Workshop Objectives

• Briefly describe clinical benefits of PROs and why they are important for performance metrics
• Describe PRO-based performance metrics (PRO-PMs)
• Describe our PCORI-funded study to develop PRO-PMs for chemotherapy
• Group work on PRO-PMs
## NQF Distinctions

<table>
<thead>
<tr>
<th>PRO</th>
<th>Definition</th>
<th>Example: Patients With Clinical Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PRO</strong></td>
<td>Construct being assessed</td>
<td>Depression</td>
</tr>
<tr>
<td><strong>PROM</strong></td>
<td>Standardized instrument, scale, or single-item measure obtained by asking patient to self-report</td>
<td>PHQ-9 ©</td>
</tr>
<tr>
<td><strong>PRO-PM</strong></td>
<td>Performance measure based on PROM data aggregated for an accountable healthcare entity and compared across systems to determine quality • Value-driven, clinically relevant, actionable metrics</td>
<td>% patients with MDD and initial PHQ-9 score &gt;9 with a follow-up score &lt;5 at 6 months (NQF #0711)</td>
</tr>
</tbody>
</table>
## Examples of Performance Metrics

<table>
<thead>
<tr>
<th>Conventional Quality Metrics</th>
<th>Tomorrow’s PROMs as Performance Metrics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortality Rate</td>
<td></td>
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<tr>
<td>30-day Readmission Rate</td>
<td></td>
</tr>
<tr>
<td>Emergency Room Use</td>
<td></td>
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<tr>
<td></td>
<td>Symptom Control</td>
</tr>
<tr>
<td></td>
<td>Physical Function</td>
</tr>
<tr>
<td></td>
<td>Maintaining Regular Activities</td>
</tr>
<tr>
<td></td>
<td>Mental and Sexual Health</td>
</tr>
<tr>
<td>Care Experiences (e.g., CAHPS)</td>
<td>Short forms for care experiences</td>
</tr>
</tbody>
</table>
Does your organization use a Patient-Reported Outcome Measures (PROMs) system?
Does your organization use a Patient-Reported Outcome Measures (PROMs) system?

- Yes: 38%
- No, but we plan to within the next three years: 17%
- Don't know: 29%
- No, and we have no plans to do so: 17%

Base: 617 (multiple responses)
Of the Sites Who Use PROMs….

In which of the following clinical care settings does your organization use PROMs?

- Ambulatory primary care: 60%
- Ambulatory specialty care: 59%
- Inpatient: 55%
- None of the above: 6%

Base: 235 (multiple responses) among those using PROMs systems
Do you think that Patient-Reported Outcome Measures (PROMs) should be formally included as part of the quality measure slate in provider-payer contracts?

Base: 617 (multiple responses)
Do you think that Patient-Reported Outcome Measures (PROMs) should be formally included as part of the quality measure slate in provider-payer contracts?

- Yes: 50%
- No: 30%
- Don’t know: 20%

Base: 617 (multiple responses)
Support for PROMs in Provider-Payer Contract Quality Measures

- **Clinicians:** 43%
- **Clinical leaders:** 52%
- **Executives:** 61%

A higher incidence of executives than clinicians think PROMs should be formally included as part of the quality measure slate in provider-payer contracts.

Base: 617 (multiple responses)
Why are Health Systems Interested in PROMs?

Better Patient Experience and Quality Are the Top Reasons to Collect and Use PROMs

What are the top two reasons for health care organizations to collect and use Patient-Reported Outcome Measures (PROMs)?

- Improve patient experience: 60%
- Improve quality metrics: 52%
- Improve patient engagement: 40%
- Improve costs associated with specific clinical interventions: 16%
- Required by payers: 15%
- Market demand: 8%

Base: 617 (multiple responses)
Multiple Benefits for Using PROMs during Care Delivery

Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial

Ethan Basch, Allison M. Deal, Mark G. Kris, Howard I. Scher, Clifford A. Hudis, Paul Sabbatini, Lauren Rogak, Antonia V. Bennett, Amylo C. Dueck, Thomas M. Atkinson, Joanne F. Chou, Dorothy Dukko, Laura Sit, Allison Barz, Paul Novotny, Michael Fruscione, Jeff A. Sloan, and Deborah Schrag
Low Agreement between Patient and Clinician Reports of Symptoms

- Fatigue
- Anorexia
- Nausea
- Vomiting
- Diarrhea
- Constipation

Patient-reported
Clinician-reported

NEJM 2010; 362:865-869.
• Intervention Group (PROMs + Nurse Alerts for Severe Symptoms
  – Able to remain on chemotherapy longer (8.2 v 6.3 months)
  – More likely to survive 1 year (75% v 69%)
  – Less likely to visit ER
  – QOL in intervention group more likely to improve
Using Patient-Reported Outcome Measures as Quality Indicators in Routine Cancer Care

