	Question	Options / Response				
Ger	eral Information					
1	Date					
		NSW				
		VIC				
		QLD				
		SA				
2	State	TAS				
		WA				
		ACT				
		NT				
	Hospital Type (in which setting have the majority of your	Public				
3	patients been registered)	Private				
	Registration					
		Hospital Pre-admission Clinic				
	In what setting are patients registered for the PROMs Pilot?	Surgeon Rooms				
4	(Select all that apply)	Mix Pre-admission and Surgeon Rooms				
		Patient Self-Register				
		Nurse				
_	Who registers patients in the PROMs Pilot System? (Select all that	Admin				
5	apply)	Surgeon				
		Patient				
		Other				
	Education	M/s /A desirable and a second and a second and				
		We (Administrators) provide patients education				
	Who is responsible for educating patients regarding the PROMs	The surgeon provides the education.				
6	Pilot? (select one)	We provide Patient Information Cards only				
		We are not involved with education of patients				
		Not sure				
	iPad use					
		Always				
7	Were patients provided with an iPad to register themselves in	Sometimes				
,	PROMs Pilot system?	Never				
		No iPad provided				
	Patient decline					
8	Have any patients declined to participate in the PROMs Pilot,	Free text				
	Patient concerns					
		Worried about the security				
0		No access to phone or computer				
9	If yes, what are the main patient concerns? (select all that apply)	Lack of assistance to complete the survey				
		The patient does not see the value in PROMs				
	Completion of PROMs questions					
		Always				
0	At your site, did patients utilise an iPad during their visit to	Sometimes				
0	complete the electronic PROMs Pilot survey questions?	Never				
		No iPad provided				
	Proportion Assist	`				
		None				
		<25%				
	Of the patients using iPads; What proportion required assistance	26-50%				
11	i.e. staff, family or interpreter to complete their PROMs Survey?	51-75%				
	, , , , , , , , , , , , , , , , , , , ,	76-100%				
		No iPad provided				
		Ινοιι αα ριονιασα				

### Appendix 2 Stakeholder Feedback Surveys

	Staff Resources					
		<15 minutes				
	Now that are familiar with the PROMs Pilot system, please	16-30 minutes				
12	estimate how much time per week is being spent registering	40 minutes – 1 hour				
	patients?	>1 hour but <4 hours				
		More than 4 hours per week				
	Staff changes					
	Since the beginning of the PROME Pilet, have there been any	Yes				
13	Since the beginning of the PROMs Pilot, have there been any changes to the staff who register patients?	No				
	Grianigos io mo oran imo regional panerno:	Not sure				
	Staff handover					
	When now staff commones does their handover/industion	Yes				
14	When new staff commence does their handover/induction include training for the PROMs Pilot system?	No				
	The load training for the FRONS Filot Systems	Not sure				
	Perceived Value					
15	Do you think collecting PROMs for joint replacement is important?	Free text				
	Patients view					
		Yes				
16	Do you think your patients see value in the collection of PROMs?	No				
		Not sure				
17	Why do patients see value?	Free text				
18	Why don't patients see value?	Free text				
19	Do you think the collection of PROMs by the AOANJRR for joint replacement should continue?	Free text				
20	Why do you think the AOANJRR PROMs should continue?	Free text				
21	Why do you think the AOANJRR PROMs should discontinue?	Free text				
	Use of PROMs					
		Patient education				
		Monitoring patient outcomes after surgery				
	What do you think your hospital/practice might use the	Staff education				
22	PROMs data for? (select all that apply	Benchmarking				
	, , ,	Research				
		Quality Improvement Activities				
	Changes to PROMs					
23	What changes could the Registry implement to make it easier for you to participate in the PROMs Pilot?	Free text				
	Quality improvement					
24	To help us support future sites, can you tell us about changes you have implemented that improved the patient registration or data collection process for the PROMs Pilot?	Free text				
25	Please provide any additional feedback about the AOANJRR PROMs Pilot Project?	Free text				

# **Total Conventional Hip Replacement**

Table i. Post-Operative vs Pre-Operative Scores for Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

