Arthroplasty Clinical Outcome Registry NSW (ACORN)

Site Manual

ACORN
Arthroplasty Clinical Outcomes Registry

Site Manual

Introduction

The Arthroplasty Clinical Outcomes Registry (ACORN) commenced in 2012 as an initiative to improve the quality, safety, and functional outcomes of joint replacement surgery by monitoring, evaluating and reporting on the results of surgery. The ultimate goal of ACORN is to use data to improve health system performance, and to improve outcomes for people undergoing joint replacement surgery, by reducing morbidity, maximising functional recovery, and enhancing health related quality of life. This goal will be achieved by:

- Providing performance benchmarks for joint replacement surgery;
- Identifying variables that place people at risk of poor outcome after joint replacement;
- Improving the understanding of the relationship between patient characteristics and outcome;
- Identifying variation in outcome between participating hospitals and using this data to improve clinical practice;
- Monitoring rates of key complications that require treatment, readmission, or reoperation to identify areas for review by clinicians and service providers;
- Generating research questions that will contribute to improved quality and safety of joint replacement surgery for people electing this procedure in the future;
- Providing a platform for research into interventions aimed at improving outcomes after joint replacement.

ACORN will provide central support to all participating sites and if sustainable funding is realised, submitted information will be able to be accessed via a dedicated website. Annual reports will be released that will provide year on year reporting of aggregated outcome measures and six-monthly reports will be provided to each participating hospital.

Background

Joint replacement surgery has been shown to be an effective intervention to improve pain, function, and quality of life in people with severe joint disease of the hip or knee. In 2010, more than 70,000 hip and knee replacements were undertaken in Australia, and the vast majority of these surgeries were undertaken in Australia's older population. The average age of people undergoing hip and knee replacement surgery is 68 years.

Whilst outcomes after joint replacement are impacted by hospital care processes and by surgical techniques and processes, there are also characteristics of the individual that may influence absolute outcome after surgery. Currently, the National Joint Replacement Registry collects data on all joint replacements, using revision surgery (re-operation) as the outcome on which success is measured. Findings from some international jurisdictions have suggested that high success rates based on revision surgery are not consistent with success rates based on patient-reported outcomes, as the published literature reports up to 25% of knee replacement recipients fail to gain significant improvement from surgery. As a result of these differential findings, it is pragmatic to include patient-relevant outcomes such as: satisfaction; pain relief; functional improvement; and health related quality of life; to more quantifiable measures like surgical revision. To the individual, improvements in pain, function, and quality of life, may be equally, or more important, than undergoing revision surgery.

Despite the establishment of patient-based outcome registries in other countries, notably Sweden, England and New Zealand, there is no such registry in Australia. The routine measurement of patient-reported outcomes will provide valuable information on the

effectiveness of this common and resource-intensive procedure, and would guide future practice changes aimed at improving the outcomes of joint replacement surgery.

Project Plan

All public and private hospitals in Australia performing hip and knee joint replacement surgery are eligible for inclusion. Initially, the project will be piloted at 6 hospitals in NSW. ACORN will be conducted as a continuous prospective, longitudinal cohort registry that routinely follows people after discharge from hospital. It will use the following Australian Commission on Safety and Quality in Health Care documents to guide its operations and implementation.

At each site, eligibility for inclusion in ACORN requires adults to be aged 18 years of age or over, and admitted to a participating hospital for the following procedures:

- primary total hip replacement
- revision* total hip replacement
- primary total knee replacement
- revision* total knee replacement
- primary uni-compartment knee replacement
- revision* uni-compartment knee replacement.

*revision surgery is any surgery in which implant components are removed, added or exchanged, including arthrodesis or amputation.

People undergoing joint replacement will be excluded from the registry if:

- they are under the age of 18 years
- they are having a total hip replacement for fracture
- they are cognitively impaired and unable to understand the consent process for participation in the registry

Prior to surgery, general information about the person undergoing hip or knee replacement surgery and their quality of life and level of function before the surgery will be collected. ACORN will follow up each person by telephone at six months after surgery and collect information about their level of function, quality of life, and any complications that may have occurred since discharge from hospital. ACORN will not exclude people of non-English speaking backgrounds from follow-up and will use family members as proxies if required, as this enables equitable follow-up of outcomes for this group of people.

Consent

The Hunter New England Human Research Ethics Committee has approved an opt-out consent process for the registry. This means that all eligible people will be included unless they specifically contact the registry to opt-out. It is therefore important that each participating site will have a designated coordinator who will explain the written information and be able to answer questions about the registry. The coordinator will:

- Explain the purpose of the registry;
- Highlight the process for contacting the registry;
- Explain the opt-out consent process used for the registry;
- Provide a copy of the Patient Information sheet to each person as part of the preadmission documentation.

Why should individual orthopaedic departments and surgeons support the registry?

