PROMIS and the American Joint Replacement Registry (AJRR): National implementation of PROMIS in a clinical data registry

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About Us

- Founded in 2009
- Originally affiliated with the American Academy of Orthopaedic Surgeons
- Stand-alone non-profit since January 2015
- Located in Orthopaedic Headquarters in Rosemont, IL
- Third attempt by ‘profession’ at hip and knee NATIONAL Registry
- Multi-stakeholder governance model
  - Profession (Surgeons)
  - Medical Device Industry
  - Health Plans
  - Hospitals
  - The Public
AJRR Mission and Vision

AJRR’s MISSION
To improve orthopaedic care through the collection, analysis, and reporting of actionable data

AJRR’s VISION
To be the National Registry for orthopaedics through comprehensive data and technology resulting in optimal patient outcomes
AJRR History & Milestones

2010

- Started Pilot Program with 15 Hospitals

2013

- Launched Pilot Program of LII and LIII Platforms with 18 Participating Sites

x200
AJRR’s Data Elements are grouped in the following categories...

- Demographics
- Level I
- Level II
- Level III
Initial Plan: AJRR Data Elements

**LEVEL I**

**Patient**
- Name (Last, First)
- Date of Birth
- Social Security Number
- Diagnosis (ICD-9)
- Gender
- Race/Ethnicity

**Hospital**
- Name and Address

**Surgeon**
- Name (National Provider Identifier)

**Procedure**
- Type (ICD-9)
- Date of Surgery
- Laterality
- Implants

**LEVEL II**

- Comorbidities (ICD-9)
- Height + Weight/Body Mass Index
- Length of Stay
- American Society of Anesthesiologists Score
- Operative and Post-operative Complications

**LEVEL III (Patient-reported Outcomes)**

- SF-36 v1
- HOOS/KOOS
- Oxford Hip and Knee Scores
- Knee Society Knee Scoring System
- Harris Hip Score
- WOMAC (Modified via HOOS and KOOS)
- SF-12, EQ-5D, WOMAC (only accepting final scores)
Original PROM/Level III Plan

- SF-36 v1
- HOOS/KOOS (and later HOOS/KOOS Short Form)
- Oxford Hip and Knee Scores
- Knee Society Knee Scoring System
- Harris Hip Score
- WOMAC (Modified via HOOS and KOOS)
- SF-12, EQ-5D, WOMAC (only accepting final scores)
Results

Tell me what to do!
Results

June 2015: Came to consensus as to “recommended” PROMs:

• HOOS Physical Function shortform (HOOS-PS)*
• KOOS Physical Function shortform (KOOS-PS)*
• PROMIS-10 Global
• VR-12
• Pain VAS
Comprehensive Care for Joint Replacement

Introduction

Webinar #1
July 15, 2015
1-2pm EDT
CJR Proposed Rule

Time frame for data collection:
90 to 0 days prior to and 270 to 365 days after THA/TKA procedure
August 2015

- AJRR participated in the Patient-reported Outcomes Summit for Total Joint Arthroplasty
  - AAHKS, AAOS, The Hip Society, The Knee Society, CMS, Yale New Haven Health Services Corporation (YNHHSC)/Center for Outcomes Research and Evaluation (CORE), National Committee for Quality Assurance (NCQA), Mathematica, CECity, and Blue Cross Blue Shield Association

- Obtained a consensus regarding the PRO and risk variables suitable for total hip and knee arthroplasty performance measures: PROs include HOOS, JR.; KOOS, JR.; PROMIS 10-Item Global Health; Veterans Rand 12-Item Health Survey
LEVEL I

Patient
• Name (Last, First)
• Date of Birth
• Social Security Number
• Diagnosis (ICD-9/10)
• Gender
• Race/Ethnicity

Hospital
• Name and Address

Surgeon
• Name (National Provider Identifier)

Procedure
• Type (ICD-9/10)
• Date of Surgery
• Laterality
• Implants

LEVEL II

• Comorbidities (ICD-9/10)
• CJR Risk Variables
• Height + Weight/Body Mass Index
• Length of Stay
• American Society of Anesthesiologists Score
• Operative and Post-operative Complications

LEVEL III (Patient-reported Outcomes)

Recommended:
• PROMIS-10 Global
• VR-12
• HOOS/KOOS, JR.