Outcome	N Pre-Op	Pre-Op Median (IQR)	Pre-Op Mean (Std)	N Post- Op	Post-Op Median (IQR)	Post-Op Mean (Std)	Unadjusted Mean Difference (95% CI)	Unadjusted P Value	Adjusted Mean Difference (95% CI)	Adjusted P Value
EQ VAS	3257	74.0 (51.0 - 80.0)	66.8 (20.1)	1567	85.0 (75.0 - 92.0)	81.5 (15.5)	14.7 (13.8, 15.6)	<.0001	14.7 (13.8, 15.6)	<.0001
Oxford Hip Score	3240	20.0 (14.0 - 27.0)	20.4 (8.8)	1563	44.0 (39.0 - 47.0)	41.7 (7.1)	21.3 (20.8, 21.7)	<.0001	21.3 (20.9, 21.7)	<.0001
HOOS-12 Pain	2236	37.5 (25.0 - 50.0)	37.7 (18.4)	1165	93.8 (81.3 - 100.0)	88.1 (16.2)	50.4 (49.3, 51.6)	<.0001	50.5 (49.3, 51.6)	<.0001
HOOS-12 Function	2226	43.8 (31.3 - 56.3)	44.5 (20.3)	1165	93.8 (81.3 - 100.0)	88.8 (13.7)	44.3 (43.3, 45.4)	<.0001	44.4 (43.4, 45.5)	<.0001
HOOS-12 Quality of Life	2219	31.3 (18.8 - 43.8)	30.5 (19.0)	1165	87.5 (68.8 - 100.0)	81.5 (18.8)	51.0 (49.7, 52.2)	<.0001	51.0 (49.8, 52.3)	<.0001
HOOS-12 Summary	2219	37.5 (25.0 - 50.0)	37.5 (17.4)	1165	91.7 (79.2 - 97.9)	86.1 (14.9)	48.6 (47.6, 49.7)	<.0001	48.7 (47.6, 49.7)	<.0001
Lower Back Pain	3259	5.0 (1.0 - 7.0)	4.2 (3.0)	1570	2.0 (0.0 - 5.0)	2.7 (2.9)	-1.4 (-1.6, -1.3)	<.0001	-1.4 (-1.6, -1.3)	<.0001
Affected Joint Pain	3228	7.0 (5.0 - 8.0)	6.9 (2.0)	1562	1.0 (0.0 - 2.0)	1.4 (2.2)	-5.5 (-5.6, -5.4)	<.0001	-5.5 (-5.6, -5.4)	<.0001

Table ii. Post-Operative vs Pre-Operative EQ-5D-5L Responses for Primary Total Conventional Hip Replacement (Primary Diagnosis OA)

Outcome	N (%) Pre-Op	N (%) Post-Op	Unadjusted Relative Risk (95% CI)	Unadjusted P Value	Adjusted Relative Risk (95% CI)	Adjusted P Value
Mobility	3150/3304 (95.3%)	598/1578 (37.9%)	0.40 (0.37, 0.42)	<.0001	0.40 (0.37, 0.42)	<.0001
Personal Care	2152/3302 (65.2%)	336/1575 (21.3%)	0.33 (0.30, 0.36)	<.0001	0.33 (0.30, 0.36)	<.0001
Usual Activities	3067/3302 (92.9%)	639/1575 (40.6%)	0.44 (0.41, 0.46)	<.0001	0.44 (0.41, 0.46)	<.0001
Pain and Discomfort	3247/3293 (98.6%)	797/1575 (50.6%)	0.51 (0.49, 0.54)	<.0001	0.51 (0.49, 0.54)	<.0001
Anxiety and Depression	1706/3293 (51.8%)	349/1575 (22.2%)	0.43 (0.39, 0.47)	<.0001	0.43 (0.39, 0.47)	<.0001

# **Total Knee Replacement**

Table iii. Post-Operative vs Pre-Operative Scores for Primary Total Knee Replacement (Primary Diagnosis OA)

Outcome	N Pre-Op	Pre-Op Median (IQR)	Pre-Op Mean (Słd)	N Post-Op	Post-Op Median (IQR)	Post-Op Mean (Std)	Unadjusted Mean Difference (95% CI)	Unadjusted P Value	Adjusted Mean Difference (95% CI)	Adjusted P Value
EQ VAS	5249	75.0 (53.0 - 81.0)	69.1 (18.7)	2483	80.0 (74.0 - 90.0)	79.2 (16.0)	10.1 (9.4, 10.8)	<.0001	10.1 (9.4, 10.8)	<.0001
Oxford Knee Score	5218	22.0 (16.0 - 28.0)	22.1 (8.3)	2471	39.0 (33.0 - 44.0)	37.6 (7.9)	15.6 (15.2, 15.9)	<.0001	15.6 (15.2, 15.9)	<.0001
KOOS-12 Pain	3264	37.5 (31.3 - 50.0)	39.5 (16.9)	1723	81.3 (62.5 - 93.8)	77.1 (19.0)	37.5 (36.5, 38.5)	<.0001	37.5 (36.5, 38.5)	<.0001
KOOS-12 Function	3249	43.8 (31.3 - 56.3)	44.9 (19.2)	1717	81.3 (75.0 - 93.8)	80.7 (16.5)	35.9 (34.9, 36.8)	<.0001	35.8 (34.8, 36.8)	<.0001
KOOS-12 Quality of Life	3243	31.3 (18.8 - 43.8)	30.8 (17.7)	1716	68.8 (56.3 - 87.5)	71.3 (20.2)	40.5 (39.4, 41.6)	<.0001	40.5 (39.4, 41.6)	<.0001
KOOS-12 Summary	3243	37.5 (27.1 - 47.9)	38.4 (16.2)	1716	77.1 (66.7 - 89.6)	76.4 (17.1)	37.9 (37.0, 38.9)	<.0001	37.9 (37.0, 38.8)	<.0001
Lower Back Pain	5260	3.0 (0.0 - 6.0)	3.4 (3.0)	2480	2.0 (0.0 - 5.0)	2.7 (3.0)	-0.7 (-0.8, -0.6)	<.0001	-0.7 (-0.8, -0.6)	<.0001
Affected Joint Pain	5197	7.0 (5.0 - 8.0)	6.7 (2.0)	2468	2.0 (0.0 - 4.0)	2.3 (2.4)	-4.4 (-4.5, -4.3)	<.0001	-4.4 (-4.5, -4.3)	<.0001

