



Transforming Measurement for Better Care

Lessons Learned From Patient-Centered Measurement Pilots

A new vision for health care measurement

Health care performance measures tell us how well the health system is doing—what works and what does not work. Effective measurement drives progress toward better care, better health, and lower costs. Typically, hospitals and health systems, insurers and payors, and researchers select what to measure and how to define and use measures. These decisions are often based on what professionals think is best for patients and caregivers. These ideas may be well-intentioned but do not always line up with what patients and caregivers want. This leads to a critical gap: health care measurement that does not routinely align with patient and caregiver needs, preferences, or values.

What is patient-centered measurement?

Patient-centered measurement is health care measurement driven by patients' and caregivers' expressed preferences, needs, and values. It involves partnering with patients and caregivers in a meaningful way to decide what things to measure, how to measure them, who should get the results, and how to use those results.

Patient-centered measurement focuses on measuring health care quality, safety, value, outcomes, and patient experiences of care in ways that reflect the needs and values of patients and caregivers. It informs progress toward better health, better care, and lower costs.

Patient-centered measurement emphasizes what is most important to patients and caregivers. When patient and caregiver priorities are the focus of measurement, health systems and clinicians, such as doctors and nurses, are rewarded for providing care that makes the biggest difference in patients' lives. As a result, patient-centered measurement makes health care measurement more meaningful. In addition, patient-centered measures provide clinicians and health systems with the information they need to provide the best care to their patients.

The question central to patient-centered measurement is, "What does health care measurement look like when it reflects what patients and caregivers say they need and want?"

What are the principles of patient-centered measurement?

To inform measurement that reflects what patients say they need and want, the American Institutes for Research (AIR) developed Principles for Making Health Care Measurement Patient-Centered. Development of the principles was funded by the Robert Wood Johnson Foundation, the Gordon and Betty Moore Foundation, and the California Health Care Foundation. Measurement is patient-centered when it is:

- **Patient-driven:** Patients' and caregivers' 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 and caregivers have access to the same data as other stakeholders and understand how data are used to inform decision making around care practices and policies.
- **Comprehensible and timely:** Patients, caregivers, and other stakeholders get timely, easy-to-understand data to inform decision making and quality improvement.
- **Co-created:** Patients and caregivers are equal partners in measure development and have decision-making authority about how data are collected, reported, and used.

With support from the Robert Wood Johnson Foundation, [AIR launched small-scale pilots](#) to show how to put these principles in place in real-world settings. AIR issued a call for pilot project proposals and funded four pilots selected through a competitive review process. Each project team had at least one patient or caregiver partner. The projects focused on different groups of people and types of health care: maternity care, cancer treatment, rehabilitation for people who experienced a traumatic brain injury, and in-center dialysis.



Pilot Projects

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

- Developed a goal-directed care planning process to better align dialysis care with patient-identified priorities.
- Developed a measure reflecting how well care aligns with patient priorities.

Redefining Functional Status: Patient-Led Cancer Outcome Measurement

- Developed a patient-driven set of measure concepts to assess individuals' functional status following cancer diagnosis.
- Includes measures to assess functional status during and after treatment and timely response actions to assessments.

"No One Listens to Me": Understanding Recovery When Patients Cannot Speak for Themselves

- Advanced understanding of how family caregivers define meaningful recovery in unconscious adults who have experienced a traumatic brain injury.
- Developed a relationship-centered strategy for creating assessments of meaningful recovery during rehabilitation.

Improving Patient Experience of Respect and Autonomy During Maternity Care

- Implemented two measures of access to person-centered and respectful maternity care to determine acceptability, feasibility, and best timing for patients to provide feedback about the maternity care they received.

Putting the Principles Into Practice

The four teams focused on the five patient-centered measurement principles when developing and implementing health care measures. Here are examples of how they applied the principles and what AIR and the projects learned along the way.

Patient-driven

A patient partner identified the funding opportunity, identified a researcher to work with, and shared his idea to create and evaluate a new care planning process.

All teams followed direction from the patient and caregiver partners. Some of the teams gathered ideas from a wider group of patient and caregivers, through interviews and social media chats.

All teams made a conscious effort to openly discuss and agree on each team member's role and responsibilities on the project. The teams told AIR this was important to ensure patients and caregivers were equal partners, while not passing on an undue burden of the work.

MEASUREMENT IS PATIENT-DRIVEN WHEN...

Roles and responsibilities are balanced among all team members. This can mean patients or caregivers are starting or leading a measurement effort with support from others who bring relevant technical skills. However, patient-driven does not mean that all the work gets passed to the patients. That is not an equal partnership.

All team members listen to patients and caregivers and act on their guidance, especially when key decisions are made.

Holistic

Teams viewed patient and caregiver experiences beyond those typically considered in a health care measure, including mental and physical health and social aspects of patients' lives. For example, one team expanded the patient population they originally considered to include people at different stages of the care journey. Doing so let them recognize that priorities and needs change over time—in this case the priorities of patients during and after cancer.