Also Available:
• SF-36 v1
• HOOS/KOOS
• Oxford Hip and Knee Scores
• Knee Society Knee Scoring System
• Harris Hip Score
• WOMAC (Modified via HOOS and KOOS)
• SF-12, EQ-5D, WOMAC (only accepting final scores)
Patient-Reported Outcomes (Level III) Capabilities

- Recommended measures are in line with CMS and CJR and include:
  
  **HOOS, JR.  KOOS, JR.  VR-12  PROMIS-10 Global**
  
  - *National benchmarks and dashboards available*

- AJRR’s patient portal is a web-based tool for clinicians
  - Other forms available:
    - HOOS, KOOS, Oxford Hip/Knee Score, Knee Society Knee Scoring System, SF-36, Harris Hip Score

- If entities have a PRO dataset/historical data they would like to submit, AJRR can accept

- AJRR collaborates with numerous PRO vendors for data submission
To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

- Completely
- Mostly
- Moderately
- A Little
- Not at all

This survey asks for your view about your LEFT KNEE. This information will help us keep track of how you feel about your LEFT KNEE and how well you are able to do your usual activities. If you are unsure about how to answer a question, please give the best answer you can.

**Stiffness**
The following question concerns the amount of joint stiffness you have experienced during the last week in your LEFT KNEE. Stiffness is a sensation of restriction or slowness in the ease with which you move your LEFT KNEE joint.

How severe is your knee joint stiffness after first waking in the morning?

- None
- Mild
- Moderate
- Severe
- Extreme
Level III/PRO Dashboard

PROMIS-10 Global Scores By Year – Nat’l & Hospital Comparison (Pre-OP)

PROMIS-10 Global STD. Error By Year – Nat’l & Hospital Comparison (Pre-OP)

PROMIS 10 - A patient who has T scores of 60 for the GPH or GMH is one standard deviation better (more healthy) than the general population.

GPH = Global Physical Health
GMH = Global Mental Health
## Participating PRO Institutions

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<thead>
<tr>
<th>Institution Name</th>
<th>Response Rate Pre-Op</th>
<th>Response Rate Post-Op</th>
<th>Response Rate All</th>
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<tbody>
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<td>0%</td>
<td>75%</td>
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<tr>
<td>AJRR Test Hospital 2</td>
<td>100%</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>AJRR Test Hospital 4</td>
<td>38.9%</td>
<td>100%</td>
<td>39.6%</td>
</tr>
</tbody>
</table>
Results

- Pre-operative PROMIS-10 Global n=4,282
- 1-year post-operative PROMIS-10 Global n=223
- “Linked” surveys (pre- and post-operative is the same person) n=159 (4% response rate)
- Institutions submitting PROMIS-10 Global n=25 (4%)
Results

Global Mental Health

• There is a significant difference pre-op vs year 1 (p=0.0025)
  – The Year 1 mental T-score value is on average 2.8 units higher (50.0 (pre) – 52.8 (post))

Global Physical Health

• There is a significant difference in pre-op vs 1-year (p=<0.001)
  – The Year 1 physical T-score is on average higher by 11.4 units (39.4 (pre) – 50.8(post))
Results

- Other arthroplasty registries generally report much higher PROM capture.
- Patient-reported outcome measures were reported from all Swedish hospitals during 2015.
- The Register now has a nationwide system to prospectively and longitudinally capture patient-reported outcomes for all patients with total hip replacement.
- The response frequency for one-year follow-ups is slightly higher than 90%.
- In 2015, a total of 40,324 PROM surveys were registered as a part of the on-going follow-up routine.
AJRR Stats Today:

1,000,000 PROCEDURES

985 participating facilities

7,300+ surgeons
Conclusions

- The current state of PROMIS in a national arthroplasty registry took many years to evolve
- AJRR has many resources available to assist participants with PRO collection
  - Platform facilitates PRO capture for many uses, including CMS bundled payment program, national benchmarking and patient tracking
- The availability of AJRR’s system encourages utilization of PROs
- Despite payers’ PRO requirements and the system’s ease of use, few participating institutions are actively using AJRR’s system