Putting patient-centered measurement principles into practice: a virtual panel of researchers, patients, and caregivers

American Institutes for Research
February 4, 2020
Announcements

- Participant lines are in listen-only mode.
- You may submit webinar questions via the question feature at any time; however, questions will be answered only during the Q&A sessions. Your questions will only be visible to the moderators.
- For technical difficulties, please contact Karen Frazier at kfrazier@air.org
- Webinar slides will be emailed to registered participants following the webinar.
- Webinar slides and a recording will be posted on https://www.air.org/PCMPilots
Agenda

1. Patient Centered Measurement Pilot Project Program
   1. What is PCM
   2. What are the 5 principles of PCM
   3. Putting the principles into practice
2. Pilot project presentations
3. Panel discussion and audience Q&A
Patient-centered measurement

**Patient-centered**

- Driven by patients’ expressed needs—not assumptions about what matters to them
- Makes a difference for and benefits patients
- Focuses on structures, processes and outcomes that patients care about, not what the system says they should care about

*Measurement that’s driven by patients’ expressed preferences, needs, and values that informs progress toward better health, better care, and lower costs.*
Principles of patient-centered measurement

Patients’ goals, preferences, and priorities drive what is measured and how performance is assessed.

Patients are equal partners in measure development and have decision-making authority about how data is collected, reported, and used.

Patients and other stakeholders get timely, easy-to-understand data to inform decision-making and quality improvement.

Measurement recognizes that patients are whole people and considers their circumstances, life and health histories, and experiences within and outside of the health care system.

Patients have access to the same data as other stakeholders and understand how data is used to inform decision-making around care practices and policies.
Four Pilot Projects Put Principles Into Practice

- **Dialysis**: Goal-Directed Dialysis Care
- **Cancer**: Redefining Functional Status
- **Severe Brain Injury**: Team Listen to Caregivers
- **Maternity Care**: Patient Experience Team

Financial support for the pilot projects provided by the Robert Wood Johnson Foundation
PCM Pilot Project Panel

Moderated by: Hala Durrah and Stephen Hoy
Patient-Led Implementation of Birth Satisfaction Surveys

How, when and where would maternity-care patients prefer to be surveyed about their experiences?

SITES: Commonsense Childbirth, Easy Access Clinic, Community Doula Program, Foundation for Health Care Quality, Smooth Transitions

TEAMS: providers, patient-partners, doulas

INFORMATION GATHERING: Steering committees/Focus Groups, Trained community partners
Maternity Care Experience of Respect and Autonomy

*Patients told us they are eager to improve birth satisfaction for themselves, and for others.*

- **Timing Matters:** new parents are often overwhelmed and need support and flexibility to complete surveys
- **They want to tell their story their way:** most patients wanted text boxes added to the survey tools
- **They want to evaluate multiple providers:** patients’ experience of care was not with a single provider
- **They want to know about the data:** translating knowledge back to this community is a priority
Redefining Functional Status for Cancer Survivors

*Project Goal:* The National Coalition for Cancer Survivorship convened cancer survivors to define a new quality measure concept to represent survivors’ ability to return to functional status following cancer treatment.

- Convened diverse committee of 10 cancer survivors, as well as Technical Expert Panel (TEP)
- Developed conceptual definition of “redefining functional status”
- Evaluated existing validated surveys for alignment with the conceptual definition
- Developed patient-centered specifications for RFS process and outcome measures (PRO-PMs)
Redefining Functional Status for Cancer Survivors

How Patients Shaped the Project:

- **Name of project:** changed from “return to functional status” to “redefining functional status”
- **Composition of committee:** added committee members with metastatic and chronic cancers
- **Scope of measurement:** considered people currently in treatment, as well as people who have completed cancer treatment
- **Measures specified:** included process measures for functional status assessment, in addition to outcome measures

Patient centered measurements are hugely important and I didn’t recognize its value prior to participating in this study. Patients aren’t always comfortable letting their provider know what they are experiencing and having a quality measurement that allows a patient to share their concerns, issues or changes can overcome the fear of speaking up.

-Matt Goldman, Multiple Myeloma Survivor and RFS Committee member
“No One Listens to Me:” Understanding Recovery When Patients Cannot Speak for Themselves

The purpose of this pilot project, is to advance knowledge of what constitutes meaningful patient-centered recovery from severe TBI.

The expected product of this proof-of-concept pilot project is the creation of patient-centered indicators of meaningful behavioral change providing the basis to understand what constitutes meaningful recovery for persons who are unconscious due to severe TBI.
“No One Listens to Me:” Understanding Recovery When Patients Cannot Speak for Themselves

We did all activities together including writing proposal, collecting data, analyzing, disseminating, problem solving, etc.

We needed to train caregiver partners in technology so we can work together better; they had to train us to listen to their experiences.

The researchers could not have collected the kind of data we got without our caregiver partners.
Goal-Directed Dialysis Care

*Dialysis Interdisciplinary Plans of Care*

**Problem-Based** → **Priority-Based**

Paradigm shift AND culture shift

3 aims: Develop a process & measure, then pilot test both

My Dialysis Plan

The University of North Carolina at Chapel Hill
My Dialysis Plan™ - Examples of Partnership

- Highly responsive to patient perspectives
- Numerous iterations in process ($n=32$) and measure ($n=11$)
- Change in project scope (video development)
- Flexible implementation during the pilot study to support dialysis care team
- Communication according to a pre-specified, co-developed communication plan and post-project stakeholder survey
Thank you!

For questions, contact PCMPilots@air.org