Another team saw the value in prioritizing what caregivers identified as meaningful change. This team's project focused on caregivers of patients who could not verbally express themselves because of a traumatic brain injury. The team found that caregivers can bridge the divide between the clinician and patient. For example, a shared history with the patient allows caregivers to identify things—like familiar sounds and smells—for the patient to respond to when clinicians conducted evaluations of neurobehavioral change.

One team explored exactly when and how to survey patients about their care experiences. When making these decisions, the team intentionally considered the life circumstances of patients, like caregiving responsibilities and privacy concerns.

MEASUREMENT IS HOLISTIC WHEN...

Measures reflect a broader view of patient and caregiver experiences.

Transparent

Teams chose multiple formats, like videos or written materials, to let patients and caregivers know what would happen with the information they share when they respond to a measure. During the measure development process, teams made a dedicated effort to share findings with people who had taken part in the process, for example by summaries of interview findings and measure results.

MEASUREMENT IS TRANSPARENT WHEN...

Health systems and insurers explain in detail how they will use the data collected from patients and caregivers.

This means not only sharing a plan but also sharing the findings with and informing patients and caregivers about what the next steps will be based on the results.

Comprehensible and Timely

Teams learned that patients and caregivers expect a timely response to measure results. They want access to aggregate findings in a format that is easy to understand. Patients and caregivers also want to know what actions health systems are taking as a result of the findings, especially when they expressed concerns or shared negative feedback in responding to a measure. As a result, one team included a process measure—of timely action taken in response to reported concerns—as part of their measure set.

MEASUREMENT IS COMPREHENSIBLE AND TIMELY WHEN...

There is a short turnaround time between when a patient or caregiver completes a measure and when results are shared.

Results are shared in a way patients and caregivers can easily understand, and include information about what actions health systems and clinicians are taking to improve the care they deliver.

Co-created

Teams established equal partnerships in many ways. Patient and caregiver partners worked on projects as co-leads, team members, or committee members. Some teams created committees that brought together patient and caregiver partners with clinicians, while other teams had separate committees for patients and clinicians.

By supporting equal partnerships, teams could more fully understand the impact of decisions. For example, patient partners on one team were concerned about using mobile devices to collect data. Although mobile devices would help teams gather data quickly, the patient partners flagged their use as an issue that would raise concerns about patients' anonymity. The team decided not to use mobile devices and tablets, and instead collected data by paper.

MEASUREMENT IS CO-CREATED WHEN...

Partnerships, no matter how they are set up, support and encourage all team members, including patients and caregivers, to contribute equally to decision making.

Team members have equal decision-making power, even when faced with hard decisions.

With patient-centered measurement principles guiding the work, we identified two key factors that lead to success

Creating and fostering equal partnerships and embracing flexibility in measurement efforts

Equal partnerships

Building strong, equal partnerships was essential for the teams to successfully implement the patient-centered measurement principles. The teams were excited to create these partnerships and were committed to successfully supporting and fostering them throughout the project. Teams created equal partnerships among researchers, clinicians, patients, and caregivers by **building a strong team, openly valuing equal partnership, and intentionally having all team members be equal partners in decision making.**

An essential element of equal partnerships is valuing the experience that patients and caregivers bring to the work. Patient and caregiver partners brought a range of experiences to teams including their care experiences as well as work and academic experience. The teams valued each partner as a whole person, looking beyond their role on the team as only a patient or caregiver.

Patient and caregiver partners were treated equally, with the same privileges, respect, and inclusion as every other member of the team. For example, all teams compensated their patient and caregiver partners. Fair compensation is a key component of equal partnership as it shows respect and enables inclusion.

Teams had success reaching agreement through both formal and informal consensus building. All team members knew what decision making processes would be used and how they worked. This transparency was valued by team members. Team roles also tended to be a factor that influenced if teams used formal or informal consensus building methods. For example, when patient and caregiver partners were more involved in the day to day project work, teams had more informal consensus building practices.

Patient and caregiver partners were equal members in team discussions and decision-making activities. For example, one team used a research method that is usually carried out by a panel of measure development experts. However, the team used this method with a committee of patients to identify and prioritize measure concepts. Measure experts were available for consultation when requested by the patient committee.

If there were times when decisions were made without the partners, other team members checked back in with partners to discuss the changes and if they were OK with the changes. Not closing this communication loop can be damaging to partnerships.

