

Implementing PRO-Based Shared Decision Reports

in the Learning Health System





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► PCORI

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Patient Reported Outcome reports enable patients and clinicians to make decisions from the same point of reference.

► Our PRO-based report provides individual patient measures:

- Generic measures of physical and emotional function
- Disease-specific function, depending on the area of interest
- Pain, pinpointed to a specific activity
- Comorbid conditions to provide context
- > Patients are the first to notice changes in symptoms
- Clinicians can interpret the changes and recommend treatment options.





Learning Health Systems redesign clinical workflows to collect patient reported data.

Pre-visit assessments are initiated via email or phone

Patients are introduced to a shared experience





Pre-visit data collection

- Patients are introduced to the pre-visit assessment process via a letter from the clinician.
- ► Options for completing the before-visit assessment:
 - Online, via email with unique link
 - Phone, with research coordinator
 - In clinician waiting room





Patient feedback populates a PRO-based report that can be used to guide a shared decision making conversation.

- Office staff make report available to the patient and the clinician at the office visit.
- Clinician and patient review the report and discuss treatment options.





National norms provide comparison to similar patients.

PAIN IN KNEE/HIPS

Right Hip Pain

100 75 75 40 40 3/2017 6/2017



Right Knee Pain

Left Knee Pain

Left Hip Pain



FUNCTION AND PHYSICAL HEALTH

Joint Function (ADL)

Overall Physical Function (PCS)





DEFINITIONS AND FORCE NORMS

HOOS/KOOS Pain:

70-100: no or mild pain 40-70: moderate pain - discuss treatment options 0-40: severe pain - surgery is common

HOOS/KOOS ADL:

70-100: no or mild disability
40-70: moderate to advanced disability - discuss treatment options
0-40: severe disability - surgery is common

SF PCS (scale 0-80):

45-80: no or mild limitations 30-45: moderate limitations 0-30: severe limitations



Arthritis care through Shared Knowledge Personalized care. Shared decisions.

Patient risk factors individualize care.

PATIENT RISK FACTORS ▼ None Low Back Pain: Diabetes: No Medical Comorbidity Index: ▼=1 Smoking: Yes Age: 69 BMI: 22 🔻 Emotional Health: ▼55 Narcotics Use:

- Discussed at individual visit
- Supports discussion on likely benefit of treatment
- Puts the diagnosis in context with the rest of the patient's health history



Individualized predicted outcomes inform the shared decision making conversation.



Patient's Likely Change in Pain, Function, and Physical Health After Surgery

Arthritis care through

Shared Knowledge

Personalized care. Shared decisions.

 Supports discussion on individualized predicted outcomes after surgery

Activities important to the patient can be discussed.





More specific expected results can enhance the shared decision making exchange.



The patient visit includes a shared decision making conversation about treatment options.

Osteoarthritis of the knee

Frequently asked	Treatment Options		
questions	Medications for Pain Relief	Joint injections (steroids)	Physical Therapy
		, contraction of the second seco	The
Will this reduce the pain I have in my knee?	Ibuprofen (also known as Advil or Motrin) is helpful for 50 in every 100 patients.	Some people get some relief of their pain and/or swelling after an injection.	In a recent study, patients experienced good relief after participating in an intensive physical therapy program that lasted for 12 weeks.
Will this treatment help improve which activities I can manage to do?	As you get pain relief, you should be able to be more active. Being more active can also help reduce your pain.	If you get pain relief, you may be able to be more active.	As you get pain relief, you should be able to be more active. Being more active can also help reduce your pain.



through Shared Knowledge Personalized care. Shared decisions.



PRO-based reports can be integrated with the standard of care.



Outcomes require a follow-up process no matter where the patient is.



Our 6-month process leverages electronic as well as human interaction.

84% of patients complete a 6-month survey.







PRO-based shared decision making can benefit accountable care in the Learning Health system.

- Patients can track symptoms and access care at the primary level.
 (eg. primary care physician, outpatient specialist)
- Patients participating in decisions can be more engaged in self management.
- Patient Reported Data can be accessed by the patient and the care team when they need it.
- Patient Reported Data can be used by care managers to individualize interventions and risk-stratify a caseload.





Consider this when using clinical data in the Learning Health System:

- Is data across the continuum of care helpful? If so, how can it be examined?
- Is it possible to obtain a truly representative sample of the population of interest?
- ► Is the comparative group meaningful?
- ► Are patient-reported measures placed in context?



1. Obtaining data across the care continuum often rests with the patient.



Ongoing tracking of pain, function, symptoms



Clinical data related to inpatient and outpatient visits



Clinical data related to communitybased care



Arthritis care through Shared Knowledge Personalized care. Shared decisions.



2. A representative sample of PRO data includes achieving an acceptable follow up rate.

- Current practice in US 20-30%. The national standard is 70%. ASK achieves >80%.
- It is not enough to collect data only for those who show up for a visit.
- Outcomes require tracking changes over time, including 6 months to a year [or more] after treatment. Many patients do not come back at expected time points for follow up.
- Collecting follow up data must occur in collaboration with the patient, often outside patient care visits.

Franklin, P. D., Lewallen, D., Bozic, K., Hallstrom, B., Jiranek, W., & Ayers, D. C. (2014). Implementation of Patient-Reported

Outcome Measures in U.S. Total Joint Replacement Registries: Rationale, Status, and Plans. The Journal of Bone and Joint



Shared Knowledge

Personalized care. Shared decisions.

Arthritis courgery-American Volume, 96(Suppl 1), 104-109. doi:10.2106/jbjs.n.00328

3. It is important to compare to a meaningful benchmark.

- Solution ASK reports compare the patient to the FORCE-TJR national registry norms.
- ► The FORCE-TJR research registry includes:
 - A national cohort of >35,000 patients
 - More than 85% retention
 - Clinicians and patients are representative
 - from 28 states
 - 75% community based
 - Fellowship trained and general surgeons
 - Urban, rural, teaching, community based
 - Public, private HMO insurance



Franklin, P. D., et. al. (2012). Beyond Joint Implant Registries. JAMA, 308(12), 1217-1218.

- 4. Clinical data puts generic measures of pain and function in context.
- The ASK assessment includes questions about low back pain, both hips and knees, comorbid conditions.
- Function measures include both physical, emotional and behavioral items.



Learning Health Systems Considerations

- ► PROs can add value to a real-time shared decision tool
- Combination of technology that follows the patient
- Supported by dedicated staff will achieve high rates of completion no matter where the patients are located





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