**Principles to Make Health Care Measurement Patient-Centered**

**Patient-centered measurement** involves partnering with patients in a meaningful way to decide what we measure, how we measure it, and how we report and use the results of measurement.

There are five principles that guide patient-centered measurement.

Individually and as a group, the principles inform a vision of health care measurement that reflects what patients say they need and want.

- **Patient-driven** - Patients’ goals, preferences, and priorities drive what is measured and how performance is assessed.
- **Holistic** - 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.
- **Transparent** - 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.
- **Comprehensible & Timely** - Patients and other stakeholders get timely, easy-to-understand data to inform decision-making and quality improvement.
- **Co-created** - Patients are equal partners in measure development and have decision-making authority about how data is collected, reported, and used.

Developed by the American Institutes for Research with funding from the **Robert Wood Johnson Foundation, Gordon and Betty Moore Foundation, and California Health Care Foundation**, the principles reflect the contributions of a diverse group of 55 individuals with experience in healthcare, measurement, and patient and family engagement, including patients, health care professionals, payers, purchasers, measurement experts, and policymakers.

Learn more about the principles at:

[http://aircpce.org/projects/developing-principles-patient-centered-measurement](http://aircpce.org/projects/developing-principles-patient-centered-measurement)
Pilot Projects to Implement the Five Principles

The American Institutes for Research, with support from the Robert Wood Johnson Foundation, funded four small-scale pilot projects that demonstrate ways to implement these five principles in real-world settings.

- **Development of a Goal-Directed Care Planning Process and Evaluation Measure for Individuals Receiving Hemodialysis**

  To better align dialysis care and patient-identified life goals, this project team will develop a life goal-directed care planning process. This patient-driven process will include routine symptom assessment and a companion measure reflecting how the dialysis care a patient receives fits with the patient’s life goals.

  *Project Coleads: Jennifer Flythe, Derek Forfang*
  *Organization: University of North Carolina at Chapel Hill*

- **Return to Functional Status: Patient-Led Cancer Outcome Measurement**

  This project team of cancer patient advocates, survivors, and caregivers will develop a measure concept that assesses a cancer survivor’s return to functional status during and after cancer treatment. This outcome measure will get to the heart of what matters to cancer patients and survivors: regaining their precancer quality of life.

  *Project Coleads: Kristen McNiff, Shelley Fuld-Nasso*
  *Organization: National Coalition for Cancer Survivorship*

- **“No One Listens to Me,” Understanding Recovery When Patients Cannot Speak for Themselves: A Sequential, Exploratory Mixed-Methods Study with Caregiver Spokespersons**

  This project team will advance knowledge of what constitutes meaningful recovery in unconscious adults and support implementation of patient-centered data reporting and measure use. The team will develop a patient-centered strategy for creating meaningful indicators of change. The team will design indicators that promote transparent, shared decision making by facilitating conversations between clinicians and caregivers on behalf of vulnerable patients who cannot advocate for themselves during recovery.

  *Project Coleads: Trudy Mallinson, Christina Papadimitriou*
  *Organizations: George Washington University, Oakland University*

- **Improving Patient Experience of Respect and Autonomy During Maternity Care: A Pilot Study to Implement Patient-Designed Quality Measures**

  This project team of patients and community partners will implement two new patient-centered measures of access to person-centered and respectful maternity care: the Mothers Autonomy in Decision Making scale (MADM) and the Mothers on Respect index (MOR-i). The project team will implement MADM and MOR-i in five care settings to determine acceptability, feasibility, and best timing for patients to provide feedback to inform improvement of health services.

  *Project Coleads: Melissa Cheyney, Saraswathi Vedam*
  *Organizations: Oregon State University, University of British Columbia*

Selected through a competitive review process from among 77 applications, the pilots started in June 2018 and will continue through November 2019. In the coming months, AIR will share these promising practices and lessons learned through a final report, webinars, and other events.

For more information, visit:

[https://aircpce.org/projects/PCM-pilots](https://aircpce.org/projects/PCM-pilots)

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