Patient-Centered Measurement: Innovation Challenge Series

Learning Collaborative 2018 Webinar

Tuesday, January 23, 2018
WELCOME
Laura Batz Townsend, BA
President & Co-Founder

Louise H. Batz Patient Safety Foundation
2017-18 Learning Collaborative Patient-Centered Measurement Webinar Series

Background

- Patient-centered measurement drives patient-centered care
- Substantial gaps exist in meaningful, patient-centered measures
- We need real-world experiences, grounded by a sound framework
2017-18 Learning Collaborative Patient-Centered Measurement Webinar Series

Objectives

- Share Principles for Making Health Care Measurement Patient-Centered
- Identify innovative practices
- Promote solutions to barriers
- Accelerate improvement

Graphic courtesy of American Institutes for Research.
2017 Innovation Challenge

Details

- Novel solutions to patient-centered measurement challenge
- Incorporate 1+ Principles for Making Health Care Measurement Patient-Centered across measurement lifecycle
- Emphasis on patient/caregiver priorities and engagement
- Existing or theoretical solutions
2017 Innovation Challenge

*Evaluation Criteria*

- Significant contribution to patient-centered measurement
- Broadly applicable
- Novel approach
- Demonstrated success
- Replicable
2017 Innovation Challenge

Submissions

- 32 submissions received Oct 16 – Nov 15, 2017
- 5 submissions selected to receive a cash award and a national platform to share ideas
  - Webinar 1: January 23
  - Webinar 2: February 8
  - Webinar 3: March 1
- All submissions become part of NQF Learning Collaborative
2017 Innovation Challenge

Winning Submissions

- Colleen A. McHorney, PhD, Evidera and Dayo Jagun, MBBS, MPH, Genentech
  Share ongoing work where patients and caregivers have a central role in conceptualizing oncology measures that address patients' concerns, values and preferences
2017 Innovation Challenge

Winning Submissions

- Saraswathi Vedam, RM, FACNM, SciD, MSFHR Health Professional Investigator, Birth Place Lab, University of British Columbia
  Describes the development and validation of patient-designed measures of autonomy and respect, as well as patient-reported items that capture mistreatment in maternity care

- Katharina Kovacs Burns, MSc, MHSA, PhD, Alberta Health Services
  Explores a strategy to engage patient and family advisors in gathering and analyzing patient experience data in real-time
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Winning Submissions

- Sameer Saini, MD, MS, VA Ann Arbor Center for Clinical Management Research and University of Michigan Institute for Healthcare Policy and Innovation
  Outlines measures of colorectal cancer screening that incorporate individual screening benefit and patient preferences

- Matthew Pickering, PharmD, RPh, Pharmacy Quality Alliance and Eleanor Perfetto, PhD, MS, National Health Council
  Propose a rubric to assess the patient-centeredness of measure development and implementation
Today’s Presenters

- Colleen A. McHorney, PhD, Senior Research Leader, Patient-Centered Research, Evidera

- Dayo Jagun, MBBS, MPH, Medical Director, Quality of Care, Evidence for Access Medical Unit, Genentech
Patient-Driven Quality Indicators in Cancer

A New Approach to Quality Measure Development
Presenters

• Colleen A. McHorney, PhD
  • Senior Research Leader, Patient-Centered Research, Evidera

• Dayo Jagun, MBBS, MPH
  • Medical Director, Quality of Care, Genentech
Acknowledgements

Evidera

• Sonja Stringer, MPH
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• Brooke Currie, MPH
• Hayley Syrad, PhD
• Owen Cooper, MSc

Genentech

• Anthony Masaquel, MPH, PhD
• Esprit Ma, MPH
• Sarika Ogale
• Sarah Donelson, MA
Outline

• Introductions
• Key points:
  • What is the patient-centered measurement challenge?
  • What do we expect to accomplish?
  • What effort is required?
  • How are patients and caregivers engaged to address their priorities?
  • What lessons did we learn?
• What do we plan to do with our results?
• Questions and discussion
What is the patient-centered measurement challenge?

• There is a definitive lack of:
  • Patients and caregivers playing a *central* role in the conceptualization of quality measures
  • Measure sets that comprehensively address patients’ *concerns, values, and preferences*

• As such, there is poor linkage between healthcare interventions, outcomes valued by patients, and quality measures intended assess these outcomes.
What motivated us to address this challenge?

- Increasing focus on patient-centeredness in research, health policy, and clinical practice
- Increasing incentives to receive and deliver value-based healthcare

FFS = fee for service
What do we expect to accomplish?

• We aspire to identify aspects of oncology care that are important to patients and caregivers and, therefore, should be assessed as quality measures across the cancer patient care pathway.

• We aim to identify the intersection between value-based care and patient-centered care by defining value from the patient perspective.