Angela M. Stover, PhD and Ethan M. Basch, MD

Patient-reported outcome (PRO) measures are increasingly being used in routine cancer care and may soon be used as indicators of the quality of care received. When a clinician reviews PRO measures with a patient during a visit, the patient has an opportunity to elaborate on symptoms that may need to be managed. Reviewing PRO measures with cancer patients increases communication between clinicians and patients, detection of problematic symptoms, and satisfaction with care. PROs are a critical tool for increasing patient centeredness in oncology clinical trials, comparative effectiveness research, and cost-effectiveness research. There also may be a future role for PROs in quality monitoring and improvement.
Case Study: NHS

The NHS Outcomes Framework

Domain 1  Domain 2  Domain 3
Preventing people from dying prematurely 
Enhancing quality of life for people with long-term conditions 
Helping people to recover from episodes of ill health or following injury

Domain 4
Ensuring people have a positive experience of care

Domain 5
Treating and caring for people in a safe environment and protecting them from avoidable harm

Effectiveness  Experience  Safety
Case Study 1: UK NHS PROM

• Since 2009, PROMs mandated: hip and knee replacement
  – Pre- and Post-procedure EQ-5D
• >80% response rate (>250,000/year)
• Analysis at Hospital Trust level
  – Adjusted for case mix
    • Age, gender, “ethnicity”
    • Procedure type and HRG code
    • Charlson, # comorbidities
    • Day case patient, self-discharged
  – Stratified by # of patients seen

<table>
<thead>
<tr>
<th></th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mobility</strong></td>
<td>I have no problems in walking about</td>
</tr>
<tr>
<td></td>
<td>I have some problems in walking about</td>
</tr>
<tr>
<td></td>
<td>I am confined to bed</td>
</tr>
<tr>
<td><strong>Self-care</strong></td>
<td>I have no problems with self-care</td>
</tr>
<tr>
<td></td>
<td>I have some problems washing and dressing myself</td>
</tr>
<tr>
<td></td>
<td>I am unable to wash and dress myself</td>
</tr>
<tr>
<td><strong>Usual activities</strong></td>
<td>(eg. work, study, housework, family or leisure activities)</td>
</tr>
<tr>
<td></td>
<td>I have no problems with performing my usual activities</td>
</tr>
<tr>
<td></td>
<td>I have some problems with performing my usual activities</td>
</tr>
<tr>
<td></td>
<td>I am unable to perform my usual activities</td>
</tr>
<tr>
<td><strong>Pain/discomfort</strong></td>
<td>I have no pain or discomfort</td>
</tr>
<tr>
<td></td>
<td>I have moderate pain or discomfort</td>
</tr>
<tr>
<td></td>
<td>I have extreme pain or discomfort</td>
</tr>
<tr>
<td><strong>Anxiety/depression</strong></td>
<td>I am not anxious or depressed</td>
</tr>
<tr>
<td></td>
<td>I am moderately anxious or depressed</td>
</tr>
<tr>
<td></td>
<td>I am extremely anxious or depressed</td>
</tr>
</tbody>
</table>
Performance of Accountable Entities in Case-Mix Adjusted Mean EQ-5D Change

Change in case mix-adjusted EQ-5D index score

No of patients

- NHS trusts
- Independent sector hospitals

99.8% confidence limits
95% confidence limits
Despite some surgeons’ concern that patients may confuse outcomes (how they feel and function) with their experience of the way care was delivered (care experiences), there is only a weak association ($r = 0.2$) between PROM scores and PREMs.

PROMs and PREMs measure different aspects and patients can and do distinguish these domains of quality.

PRO-PM Study

- **Goal:** Develop patient-centered approach to assessing quality of chemotherapy care that captures what is important to stakeholders

- **Aim 1:** Key informant interviews in six U.S. cancer centers

- **Aim 2:** Literature Review (and Cognitive Interviews)

- **Aim 3:** Live testing in six U.S. cancer centers
PRO-PM
Patient Reported Outcomes Performance Measures

Stakeholders

Coordinating Center
UNC-CH

ASCO
NCQA
MNCM

Patient Investigators

Methodologist Researchers

Clinicians and clinical staff

Patient Investigator Organizations

Research Advocacy Network
Patients and Partners
Cancer Information & Support Network

Recruitment Sites
Hospital Admins and Quality Officers

MD Anderson
Memorial Cancer Center
Palo Alto Med. Foundation
Smilow Cancer Center (Yale)
North Carolina Cancer Hosp.