ACORN is a registry initiated by orthopaedic surgeons to improve their understanding of patient specific outcomes after joint replacement. The information it collects may be used to improve the quality and safety of surgery by reporting outcomes to participating sites, and by providing a means of comparing the outcomes from one site with the aggregated results from other sites. Any analysis and public reporting of the data will be de-identified.

Benefits of participation in the registry include:

- Improving future outcomes by monitoring, identifying and addressing gaps in quality care.
- Benchmarking through identification of strengths and weaknesses by comparing performance and outcomes of current practice.
- Enhancing quality and efficiency by using the data to make fact-based decisions
- Joining a community of clinicians driven by a desire to provide quality health care
- Interacting with your peers to create opportunities to share quality improvement strategies.

Requirements for participation

Each participating orthopaedic department will be responsible for collection of the initial minimum data set (MDS). The majority of this information is already collected as part of the person's admission process. The initial MDS includes information from both the preoperative and postoperative periods of admission. Experience has informed the best model for hospitals with respect to data collection. Collection of the preoperative information at the time of the preadmission process, with acute care information collected by a designated clinician such as a nurse or physiotherapist, provides a process that reduces burden on individual clinicians.

Hospitals nominate a Site Coordinator to be responsible for data collection, its quality and completeness, and provide a contact person for the registry. Ideally, the Site Coordinator will be someone with a clinical background, such as a Nurse Unit Manager, Clinical Nurse Consultant or Allied Health Clinician, who is able to interpret and understand the data definitions, and who will take personal responsibility for the completeness of recruitment of the eligible population at their hospital. Qualities that would make a person successful in this role include attention to detail, self-motivation and a commitment to the project.

Other requirements for successful participation include:

- ability to submit 100% of eligible cases admitted to the participating hospital;
- ability to work with ACORN staff to obtain research governance approval from the relevant Research Governance Office;
- ability to provide the approved ACORN Patient Information Sheet to all eligible patients prior to surgery;
- agreeing to provide independent corroboration from clinical information regarding number of eligible records submitted to the registry; and,
- engagement of executive sponsorship to provide support for those involved in the registry.

How to participate

Orthopaedic departments wishing to participate can contact the Chair of the Steering Committee on 02 8738 9254 or the Registry Coordinator on 02 8738 9252. Alternatively, the department can complete the information form (Appendix 1) and fax to 02 9602 7187.

Once received, the Chair of the Steering Committee will contact the Orthopaedic Surgeon Head of Department to discuss commencement of participation.

Initial Data Collection

Prior to surgery, and within 8 weeks of operation, participants will complete one joint-specific survey (12 question Oxford Hip or Knee Score), and one generic, quality of life survey (6 question EQ-5D-5L and VAS) and the front page of the initial data collection sheet (see Appendices 2, 3, 4, 5). The information collected includes demographic data, anthropometric data, medical history, expectations of outcome, and contact details of the patient and another contact person to assist with follow-up.

At the conclusion of the acute episode of care, the Site Coordinator is responsible for collating the data collection instruments for each person. To finalise the data collected for each participant, Site Coordinators are asked to pay particular attention to the following areas:

- *Preoperative Data Collection*
  - Oxford and EQ5D/EQVAS – record the date of survey completion on the front page of each.
  - Oxford and EQ5D – check that only one box in each question/dimension is chosen. If two boxes are ticked, need to clarify best answer with patient at the time.
  - EQ5D and EQVAS both need to be completed. For the EQVAS, both the vertical scale and a number are to be completed. That is, confirm the patient has made a mark on the vertical scale and then translated that number to the box. Whole numbers only are valid. Decimal places are not valid.
  - Highest year of school completed and highest non-school qualification. Select 'none' if it doesn't apply, rather than leaving it blank.
  - Medical history is person reported.
  - Low back problems and other lower joint problems refers to musculoskeletal problems of back/hip/knee/ankles/feet that interfere with a person's function.
  - Make sure any previous hip or knee replacement is reported, not only the joint that is related to the current procedure, and chose 'none' if no previous hip or knee replacement.
  - Expectations are to be completed prior to surgery.
  - Measured height and weight are recorded.

- *Admitted Data Collection*
  - High care bed yes/no and if yes, then planned or unplanned
  - Transfusion recorded yes/no, and source of transfusion if yes
  - Complications, discharge destination recorded

All preoperative and acute care information will be returned centrally where entry to the central database will occur. The site coordinator will undertake quality assurance checks of the data during entry to the database.

Paper forms will be held at participating sites and will be transferred centrally by password protected electronic submission after being scanned. Alternatively, participating sites will post the completed paper forms in Australia Post Express Post pre-addressed envelopes on a monthly basis. The registry will clarify any missing or unusual data with the appropriate Site Co-ordinator on a regular basis.