Less than 7% of endorsed quality measures for cancer care assess patients’ perceptions or experiences of their care (Spinks 2011; Sohn 2016)
Quality indicators in cancer

Current quality indicator for outcomes

- Surgical mortality
- Emergency-room visits
- Hospital readmission
- Length of stay
- Administrative data – narrow measures of convenience
- Incomplete assessment of quality

Patient-centered quality indicator for outcomes

- Health-related quality of life
- Symptom management
- Patient experience
- Requires patient surveys
- Integration into EHR

Do traditional measures actually improve care, and do they matter most to patients and their families?

Value should be defined around the patient – what matters most to patients in terms of quality

HER = electronic health record
For illustration only; based on a quality measure under development by the National Committee for Quality Assurance. Available here: http://www.ncqa.org/Portals/0/PublicComment/MIF_PRO_Public_Comment.pdf?ver=2016-10-04-144602-713
**Quality indicator: What could it look like?**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patients receiving outpatient chemotherapy treatment should be assessed using a validated multi-symptom assessment tool at every chemotherapy administration during the treatment episode</td>
<td>• <strong>Denominator</strong>: Patients aged 18 years and older before the start of the measurement period with a diagnosis of any cancer and at least two outpatient encounters for chemotherapy treatment at the reporting facility during the measurement period</td>
</tr>
<tr>
<td></td>
<td>• <strong>Numerator</strong>: Number of patients who completed a multi-symptom assessment tool (MDASI, PRO-CTCAE, EORTC QLQ-C30, or FACT) at every chemotherapy administration during the treatment period</td>
</tr>
</tbody>
</table>

EORTC QLQ-C30 = European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Core 30; FACT = Functional Assessment of Cancer Therapy; MDASI = MD Anderson Symptom Inventory; PRO-CTCAE = Patient-reported Outcome Common Terminology Criteria for Adverse Events

For illustration only; based on a quality measure under development by the National Committee for Quality Assurance. Available here: http://www.ncqa.org/Portals/0/PublicComment/MIF_PRO_Public_Comment.pdf?ver=2016-10-04-144602-713
Why focus on cancer?

Second Leading Cause of Death

Unmet Medical Need

Changing Treatment Landscape

Evolving Patient Priorities

Cancer as a Chronic Disease

Note: We selected a mix of solid and liquid tumor types as an initial set: Colorectal cancer (CRC), non-Hodgkin's lymphoma (NHL), chronic lymphocytic leukemia (CLL), non-small cell lung cancer (NSCLC), bladder cancer (BdCA), and renal cell carcinoma (RCC)
Methods: Patient and caregiver priorities are addressed in multiple ways

- **Targeted Literature Review**
  - Assess components and attributes of high-quality care from the patient perspective
  - Inform concepts explored in focus groups and interviews

- **Clinician In-Depth Interviews**
  - What patients have described as *important, meaningful, and beneficial* in terms of high-quality care
  - Includes medical/radiation oncologists, advanced practice nurses, and surgeons (urology, cardiothoracic, general)

- **Patient and Caregiver Online Focus Groups**
  - Patient care pathway as a framework for eliciting patient insights
  - Patients and caregivers in separate groups and organized by cancer type

- **Patient Survey**
  - Prioritize among concepts defined in the focus groups
  - Engage a larger patient population than the focus groups

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**Collaboration with Patient Partners**

- Reviews and material contributions to online focus group discussion guides
- Use of appropriate patient-relevant terminology

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*Patient survey will be conducted for only NSCLC, RCC, and BdCA

# Patients partners were engaged for CRC, NHL, and CLL only
## Effort required: Summary of the numbers

<table>
<thead>
<tr>
<th>Targeted Literature Reviews</th>
<th>Clinician In-Depth Interviews</th>
<th>Patient and Caregiver Online Focus Groups</th>
<th>Patient Survey*</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 287 articles met inclusion criteria</td>
<td>• 8 MedOncs</td>
<td>• 86 patients</td>
<td>• 135 patients and caregivers</td>
</tr>
<tr>
<td>• 57 included in review</td>
<td>• 4 HemOncs</td>
<td>• 28 caregivers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 7 RadOncs</td>
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<tr>
<td></td>
<td>• 7 APN</td>
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<tr>
<td></td>
<td>• 3 Urologists</td>
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<td></td>
<td>• 3 Oncology surgeons</td>
<td></td>
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<tr>
<td></td>
<td>• 3 Thoracic surgeons</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 2 General surgeons</td>
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</tr>
</tbody>
</table>

APN = advanced practice nurse; HemOnc = hematology oncologist; MedOnc = medical oncologist; RadOnc = radiation oncologist

*Patient survey will be conducted for only Non-small Cell Lung Cancer, Renal Cell Carcinoma, and Bladder Cancer

# Patients partners were engaged for CRC, NHL, and CLL only
Targeted Literature Reviews

• Identify *patient-centered* attributes of the process and outcomes of cancer treatment from the peer-reviewed literature

• What are the components and attributes of cancer care quality from a *patient-centered point of view*?

