Implementing PRO-Based Shared Decision Reports in the Learning Health System
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➤ PCORI

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➤ AHRQ

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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: 75, 75
- Right Knee Pain: 56, 24
- Left Knee Pain: 75, 50
- Left Hip Pain: 100, 100

**FUNCTION AND PHYSICAL HEALTH**
- Joint Function (ADL): 51, 36
- Overall Physical Function (PCS): 40, 34

**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
Patient risk factors individualize care.

- 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

### PATIENT RISK FACTORS

- **Low Back Pain:** None
- **Diabetes:** No
- **Medical Comorbidity Index:** =1
- **Smoking:** Yes
- **Age:** 69
- **BMI:** 22
- **Emotional Health:** 55
- **Narcotics Use:**
Individualized predicted outcomes inform the shared decision making conversation.

➤ Supports discussion on individualized predicted outcomes after surgery

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

- **Knee Pain (KOOS)**
  - Today: 19
  - By 12 months: 77

- **Knee Function (KOOS)**
  - Today: 51
  - By 12 months: 81

- **General Physical Health (SF PCS)**
  - Today: 40
  - By 12 months: 50
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

<table>
<thead>
<tr>
<th>Frequently asked questions</th>
<th>Treatment Options</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Medications for Pain Relief</td>
</tr>
<tr>
<td>Will this reduce the pain I have in my knee?</td>
<td>Ibuprofen (also known as Advil or Motrin) is helpful for 50 in every 100 patients.</td>
</tr>
<tr>
<td>Will this treatment help improve which activities I can manage to do?</td>
<td>As you get pain relief, you should be able to be more active. Being more active can also help reduce your pain.</td>
</tr>
</tbody>
</table>
PRO-based reports can be integrated with the standard of care.

A.S.K. REPORT-generated in real-time, shared decisions in the exam room.
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.

- 40% online
- 15% on paper
- 7% 1 call
- 22% > 1 call
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 community-based care
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.

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

- 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

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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