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Initial Data Collection Form Data Descriptions and Definitions

Administrative Information

Registry ID	This number is generated centrally on submission of a new patient record.
Date of Data Collection	This is the date the data collection is commenced at the hospital.

Demographic Information

Patient label	Place the patient label in the space provided. If a label is used, it replaces manual entry of several of the required demographic data elements listed below.
Name	Record first, middle, and last name.
Street Address	This is the number, name and suffix of the primary place of residence. For example, 23A Smith Place.
Suburb and Postcode	This is the suburb and its Australian postcode of the primary place of residence.
Date of Birth	Asked as: *what is (the person's) date of birth?* Recorded in the format DD/MM/YYYY.
Gender	M/F
MRN	Hospital specific Medical Record Number
Telephone Numbers	This is the patient's preferred contact number, if they have one. Record the full number, including prefix, with no punctuation (hyphens or brackets). Use B for business or work, H for home, T for temporary. For example, 02 8777 2233 H is correct, not (02) 8777 2233 (H), or for a mobile number, use M for personal mobile, O for business or work mobile, and T for temporary. For example, 0412 123456 M. If unknown, leave blank. More than one number may be recorded.
Height (cm) measured	This is the height of the person measured in centimetres to one decimal place. Ideally it is standing height, measured at the time of commencing data collection. Used to calculate BMI for risk-adjustment. The measurement of height requires a vertical metric rule, a horizontal headboard, and a non-compressible flat even surface on which the subject stands, without shoes. The graduations on the metric rule should be at 0.1 cm intervals, and the metric rule should have the capacity to measure up to at least 210 cm. If unable to be measured, self-reported height is required. Notate beside the height on the data form SR (self-reported).

Weight (kg) measured	The weight (body mass) of a person measured in kilograms to one decimal place. This should be measured at the time of commencing the initial data collection. Used to calculate BMI for risk-adjustment. Scales should have a resolution of at least 0.1kg and should have the capacity to weigh at least 200 kg. If unable to be measured, self-reported weight is required. Notate beside the weight on the data form SR (self-reported).
Email Address	The person's email address to enable electronic follow up.
Other contact person/next of kin: name, relationship, contact phone	This person will be contacted at the 6 month follow up if the registry has been unsuccessful in its attempts to contact the person who is recorded as having had the joint replacement. **This other contact person should provide permission to have their details submitted.** NAME / RELATIONSHIP / PHONE e.g. Mary Smith / Friend / 02 9333 5555
Health insurance for surgery	This field relates to the payer for the joint replacement surgery. If the person is having surgery through the public hospital system and paid by the Australian universal health care system, then this is recorded as public. If they have surgery through the public system, but have another funding source, such as DVA, private insurance, or are self funded, then the appropriate option would be selected, which is not public.
Preferred Language	This question aims to measure proficiency of speaking English. It is a two step question firstly asking the person how well they speak English and then the language they prefer their medical care.
Highest year of school completed	This relates to secondary school. Completion of the previous leaving certificate is the equivalent of completing year 12.
Highest non-school qualification	This relates to any qualification attained after leaving secondary school.

Questionnaires

Oxford Hip/Knee Score	The Oxford Hip Score or Oxford Knee Score are completed preoperatively within 6 weeks of the persons planned surgery. The questionnaire is answered thinking about the index joint and its average behaviour over the **previous 4 weeks**. The person will be asked to complete the questionnaire with the instructions: *please answer each question by thinking about the knee/hip to be replaced and the impact on your level of pain and function, on average, over the previous four weeks. If unable to decide between two answers, then choose the worst answer so as to choose only one answer per question.*

	The survey consists of 12 questions about pain, function, and mobility. Only one answer is to be completed per question unless the person is having bilateral surgery and then two answers are allowed, with notation as to the joint relevant to the answer e.g.(R) or (L). The person administering the questionnaire is responsible for checking that all questions are answered, and answered only once. This is to be done at the time the person completes the survey.
EQ-5D-5L and EQ-VAS	The EQ-5D is a generic health related quality of life tool completed preoperatively within 6 weeks of the persons planned surgery. There are two sections to the survey: the EQ-5D and the EQ-VAS. The questionnaire is answered thinking about the person's **general health today** (the day the survey is completed). For the EQ-5D the person will be asked to choose the statement in each of the five domains that best describes them today. Only one answer is allowed. The person will be instructed to answer the domains by *thinking about your health today, which statement best describes your mobility/personal care/usual activity/pain or discomfort/anxiety or depression today.* For the EQ-VAS the person will be asked to rate their health today on a scale from 0-100, where 100 is the best health and 0 is the worst health. *Thinking about your health today, mark the scale at the point between 0 and 100 that best indicates your health today? Write that number in the box beside.* For a complete questionnaire, there must be one answer chosen for each domain, and both the vertical scale and the box must be completed. Only whole numbers are allowed for the EQ-VAS – numbers with decimal places are invalid. The person administering the questionnaire is responsible for checking that all questions are answered, answered only once, and there are no decimal places used in the EQ-VAS. This is to be done at the time the person completes the survey.
Expectation Pain	This is a subjective report of the person's expectation of the six-month outcome of their upcoming joint replacement, with respect to pain.
Expectation Function	This is a subjective report of the person's expectation of the six-month outcome of their upcoming joint replacement, with respect to function.