• How do patients prioritize different attributes of the quality of cancer care?

• The targeted literature review provided valuable insights for the development of the clinician and patient/caregiver interview guides.
### Clinician Interviews

- 37 clinician interviews conducted

- All clinicians were currently involved in some type of value-based payments

- Have your patients ever articulated to you comments about the quality of their cancer care?

- What have your patients told to you *is important and beneficial to them* in terms of quality of cancer care?

- What areas of concerns or problematic events have your patients mentioned to you about the quality of their cancer care?

- What areas of praise or admiration have your patients mentioned about the quality of their cancer care?

- Clinicians were asked to provide two perspectives: (1) what represents the quality of care of each care pathway from the clinicians perspective and (2) what represents the quality of care of each care pathway from the patient perspective
Clinician responses were coded into 17 discrete quality-of-care themes

<table>
<thead>
<tr>
<th>Quality-of-Care Themes</th>
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<tbody>
<tr>
<td>Symptom/side-effect management</td>
</tr>
<tr>
<td>Cost-finances/insurance</td>
</tr>
<tr>
<td>Psychosocial/emotional well-being</td>
</tr>
<tr>
<td>Clinical outcome</td>
</tr>
<tr>
<td>Physician communication</td>
</tr>
<tr>
<td>Patient expectations</td>
</tr>
<tr>
<td>Timeliness of care</td>
</tr>
<tr>
<td>Interpersonal care/style</td>
</tr>
<tr>
<td>Family support</td>
</tr>
<tr>
<td>Coordination of care</td>
</tr>
<tr>
<td>Quality of life</td>
</tr>
<tr>
<td>Physical well-being</td>
</tr>
<tr>
<td>Technical quality (standard of care)</td>
</tr>
<tr>
<td>Access/logistics</td>
</tr>
<tr>
<td>Patient involvement</td>
</tr>
<tr>
<td>Patient knowledge</td>
</tr>
<tr>
<td>Patient-centered care</td>
</tr>
</tbody>
</table>

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Patient and Caregiver Online Focus Groups: Approach

- Used focus groups to discover attributes of oncology care that are important and meaningful to cancer patients and their caregivers
- Group interaction tends to produce insights that do not surface in individual interviews
- Stratified groups by gender
- Caregiver focus groups were conducted separately from the patient groups
- Patient focus groups were held separately for each cancer diagnosis
- Conducted online focus groups because they offer: (1) cost efficiency; (2) potential to reach a broad geographic scope; and (3) a convenient and comfortable way of participating among cancer survivors
- Online focus groups were synchronous (in real time with “Brady-Bunch” like viewing of participants)
Effort required: Online focus groups

<table>
<thead>
<tr>
<th>Patient and Caregiver Online Focus Group: Key Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Reflecting on your whole pathway—from start to finish (or from start to now)—what does “quality of care” mean to you personally? It is not limited to what you actually experienced. It can also be ideal quality of care that you wished you had received</td>
</tr>
<tr>
<td>• Reflecting on your whole pathway, how would you have changed your care you received (the health care system, your health care providers, and your health care experiences)?</td>
</tr>
<tr>
<td>• For each pathway phase, we asked: (1) how would you have liked to change the health care you received if you were able to do so? and (2) what care, support, resources, or information did you feel you needed but was not provided to you?</td>
</tr>
</tbody>
</table>
Patient and caregiver responses were coded into 21 discrete quality-of-care themes

<table>
<thead>
<tr>
<th>Quality-of-Care Themes</th>
<th>Information giving/provide communication</th>
<th>Community health and social services</th>
<th>Physical comfort</th>
</tr>
</thead>
<tbody>
<tr>
<td>Humaneness/art of care</td>
<td>Access to care</td>
<td>Patient values, preferences, choice, autonomy</td>
<td></td>
</tr>
<tr>
<td>Technical competence</td>
<td>Patient-centeredness/individualism</td>
<td>Costs/finances/insurance</td>
<td></td>
</tr>
<tr>
<td>Timeliness of care</td>
<td>Treatment expectations</td>
<td>Physical facilities</td>
<td></td>
</tr>
<tr>
<td>Psychosocial/emotional support</td>
<td>Coordination of care</td>
<td>Treatment convenience</td>
<td></td>
</tr>
<tr>
<td>Symptom/side-effect management</td>
<td>Enough time with clinician</td>
<td>Bureaucratism</td>
<td></td>
</tr>
<tr>
<td>Caregivers/family/friends</td>
<td>Pain management</td>
<td>Help with self-management/health promotion</td>
<td></td>
</tr>
</tbody>
</table>
Effort required: Patient and caregiver survey