ASCO – American Society of Clinical Oncology
NCQA – National Committee for Quality Assurance
MNCM – Minnesota Community Measurement
Six Cancer Centers

- Palo Alto Medical Foundation
- MD Anderson
- UNC – Chapel Hill
- Yale Smilow Cancer Center
- Health Partners – Oncology Research
- Memorial Cancer Institute
Step 1: Interviews with 124 Stakeholders

- Patients (56)
- Caregivers (21)
- Patient Advocates (5)
- Health Dec Makers (16)
- Researchers (15)
- Clinicians (11)
Perceptions of PRO-PMs: Clinicians

“I think when physicians hear the words ‘performance metric,’ they think about payment... their institution’s assessment of their performance...they think about something that is going to be used to either incentivize them or punish them.” (Clin 3)

“I think [PRO-PMs] really could help...whole practices, just to know what we’re potentially missing...it can be hard to learn from the successes or mishaps of my colleagues cuz we just don’t see that data about each other. We don’t have...a clear sense of, are there any cultural or strategy differences about how we do this?” (Clin 6)
“The community has embraced the value of transparency, and so what we have experienced and what we hope to continue, is groups are looking at each other's rates, and people really don't want to be at the bottom.” (Dec Maker 8)

“…all the symptom management is going to be very important so that when we understand our cost of care, [whether] we're running high compared to others…[that] we understand why. All this data is important for us.” (Dec Maker 5)
“…Cuz I could compare myself to the average …average score. If I’m a five and everybody else is a two, I would wonder why my fatigue is more than everybody else.” (Pt 34)

“Yeah, [comparing symptom scores across practices] might be interesting, mainly because now my hospital group is like—was bought by a much larger one. I have a lot of options for an infusion center. So say I had to go to a different one because mine was full, like that might be useful to know that I'll have a really similar experience in terms of like, ‘Oh, my symptoms won't get worse,’ or, ‘Oh, if I go to this one, my symptoms might be better.’ That's a, I feel like, a recent, unique thing.” (Pt 23)
### Stakeholder Interview Results

<table>
<thead>
<tr>
<th>9 Candidate Symptoms</th>
<th>12 Candidate Risk Adjusters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Age, Gender, Race/ethnicity</td>
</tr>
<tr>
<td>Depression, anxiety</td>
<td>Insurance type</td>
</tr>
<tr>
<td>Insomnia</td>
<td>Cancer type</td>
</tr>
<tr>
<td>Constipation, diarrhea</td>
<td>Education, working</td>
</tr>
<tr>
<td>Nausea</td>
<td>Married/partnered</td>
</tr>
<tr>
<td>Numbness</td>
<td>Trouble paying bills</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>Palliative care</td>
</tr>
<tr>
<td>Emetic risk (for nausea)</td>
<td>Emetic risk (for nausea)</td>
</tr>
<tr>
<td>Comorbid conditions</td>
<td>Comorbid conditions</td>
</tr>
</tbody>
</table>
Step 2: PROM Collection from Home

- Patients receiving systemic chemotherapy asked to complete PRO items from home 5-15 days following start of cycle
  - Email or automated phone reminders on days 6-9
  - Human reminder call starting day 10 (up to day 15)
Multisite Testing at Six Cancer Centers

653 patients enrolled
(~110 per practice)

46/653 (7%) did not complete
- 27 lost to follow up
- 9 hospitalized/too ill
- 3 forgot, 2 technology issues

607 (93%) patients completed PRO-PM
- 470/607 (72%) completed PRO-PM on own without reminder call
- 89/607 (15%) completed PRO-PM after reminder call
- 48/607 (8%) completed PRO-PM via phone interview
Example Measure Specification: Pain PRO-PM

How OFTEN Did You Have Pain?
Never (0), Rarely (1), Occasionally (2), Frequently (3), Almost Constantly (4)

Chemotherapy Cycle Days

Frequent or Almost Constant Pain

1 5 15 20 25
Step 3: From PROM to PRO-PM

PRO-CTCAE Item:
How OFTEN Did You Have Pain?
Never (0), Rarely (1), Occasionally (2), Frequently (3), Almost Constantly (4)

PRO-PM Measure Specification:
Proportion of adult patients receiving systemic cancer therapy whose pain frequency rating was frequently or almost constantly during days 5-15 of cycle

• Outcome being measured (“numerator”)
• Population (“denominator”)
• Time course
• Risk/case-mix adjustment
## Risk Adjustment Variables Tested