Medical History

Previous Hip Replacement	Record whether there has ever been **any** previous hip replacement and the side of the previous surgery. Also record if there has been no previous hip replacement. This is answered with no reference to the current index surgery.

Previous Knee Replacement	Record whether there has ever been **any** previous knee replacement and the side of the previous surgery. Also record if there has been no previous knee replacement. This is answered with no reference to the current index surgery.
Low back problems or other lower limb problems	It has been shown that low back pain and other lower limb arthritis impair a person's absolute recovery after hip and knee replacement. These two questions are self-reported answers and are asked as to whether the person has musculoskeletal problems with their lumbar spine/low back region or any lower limb joint other than the joint to be replaced that impairs their mobility and/or function. If someone has had a previous joint replacement surgery, it is likely they would answer yes to impairment from other lower limb arthritis.
Comorbid Conditions	These are asked with two questions: firstly, has the person ever been told by a doctor they have a specific condition of the general, body systems listed; and secondly, if yes, does the person take daily medication for that condition(s). This method of asking attempts to gain consistency in response across individuals and sites, and to determine the severity of the condition. If a doctor has not told a person they have any comorbid condition record at the bottom of the section. Heart disease – any heart or cardiac condition, excluding high blood pressure but including high cholesterol, MI, AF, HF, pacemaker etc. High blood pressure – hypertension. Diabetes – varying severity will require different management. For example, a person might say yes to the first question, but be diet controlled and therefore will answer no to the second question. Stomach disease/condition – will include ulcers, gastritis, reflux, and any other gastrointestinal condition. Lung disease/condition – any respiratory condition such as asthma, COPD/COAD/CAL, obstructive sleep apnoea etc. Kidney condition/disease – any kidney condition the person has been told they have. In this category the second question regarding medication includes dialysis. Liver disease/condition – such as jaundice, hepatitis etc. Neurological disease/condition – any central or peripheral nervous system condition, such as Parkinson's, MS etc. If dementia has been diagnosed and this impairs the person's cognition and understanding, then they will be excluded by the registry. Depression/Anxiety

Surgical and Acute Admission Details

Date of Admission	This is the date the patient is admitted to the hospital for their surgery. It may or may not be the same as the date of surgery. To be recorded in the format DD/MM/YYYY.
Date of Surgery	The date on which the index procedure commenced during an inpatient episode of care. To be recorded in the format DD/MM/YYYY. If the date of surgery is the same as the date of admission, place a tick on the paper form in the date of surgery section.
ASA	American Society of Anaesthetists Score. A medical measure of comorbidity and used for risk-adjustment. It will usually be found within the preadmission anaesthetic assessment, or on the operating theatre anaesthetic form.
Surgeon	Last name and first name of the orthopaedic surgeon who will perform the surgery.
Joint to be replaced	Select the correct option for the index admission – hip/knee, right/left/both. If a unicompartment joint replacement, write 'uni' after ticking the correct option.
Surgery type and reason	Select primary or revision and then the reason for the surgery.
Bilateral Joint Replacement	A bilateral joint replacement is where both hips and/or both knees are replaced during a single hospital admission and single operating theatre admission. If this is the planned procedure, then the side of surgery is recorded as 'both' and **only one** Oxford Score is completed, using the worst joint as the reference for answers. The worst joint for each question in the Oxford Score may change.

Procedure Recovery Details

ICU/HDU Admission	Record any admission to a high care bed (high dependency unit or intensive care unit or other) during the transition from the operating theatre/recovery to the general ward, and whether it was planned or unplanned. This provides information regarding processes of care at each hospital.
Blood transfusion	Record yes or no to a transfusion. If yes, the number of units and the source of the blood need to be recorded.
Complications	These are any unplanned or unexpected events that occur during the surgical admission, from admission for surgery until discharge to home, rehabilitation or other discharge destination. They are required to be documented and result in a change to usual care.
Discharge destination	The destination from the acute care ward.

Discharge date	The date the person was discharged from the acute care ward.

Definitions of Complications

Complications are defined as any change to the usual pathway of care. To qualify as a complication for ACORN, the complication must be recorded in the medical record and have required treatment (for example, extension of antibiotic prophylaxis, a MET call for a cardiovascular event).