Patient and Caregiver Survey

• Will cross-validate qualitative findings with survey research

• Survey development in process

• Survey will likely include forced rankings and importance ratings of quality-of-care attributes

• May include some quality-of-care vignettes for forced rankings and importance ratings

• Will likely focus on the entire cancer-care pathway overall instead of being pathway specific
Limitations

Selection Bias
Survivorship/Minimization Bias
Only Six Cancers

Few Caregivers of Patients Who Died
Pediatric Population Largely Excluded
### Effort required: Recruiting our patient partners

#### People
- Genentech and Evidera identified and worked with patient-advocacy organizations
  - Colon Cancer Alliance and Fight Colorectal Cancer
  - Lymphoma Research Foundation
  - CLL Society Inc.
- Each advocacy organization supported our recruitment of patient partners and recommended several candidates

#### Funding
- Patient partners were compensated for their time

#### Time
- Contracting with the patient partners took up to five weeks
Effort required: Onboarding our patient partners

• **Genentech and Evidera had a 30-minute teleconference with each patient partner for the following purposes:**
  
  • Genentech’s motivation for initiating the collaboration
  
  • Evidera’s methodologies for study execution
  
  • The partner’s personal pathway through cancer care

• **Patient partners were tasked to review and comment on the following:**
  
  • Focus-group discussion guide
  
  • Qualitative report
  
  • Draft manuscript

• **One patient partner took part in a mock online focus group so we could test the online platform and time the length of the discussion**

• **One patient partner completed the focus group discussion questions in writing**
Lessons learned from our patient partners: Words matter

• Do not use the phrase “patient journey”

“For me and many of my friends/group support acquaintances, it is difficult to call NHL a journey since it is a lifelong condition (at least for now). When I opened the document it refers to it as a pathway. I really appreciate that terminology much better as it is indicative of something we are experiencing and going through, but more than likely not just once. A journey is an adventure and something pleasant, I want to be positive about my diagnosis, but that’s just too much for us who have been coping with it for longer than the initial diagnosis and first couple of treatments. Anyway, so great job finding a more appropriate phrase to use during the process!”

• It is acceptable to use the word “survivorship” (as in survivorship plan)—that word should not be upsetting or off-putting to cancer survivors

• Two partners commented that the term “palliative” care can be misunderstood by individuals. This term triggers “end of life/hospice” for some cancer patients. They were not sure everyone understands the meaning

• Partners did not like the term “redesign” (“as in how would you redesign your cancer care if you had the power to do so”). They preferred “customize” or simply “change the care you received”

Note: The current World Health Organization’s definition of palliative care is “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual
Lessons learned: Factors for future adoption

Successful development and adoption of patient-driven, cancer-quality measures will require:

• A deeper analysis of the data to prioritize among measure concepts for further use
• Accounting for patient-to-patient variation in clinical, demographic, and socioeconomic characteristics
• Direct and ongoing patient involvement at every step
• Cross-disciplinary collaboration across clinicians, researchers, payers, health systems, and policymakers
### Challenges to patient-centered quality-of-care assessment

<table>
<thead>
<tr>
<th>Evidence-based</th>
<th>Disease-specific vs. cross cutting</th>
<th>Accepted as valid and relevant by stakeholders (provider and payer buy-in)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feasible to implement (workflow integration)</td>
<td>Interpretable and actionable</td>
<td>Risk adjustment</td>
</tr>
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Patient-centered care is recognized as a important quality aim. But, when will it be measured and monitored as such?
Next steps

**Dissemination of Our Findings**
- Peer-reviewed publication
- Executive exchanges

**Stakeholder Engagement**
- Patient groups, providers, and payers
- Discuss implications and use cases for our results
Questions and Discussion
Audience Question & Answer
Wrap Up & Announcements
### Acknowledgements

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*Laura Batz Townsend, BA, President & Co-Founder, Louise H. Batz Patient Safety Foundation*
2017-18 Learning Collaborative Patient-Centered Measurement Webinar Series

*Focus on Patient-Centered Healthcare Measurement*

- Register to learn from other 2017 Innovation Challenge winners...
  - *February 8, 2018 at 1pm ET*
  - *March 1, 2018 at 1pm ET*

- Register for [NQF’s Annual Conference](#), March 12-13 in Washington, DC, for a special session, **NQF Measure Incubator™—Past, Present, and Future**

- To learn more, please contact NQF at [incubator@qualityforum.org](mailto:incubator@qualityforum.org)

- Share your ideas with us #ptvoice #ptcenteredmeasures