<table>
<thead>
<tr>
<th>Area</th>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographic</strong></td>
<td>Age (65+)</td>
<td>&lt;65 vs. 65+</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>Male vs. Female</td>
</tr>
<tr>
<td><strong>Clinical</strong></td>
<td>Cancer type</td>
<td>5 Categories</td>
</tr>
<tr>
<td></td>
<td>Palliative care</td>
<td>Yes vs. No</td>
</tr>
<tr>
<td></td>
<td>Emetic risk</td>
<td>Yes vs. No</td>
</tr>
<tr>
<td></td>
<td>Comorbidityity</td>
<td>0-1 vs. 2+</td>
</tr>
<tr>
<td><strong>Social Determinants</strong></td>
<td>College</td>
<td>Yes vs. No</td>
</tr>
<tr>
<td></td>
<td>Work</td>
<td>Yes vs. No</td>
</tr>
<tr>
<td></td>
<td>Married/Partnered</td>
<td>Yes vs. No</td>
</tr>
<tr>
<td></td>
<td>Insurance</td>
<td>Medicare, Medicaid, Private, Other</td>
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<tr>
<td></td>
<td>Race/Ethnicity</td>
<td>White Non-Hispanic vs. Other</td>
</tr>
</tbody>
</table>
Risk Adjustment Process

• Criteria to Select Symptoms
  o Clinically actionable
  o Between site variation

• Steps for Risk Adjustment
  1. Model fit statistics (AIC) from hierarchical regression models guided selection of variables
  2. Expected values calculated from model predictors
  3. Observed: expected ratios calculated and rescaled using population means
  4. C-statistic used to evaluate explanatory power
Results: Raw Aggregate Symptoms

- Nausea: p = 0.06
- Constipation: p = 0.04
- Insomnia: p = 0.04
- Pain: p = 0.02
Demographic Comparisons by Site

- Age 65+*
- Gender (Female)
- White Non-Hispanic*
- College Educated*

*p<0.001
Results

All p<0.01
Social Determinants of Health by Site

*p<0.001
Results: Modest Impact of Adjustment

- **Nausea**
- **Insomnia**
- **Pain**
- **Constipation**

Observed Score: ●
Case Mix Adjusted Score: +
Composite Measure in Development

• Included all clinically actionable single items
  ○ Excluded fatigue and appetite per stakeholder input
• Single item scores summed (range 0-40)
• No a priori cut-point for dichotomization
  • All possible cut-points considered
• Reliability testing: Variation in presence or absence of symptom by site assessed using X²
• Validity testing: Relative risk of low physical function, as measured by patient-reported Eastern Cooperative Oncology Group (ECOG) performance status, dichotomized at ECOG 0-1 vs. 2+
• Early results showing more site variation for composite scores than individual scores
Conclusions

• Home-based PROM collection from patients during systemic cancer treatment is feasible towards quality assessment

• 4 chemotherapy single-item PRO-PMs developed
  ○ Clinically actionable symptoms
  ○ Aggregated to practice level
  ○ 3 adjustment variables: modest impact but changed ordering

• Early results for composite measures showing more site variation

• Plans underway for broader testing
Additional Initiatives

• MNCM: state-based mandate to publicly report PRO-PMs in a variety of health conditions
  o E.g., depression, chemotherapy, etc.

https://mncm.org
Additional Initiatives: CMS

• CMS’ 3-Year Cooperative Agreements for PRO-PMs
  ○ Measures intended for use in CMS’s Quality Payment Program (QPP)
    ○ Including MIPS and Alternative Payment Models (APMs)
  ○ www.nationalcoalitionhpc.org/macra

• MACRA Palliative Care Measures project (CMS)
  ○ Katherine Ast, MSW, LCSW (Director, Quality and Research, AAHPM)
  ○ PRO-PMs for outpatient palliative care: communication, pain management

• Pacific Business Group on Health (PBGH)
  ○ 3 PRO-PMs assessing HRQOL, pain, fatigue following chemotherapy
  ○ Breast, colon, lung cancer
  ○ PROMIS measures
Patient Reported Outcomes (PROs) in Performance Measurement

January 10, 2013

www.rti.org
Group Work

PROMIS Item:
In the last 7 days, I felt depressed.
Never (0), Rarely (1), Sometimes (2), Often (3), Always (4)

PRO-PM Measure Specification for your population:
Proportion of [population] in [clinic] receiving [treatment] whose depression response was frequently or almost constantly during [time period]

• Outcome being measured ("numerator")
• Population ("denominator")
• Time course
• Risk/case-mix adjustment

What risk adjusters make sense for your populations?
Implementation considerations: when and how to administer?