Delirium	Delirium is a common, life threatening neuropsychiatric syndrome characterised by an acute onset of altered cognition, resulting in reduced and fluctuating levels of consciousness, with impaired concentration and altered sleep/wake cycle. It is most common in people with dementia however can affect any older person in hospital. Must be documented in the medical record as a definite complication during admission.
SSI of the operative site.	For infection to be included as a complication in the ACORN dataset, one of the following four options are required to be met: 1. Infection requires oral antibiotics to be prescribed that are additional to routine antibiotic prophylaxis for joint replacement surgery; 2. Infection requires IV antibiotics prescribed that are additional to routine antibiotic prophylaxis for joint replacement surgery; 3. Return to the operating theatre for reoperation that does NOT involve removal or replacement of any part of the prostheses; or 4. Return to operating theatre for reoperation that DOES involve removal or replacement of any part of the prostheses.
Wound dehiscence	A wound ruptures along the surgical suture.
VTE	Venous Thromboembolism (VTE), deep venous thrombosis (DVT) or pulmonary embolism (PE), is a significant complication for people admitted for hip and knee arthroplasty. VTE must be documented as investigated, diagnosed, and requiring treatment. Routine prophylaxis is separate to VTE as a complication.
Fat emboli	The sudden obstruction of a vessel by a fat embolus. Must be documented in the medical record as a definite complication during admission.
Bladder infection/retention	Must be documented in the medical record as a definite complication during admission and treatment specific to the infection/retention implemented.
Reoperation	Any unplanned reoperation on the index joint during the admitted period.
Dislocation	Documented dislocation requiring reduction and/or reoperation

	during the index admission.
Respiratory infection	A documented acute respiratory infection requiring treatment.
Fracture	Any periprosthetic fracture directly related to the operative procedure
Nerve Injury	Any documented injury to a nerve during surgery that results in loss of motor function.
CVS	Any complication of the cardiovascular system. This includes atrial fibrillation, hypotension requiring change to usual care, an infarct, a stroke or any other cardiac/vascular event that was unexpected.
Death	Death during the index admission for joint replacement surgery.
Other	Any unplanned or unexpected event during admission for the joint replacement surgery that is not listed above and requires intervention or treatment that is additional to usual care. For example, a fracture resulting from a fall during the index admission would be included here. Specify the complication.

Consent to Follow-Up

Patient Information Sheet	As the Registry has an opt-off consent process, it is essential that every eligible person receives' a patient information sheet explaining their inclusion on the registry. Ticking 'yes' indicates that the person has received the registry information sheet.
Opted out	It is important that every eligible person is aware that they will be followed up by telephone or mail at six months after their surgery. If a person elects to opt-off from follow-up, tick 'yes' and record the date and reason beside the answer.
Oxford Score	The Oxford Hip Score or Oxford Knee Score are completed preoperatively and forwarded to the registry with the surgical data form.
EQ-5D-5L	The EQ-5D is a generic health related quality of life tool completed preoperatively and forwarded to the registry with the surgical data form.

NOTES:

- Date of admission is the preferred date to be recorded; date of surgery ticked if the same as admission date. Record separate dates if admission is prior to surgery date.
- A temperature with no underlying diagnosis and/or treatment is not recorded as a complication.
- Anaemia is a possible consequence of joint replacement surgery and is therefore not considered to be unplanned or unexpected, therefore would not be classified as a complication.

Sending the data

Preferably, the data is scanned, the electronic file password protected, and emailed directly to the registry. Alternatively, addressed Express Post envelopes can be supplied to each site for forwarding of the completed data sets. Ideally, the data will be posted by the 13th of each month, inclusive of the previous months patients. For example, people operated on in March, up to 31 March, will be completed, collated, and posted by the 12th April for receipt at the registry by the 19th April. This will allow a 12-day acute care stay for the people operated on the last day of the month.

On receipt of the posted data pack by the registry, each person's record will be reviewed, and a list of data items that are missing, incomplete, or require clarification will be created and forwarded back to the designated site coordinator. It is intended that this process will be completed by the end of each month. Using the example above, the data will be received and reviewed by the registry by the 20th April and returned to the site coordinator for completion and return centrally by the 30th April.

Outcome Measures

Key outcomes measured include pain and function, health related quality of life, satisfaction, readmission and complications at 6 months after surgery. These outcomes will be correlated with patient preoperative variables, such as demographics and co-morbidities, and results reported back to participating departments for quality improvement. Primary outcomes include:

- Pain and function (Oxford Hip or Knee Score)
- Health-related quality of life (EQ-5D-5L)

In addition to these, secondary outcomes include:

- Unplanned readmission (admission not planned at the time of discharge from index joint replacement surgery)
- Reoperation (operation on the index joint not planned at time of index surgery, either during admission or after discharge)
- Length of hospital stay for the index admission
- Complications relating to surgery (PE, symptomatic DVT, infection requiring treatment, dislocation, manipulation under anaesthesia either during admission or after discharge)
- Discharge destination
- Satisfaction and success

Reporting

Data analysis and reporting will include aggregated data only and will not identify any individual participant or surgeon. Variables that will be able to be reported include:

- Demographic data
- Preoperative health status, level of pain and function
- Postoperative health status, level of pain and function
- Complications and readmissions
- Acute care measures and discharge destination

Every six months, participating hospitals will be provided with individual reports comparing the aggregated outcome against the aggregated outcome of all other participating hospitals. This provides an opportunity to review outcomes relative to other hospitals undertaking joint replacement surgery.