Table iv. Post-Operative vs Pre-Operative EQ-5D-5L Responses for Primary Total Knee Replacement (Primary Diagnosis OA)

Outcome	N (%) Pre-Op	N (%) Post-Op	Unadjusted Relative Risk (95% CI)	Unadjusted P Value	Adjusted Relative Risk (95% CI)	Adjusted P Value
Mobility	5009/5325 (94.1)	1187/2495 (47.6)	0.51 (0.49, 0.53)	<.0001	0.51 (0.49, 0.53)	<.0001
Personal Care	2214/5322 (41.6)	500/2490 (20.1)	0.48 (0.45, 0.52)	<.0001	0.48 (0.45, 0.52)	<.0001
Usual Activities	4621/5318 (86.9)	1253/2489 (50.3)	0.58 (0.56, 0.60)	<.0001	0.58 (0.56, 0.60)	<.0001
Pain and Discomfort	5197/5316 (97.8)	1702/2487 (68.4)	0.70 (0.68, 0.72)	<.0001	0.70 (0.68, 0.72)	<.0001
Anxiety and Depression	2515/5314 (47.3)	608/2487 (24.4)	0.52 (0.48, 0.55)	<.0001	0.52 (0.48, 0.56)	<.0001

# **Total Reverse Shoulder Replacement**

Table v. Post-Operative vs Pre-Operative Scores for Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

Outcome	N Pre- Op	Pre-Op Median (IQR)	Pre-Op Mean (Std)	N Post- Op	Post-Op Median (IQR)	Post-Op Mean (Std)	Unadjusted Mean Difference (95% CI)	Un- adjusted P Value	Adjusted Mean Difference (95% CI)	Adjusted P Value
EQ VAS	114	74.0 (53.0 - 78.0)	68.3 (17.0)	66	80.0 (70.0 - 90.0)	74.3 (21.9)	6.0 (0.3, 11.7)	0.0404	5.6 (-0.0, 11.3)	0.0515
Oxford Shoulder Score	114	22.5 (16.0 - 30.0)	22.6 (8.5)	66	41.0 (36.0 - 45.0)	38.9 (7.4)	16.3 (14.2, 18.5)	<.0001	16.2 (14.1, 18.2)	<.0001
Neck Pain	114	4.0 (0.0 - 7.0)	3.9 (3.2)	66	0.0 (0.0 - 3.0)	1.8 (2.7)	-2.1 (-2.9, -1.3)	<.0001	-2.0 (-2.8, -1.3)	<.0001
Affected Joint Pain	113	8.0 (7.0 - 9.0)	7.4 (1.8)	66	1.0 (0.0 - 3.0)	2.2 (2.5)	-5.2 (-5.9, -4.5)	<.0001	-5.2 (-5.8, -4.5)	<.0001

### Table vi. Post-Operative vs Pre-Operative EQ-5D-5L Responses for Primary Total Reverse Shoulder Replacement (Primary Diagnosis OA)

Oułcome	N (%) Pre-Op	N (%) Post-Op	Unadjusted Relative Risk (95% CI)	Unadjusted P Value	Adjusted Relative Risk (95% CI)	Adjusted P Value
Mobility	48/117 (41.0)	17/67 (25.4)	0.62 (0.41, 0.93)	0.0226	0.65 (0.43, 0.99)	0.0430
Personal Care	74/117 (63.2)	20/66 (30.3)	0.48 (0.33, 0.70)	0.0001	0.48 (0.33, 0.70)	0.0001
Usual Activities	100/117 (85.5)	36/66 (54.5)	0.64 (0.51, 0.80)	0.0001	0.65 (0.52, 0.81)	0.0001
Pain and Discomfort	115/117 (98.3)	43/66 (65.2)	0.66 (0.55, 0.79)	<.0001	0.66 (0.56, 0.79)	<.0001
Anxiety and Depression	54/117 (46.2)	21/66 (31.8)	0.69 (0.49, 0.97)	0.0325	0.71 (0.51, 0.99)	0.0447