Integrating Patient-reported Measures and Predictive Data in a Shared Decision Report for Knee and Hip Arthritis Treatment Decisions

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• AHRQ

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PROs for shared decision making

*Shared decision making* is a key component of patient-centered health care. Patients and clinicians working together to select treatments and care plans can improve patient outcomes.

The use of patient-reported outcomes (PROs), in addition to EHR data, to facilitate patient-clinician shared decisions is new and poses new informatics challenges.
The electronic health record (EHR) digitally aggregates patient’s health data at each episode. EHR systems:
• Capture and store clinical data per episode for medical, legal, and administrative purposes.

**EHR Limitations**
• EHRs collect data *locally*. If the patient visits different hospitals or clinicians, today’s EHR does not integrate patients’ health data across clinical settings and time.
• EHRs collect data *when the patient visits* a hospital or MD, and may miss data if the patient does not visit; thus, data are potentially incomplete and biased.
• Decision tools *within* EHRs are based on local data, not national data.
A.S.K. Study:
Arthritis care through Shared Knowledge

• Develop and test a novel shared decision tool (with patient-centered predictive analytics) for surgeons and patients with knee/hip osteoarthritis (OA) who are considering total joint replacement (TJR) surgery.

• Evaluate if this tailored shared decision tool will
  (a) enhance OA patient's decision quality,
  (b) influence OA outcomes after medical or surgical treatment.
A.S.K. Study based on FORCE-TJR Registry

FORCE-TJR: Function and Outcomes Research for Comparative Effectiveness in Total Joint Replacement

National TJR research cohort/registry

Primary outcome = Patient-reported pain and functional (plus clinical data)

Beyond Joint Implant Registries

A Patient-Centered Research Consortium for Comparative Effectiveness in Total Joint Replacement

Patricia J. Franklin, MD, MPH, MBA
Jeromo J. Allison, MD, MS
David C. Ayers, MD

Despite the proven effectiveness of total joint replacement (TJR) surgery in relieving advanced knee and hip arthritis pain, TJR outcomes have come under intense public scrutiny in recent years. The 2010 recall of ASR metal-on-metal hip implants heightened awareness of the importance for implant safety surveillance for this high-cost and high-use procedure and exposed the need for a national systematic patient-centered outcomes monitoring system. These safety concerns and the exponential growth in TJR use—

To address this need, the Agency for Healthcare Research and Quality funded a 4-year $12 million research program, Function and Outcomes Research for Comparative Effectiveness in TJR (FORCE-TJR). Led by a team of researchers at the University of Massachusetts Medical School in cooperation with a national network of surgeons, FORCE-TJR assembled a consortium of orthopedic practices to serve as a research laboratory to generate CER to guide surgeon and patient decisions. The FORCE-TJR has a national scope, is representative of US practices, includes longitudinal patient-reported outcomes, and has the ability to measure implant failure as well as important clinical outcomes and complications.

The FORCE-TJR Approach

Joint Registry Update

Joint Replacement Registries in the United States:
A New Paradigm

David C. Ayers, MD, and Patricia J. Franklin, MD, MPH, MBA

JAMA 2012; 308(12): 1217-18
FORCE-TJR: US representative sample of 200 surgeons; 30,000 patients in 28 States

- Stratified random sample of US surgeons
- 75% are community-based
- Fellowship-trained and general orthopedic surgeons
- High and low volume surgeons/hospitals; urban and rural
- Teaching hospitals, non-teaching
- Private, public and HMO insurance
- All major implant manufacturers

National norms from 2011-2016 Medicare and Private Insurers
FORCE-TJR: key capabilities to build shared decision tools

- Collect data from patients directly (not limited to one EHR), but can return data to patient or EHR for storage
- Data capture process is pre-determined and scheduled, so does not miss follow-up time points
- Complete, pre-defined risk and outcome data as well as PRO data
- Capture data from representative patients across country, so can provide national norms and support access to national databases
Patient-reported symptoms and risks compared with national norms

- Collect PRO and symptom data from patients directly
- Data capture process is predetermined and scheduled, so will not miss follow-up time points
- Obtain needed risk and outcome data from patient survey
- Capture data from OA patients across country, so can provide national norms and support access to national databases

Trended Symptoms over Time

Patient Risk Profile

Color-coded Norms
Predictive Analytics: What outcomes are patients like me likely to achieve?

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- Obtain needed risk and outcome data from patient survey
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> Multi-variable risk models for key outcomes

> Individualized predictive outcomes based on similar patients
A.S.K. predictive shared-decision reports generated real-time for patient and clinician
Patient Feedback on Report Design

“An graph might work. I’m a visual person…. to see the little stacks (bar graphs), like you came in here a year ago and you were at 20 and one year later you are at 70 and you’re working towards a goal of 80.”

“In my mind [the report] is part of the treatment plan. A lot of times they leave the patient out. They give the diagnosis and tell them to take that pill or whatever. By giving the answers to the questions, it helps you be involved in the actual decision making and to understand why.”
Clinician Feedback on Report Design

MD (CT): “The report is great for highlighting the risks to patients, and managing expectations.”
Hospital IT Review/Approvals Require Time; All Approved A.S.K.

One-page IT overview
Site Review
Site IT Questionnaire
Completing Questionnaire
Return Questionnaire; other documents
Schedule r review
Meeting to review detailed documents
Site Review
Approval

A.S.K. Team

Site IT Department

Web-based data capture and reporting is new to clinics.

*Process in Orange takes time.
A.S.K.: Integrate Patient, National, EHR Data

1. Survey Request
2. Survey Return
3. Shared Decision Report
5. API (Future)

Individual Survey Data → Real-Time Generated Report → Update Registry Data

FORCE Survey System

FORCE National Registry Database

WEB-BASED

National Norms Statistical Models

ForceCare 

Arthritis care through Shared Knowledge

Personalized care. Shared decisions.
A.S.K. Shared decision report based on patient-reported data

1. Trended patient-reported symptoms/PROs
   - Pain, activities of daily living, physical function
2. Risk factors for post-TJR complications
3. Predicted TJR outcomes for similar patients
   - Pain relief, functional gains
4. Predicted TJR impact on pain with patients’ priority activities
5. Complication risks
6. Summary evidence for non-surgical treatments
Technical Lessons Learned

• **Returning data to EHRs**
  • Longitudinal registry data collected in parallel can supplement EHR data.
  • Returning data to EHRs may involve processes like identifier matching, new field creation, automated and secure data transfer, etc.

• **Security and privacy review by hospitals/practices**
  • To protect patients’ data, security and privacy checks are required by all sites. The review and approval process varies and ranges from 1-2 months to 4-5 months.
  • Research IT implementation is a new concept.
Dissemination and EHR Inter-operability

• FORCE-TJR web system can collect patient-reported data as a third-party platform, and readily interface with EHRs (e.g., API) for storage of the PRO data and decision reports.

• Discrete data and/or reports can be emailed to patients and additional clinicians (e.g., primary care doctors) - even if not using same EHR.

• Longitudinal direct-to-patient data capture is automated and can support EHRs to store complete “picture” of treatment impact, disease progression.
Thank You!

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