In addition, publication of outcomes in peer-reviewed journals will assist with dissemination of ACORN findings. Analysis of areas for improvement will be provided to contributing facilities

annually, with ad-hoc reporting available to contributing sites as requested. Individual surgeons may request outcome data for their own patients in non-identified forms.

Appendix 1: Participation Form

Please the complete the requested information below and fax to 02 9602 7187.

Date: _____

To: The Steering Committee ACORN

Facility Name:	
Facility Address:	
Facility Postal Address:	

Head of Orthopaedic Department Name:	
Signature:	
Date of Signature:	
Email Address:	
Contact Phone Number:	

Hospital Executive Member Name:	
Executive Member Role:	
Signature:	
Date of Signature:	
Email Address:	
Contact Phone Number:	

Site Coordinator Contact Name:	
Clinical Role:	
Signature:	
Date of Signature:	
Contact Email:	
Contact Phone Number:	

Appendix 2: Oxford Hip Score (OHS)

PROBLEMS WITH YOUR HIP

Tick (✓) one box for every question.

1. During the past 4 weeks…

How would you describe the pain you usually have from your hip?

None	Very mild	Mild	Moderate	Severe
☐	☐	☐	☐	☐

2. During the past 4 weeks…

Have you had any trouble with washing and drying yourself (all over) because of your hip?

No trouble at all	Very little trouble	Moderate trouble	Extreme difficulty	Impossible to do
☐	☐	☐	☐	☐

3. During the past 4 weeks…

Have you had any trouble getting in and out of a car or using public transport because of your hip? (whichever you tend to use)

No trouble at all	Very little trouble	Moderate trouble	Extreme difficulty	Impossible to do
☐	☐	☐	☐	☐

4. During the past 4 weeks…

Have you been able to put on a pair of socks, stockings or tights?

Yes, easily	With little difficulty	With moderate difficulty	With extreme difficulty	No, impossible
☐	☐	☐	☐	☐

5. During the past 4 weeks…

Could you do the household shopping on your own?

Yes, easily	With little difficulty	With moderate difficulty	With extreme difficulty	No, impossible
☐	☐	☐	☐	☐

6. During the past 4 weeks…

For how long have you been able to walk before pain from your hip becomes **severe**? (with or without a stick)

No pain/More than 30 minutes	16 to 30 minutes	5 to 15 minutes	Around the house only	Not at all/pain severe when walking
☐	☐	☐	☐	☐

7. During the past 4 weeks…

Have you been able to climb a flight of stairs?

Yes, easily	With little difficulty	With moderate difficulty	With extreme difficulty	No, impossible
☐	☐	☐	☐	☐

8. During the past 4 weeks…

After a meal (sat at a table), how painful has it been for you to stand up from a chair because of your hip?

Not at all painful	Slightly painful	Moderately painful	Very painful	Unbearable
☐	☐	☐	☐	☐

9. During the past 4 weeks…

Have you been limping when walking, because of your hip?

Rarely/ never	Sometimes, or just at first	Often, not just at first	Most of the time	All of the time
☐	☐	☐	☐	☐

10. During the past 4 weeks…

Have you had any sudden, severe pain - 'shooting', 'stabbing' or 'spasms' - from the affected hip?

No days	Only 1 or 2 days	Some days	Most days	Every day
☐	☐	☐	☐	☐

11. During the past 4 weeks…

How much has pain from your hip interfered with your usual work (including housework)?

Not at all	A little bit	Moderately	Greatly	Totally
☐	☐	☐	☐	☐

12. During the past 4 weeks…

Have you been troubled by pain from your hip in bed at night?

No nights	Only 1 or 2 nights	Some nights	Most nights	Every night
☐	☐	☐	☐	☐

Finally, please check back that you have answered each question.

Thank you very much.

Appendix 3: Oxford Knee Score (OKS)

PROBLEMS WITH YOUR KNEE

Tick (✓) one box for every question.

1. During the past 4 weeks…

How would you describe the pain you usually have from your knee?

None	Very mild	Mild	Moderate	Severe
☐	☐	☐	☐	☐

2. During the past 4 weeks…

Have you had any trouble with washing and drying yourself (all over) because of your knee?

No trouble at all	Very little trouble	Moderate trouble	Extreme difficulty	Impossible to do
☐	☐	☐	☐	☐

3. During the past 4 weeks…

Have you had any trouble getting in and out of a car or using public transport because of your knee? (whichever you tend to use)

No trouble at all	Very little trouble	Moderate trouble	Extreme difficulty	Impossible to do
☐	☐	☐	☐	☐

4. During the past 4 weeks…

For how long have you been able to walk before pain from your knee becomes **severe**? (with or without a stick)

No pain/More than 30 minutes	16 to 30 minutes	5 to 15 minutes	Around the house only	Not at all/pain severe when walking
☐	☐	☐	☐	☐

5. During the past 4 weeks…

After a meal (sat at a table), how painful has it been for you to stand up from a chair because of your knee?

Not at all painful	Slightly painful	Moderately painful	Very painful	Unbearable
☐	☐	☐	☐	☐

6. During the past 4 weeks…

Have you been limping when walking, because of your knee?

Rarely/ never	Sometimes, or just at first	Often, not just at first	Most of the time	All of the time
☐	☐	☐	☐	☐

7. **During the past 4 weeks…**

Could you kneel down and get up again afterwards?

Yes, easily	With little difficulty	With moderate difficulty	With extreme difficulty	No, impossible
☐	☐	☐	☐	☐

8. **During the past 4 weeks…**

Have you been troubled by pain from your knee in bed at night?

No nights	Only 1 or 2 nights	Some nights	Most nights	Every night
☐	☐	☐	☐	☐

9. **During the past 4 weeks…**

How much has pain from your knee interfered with your usual work (including housework)?

Not at all	A little bit	Moderately	Greatly	Totally
☐	☐	☐	☐	☐

10. **During the past 4 weeks…**

Have you felt that your knee might suddenly 'give way' or let you down?

Rarely/ never	Sometimes, or just at first	Often, not just at first	Most of the time	All of the time
☐	☐	☐	☐	☐

11. **During the past 4 weeks…**

Could you do the household shopping on your own?

Yes, easily	With little difficulty	With moderate difficulty	With extreme difficulty	No, impossible
☐	☐	☐	☐	☐

12. **During the past 4 weeks…**

Could you walk down one flight of stairs?

Yes, easily	With little difficulty	With moderate difficulty	With extreme difficulty	No, impossible
☐	☐	☐	☐	☐

Finally, please check back that you have answered each question.

Thank you very much.

Appendix 4: EQ-5D-5L

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Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY

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 ❑

PERSONAL CARE

I have no problems with washing or dressing myself ❑
I have slight problems with washing or dressing myself ❑
I have moderate problems with washing or dressing myself ❑
I have severe problems with washing or dressing myself ❑
I am unable to wash or dress myself ❑

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ❑
I have slight problems doing my usual activities ❑
I have moderate problems doing my usual activities ❑
I have severe problems doing my usual activities ❑
I am unable to do my usual activities ❑

PAIN / DISCOMFORT

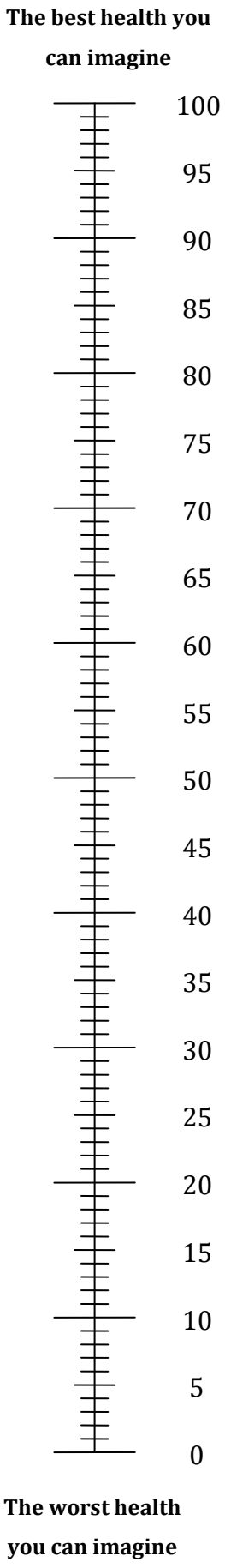
I have no pain or discomfort ❑
I have slight pain or discomfort ❑
I have moderate pain or discomfort ❑
I have severe pain or discomfort ❑
I have extreme pain or discomfort ❑

ANXIETY / DEPRESSION

I am not anxious or depressed ❑
I am slightly anxious or depressed ❑
I am moderately anxious or depressed ❑
I am severely anxious or depressed ❑
I am extremely anxious or depressed ❑

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



Appendix 5: Initial Data Collection Sheet

Hospital: **State / Territory:**

Date data collection commenced: / /

1. Demographic Information (label if available)

Name	Street Address	Suburb and Postcode
Date of Birth	**Sex**	**Hospital MRN**
__ __/__ __/__ __ __ __	o Male o Female	
Telephone Numbers(s)	**Height measured (m)**	**Weight measured (kg)**
Email Address:		
Other Contact Person: Name/Relationship/Telephone		

Health Insurance for Surgery		
o Public hospital insurance	o Private health insurance	o Self funded
o Other third party payer	o Workers' compensation insurance	o Other compensation payer
o DVA	o Other	o Unknown
Preferred Language		
How well do you speak English? (tick only one) o Very well o Well o Not very well o Not at all		
In what language do you prefer your medical care? o English o Other (please specify)		
Highest Year of School Completed		
o Year 12 o Year 11 o Year 10 o Year 9 o Year 8 or below o No schooling o Unknown		
Highest Non-School Qualification		
o Trade Certificate	o Advanced Diploma/Diploma	o Graduate Diploma/Graduate Certificate
o Bachelor Degree	o Postgraduate Degree	o None o Unknown

2. Expectations after Surgery

Level of Pain 6-months after Surgery			
What are your expectations of your **knee/hip pain** six months after your surgery?			
o No pain	o Slight pain	o Moderate pain	o Severe pain
Functional Ability 6-months after Surgery			
What are your expectations of your **functional ability** six months after your surgery?			
o No limitation	o Some limitation	o Moderate limitation	o Severe limitation

3. Medical History

Previous hip or knee replacement – please tick all that apply to you			
o Only right hip	o Only left hip	o Both hips	o I have never had any hip replaced before
o Only right knee	o Only left knee	o Both knees	o I have never had any knee replaced before
Low back problems or other lower limb joint problems			
o I have low back problems that interfere with my mobility		o I do not have low back problems	
o I have other joint problems in my leg(s) that interfere with my mobility		o I do not have other joint problems	

PLEASE CONTINUE THIS SECTION OVER THE PAGE...

Have you ever been told by a Doctor you have any of the following conditions			
Heart disease, such as AF, high cholesterol, other	Yes / No	If yes, do you take daily medication	Yes / No
High blood pressure	Yes / No	If yes, do you take daily medication	Yes / No
Diabetes	Yes / No	If yes, do you take daily medication	Yes / No
GIT or Stomach Condition	Yes / No	If yes, do you take daily medication	Yes / No
Lung Condition	Yes / No	If yes, do you take daily medication	Yes / No
Kidney Condition	Yes / No	If yes, do you take daily medication	Yes / No
Liver Condition or Disease	Yes / No	If yes, do you take daily medication	Yes / No
Neurological Condition or Disease	Yes / No	If yes, do you take daily medication	Yes / No
Anxiety or Depression	Yes / No	If yes, do you take daily medication	Yes / No
OR o I have never been told by a Doctor I have any of the conditions listed above			

Thank you. Section 4 below is to be completed by hospital staff.

4. Surgical and Acute Admission Details

Date of Admission	Date of Surgery	ASA Score
__ __/__ __/__ __ __ __	__ __/__ __/__ __ __ __	o 1 o 2 o 3 o 4 o 5

Joint to be Replaced during Index Admission	Surgeon Name
o Right hip o Left hip o Both hips o Right knee o Left knee o Both knees	

Surgery Type and Reason

o **Primary** joint replacement o OA o RA o DDH o Other inflammatory arthritis o Osteonecrosis/AVN o Tumour o Other (specify)	o **Revision** joint replacement o Loosening o Lysis o Dislocation o Implant breakage o Infection o Fracture o Other (specify)

ICU / HDU Admission

o Yes, admitted to a high care bed If yes, o Planned admission OR o Unplanned admission
o Not admitted to a high care bed

Blood Transfusion

o No o Yes If yes, o Donor OR o Autologous Number of units:

Complications During Index Admission

o Yes (select as many from the list below as apply) o No complications
o Bladder infection o Bladder retention o CVS (stroke, MI, arrhythmia) o Delirium o Dislocation
o DVT o Fracture o Nerve injury o PE o Reoperation
o Respiratory infection o Surgical Site Infection (SSI) o Other (specify)

Discharge Destination	Date of Discharge (from ward) __ __/__ __/__ __ __ __
o Usual residence / residence of relative/friend	o Inpatient rehabilitation (same hospital)
o Inpatient rehabilitation (other hospital)	o Hostel (if not usual place of residence)
o Nursing home (if not usual place of residence)	o Another acute hospital
o Other (specify)	

Site Coordinator Checklist

Participant Information Sheet provided?	o Yes	o No	Oxford Score completed and attached	o Yes	o No
Has the participant opted-out?	o Yes	o No	EQ5D/EQVAS completed and attached	o Yes	o No