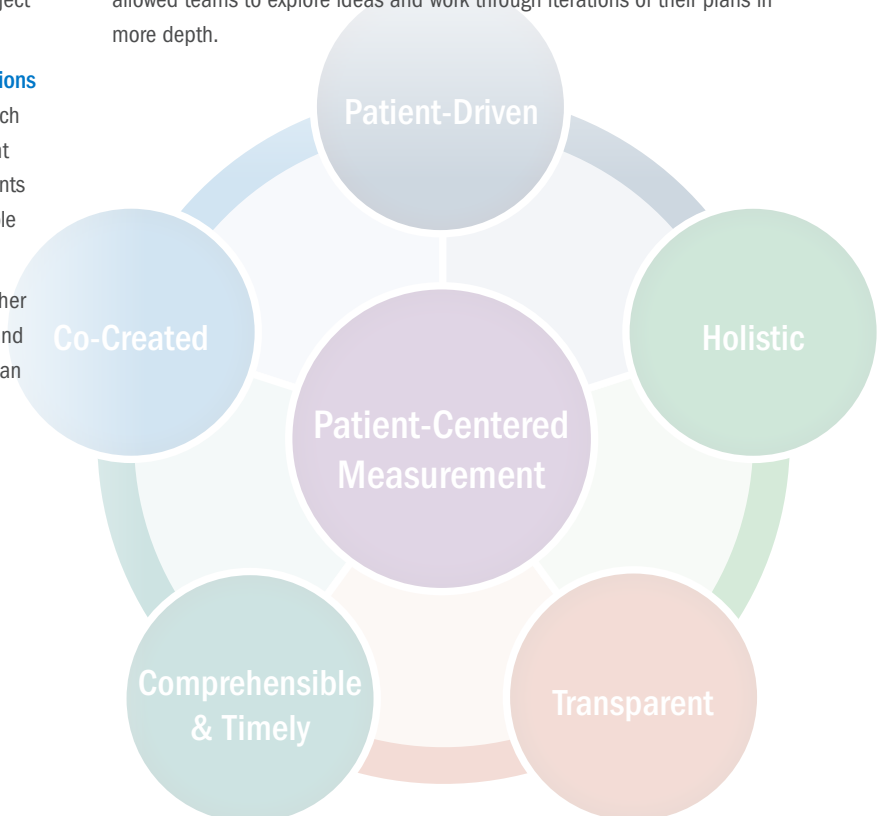
Flexibility

A key part of teams successfully applying the patient-centered measurement principles was their willingness to embrace a flexible approach to their work. By acknowledging that plans may need to change, teams could be comfortable with some uncertainty during the project.

One issue the teams struggled with was deciding on which health care provider's actions a measure should report. Patient and caregiver partners explained that their care experience varied across different clinicians, nurses, and other care team members. One team decided to keep a broad definition of health care providers. Another team initially decided to focus on the individual who performed a specific procedure. After receiving additional guidance from patients, the team created a way for respondents to say which care team member they wanted to reflect on through the survey. Ultimately, the teams valued the flexible approach they took when making these decisions.

Teams adjusted their measure concepts and how they described and framed the purpose of the measure after interactions with patient and caregiver partners. For example, one team found that their original measure name was not meaningful to their patient partners. The team believed that the measure name should come from the patient community but also have meaning with other stakeholders. While the measure development work continued, the entire team worked through name options, ultimately picking something that fully captured the concepts they wanted to measure.

Embracing new opportunities and taking a flexible approach to their projects allowed teams to explore ideas and work through iterations of their plans in more depth.





Ready to implement patient-centered measurement principles in your health care measurement efforts?

Here are some considerations and guidance for putting the patient-centered measurement principles into practice:

1 **PRIORITIZE REPRESENTATION WHEN BUILDING A TEAM.**

Teams should intentionally include patient and caregiver team members who have relevant, lived experience with the care being measured. Health care systems and research institutions have made it difficult for patients and caregivers to engage in partnerships because of a lack of support, compensation, and flexibility. Supporting diverse partnerships requires working creatively to make the partnership supportive and accessible to potential partners. For example, teams should specifically ask what the team could do to make partnership possible, like providing fair compensation, finding out the best time for meeting times, and determining the best methods of communication. Teams need to make sure that their partners know their work on the team is meaningful.

2 **TEAM TRAINING LEADS TO BETTER MEASUREMENT.**

To foster equal partnership, it is important for teams to conduct training and development activities tailored to their team members' needs. These trainings are for all team members, not just patient and caregiver partners. Trainings provide a chance for all team members to share important knowledge and understanding about how the team will work together, each team member's role, and the basic knowledge that is needed to work together on the project.

3 **EQUAL PARTNERSHIPS ARE MEANINGFUL AND BRING INNOVATION TO HEALTH CARE MEASUREMENT.**

Patient and caregiver partners appreciate having their voices heard and having their stories and perspectives drive measurement projects. They find satisfaction and agency in contributing to something that can help others like them. Researchers find that partnering with patients and caregivers leads to innovative and better results.

4 **PATIENT AND CAREGIVER PARTNERSHIPS STRENGTHEN MEASUREMENT TEAMS.**

Equal partnerships strengthen the way measurement teams work together. In such partnerships, patients and caregivers can speak up when something is not working or when they recognize a better way to approach a task or solve a problem. Teams should not wait until they have a fully formed plan to reach out to potential patient and caregiver partners. Patient and caregiver partners can support teams in the planning stage, and their input should be sought when teams start thinking about patient-centered measurement work.

5 **ADOPT PATIENT-CENTERED MEASUREMENT PRINCIPLES FROM THE BEGINNING OF THE MEASURE DEVELOPMENT PROCESS.**

For a measure to be patient-centered, a patient-centered approach needs to be adopted starting at the development phase, continuing through the use of the measure to collect data. If a measure has not been developed with a patient-centered approach from the start, implementation teams should be prepared to adopt a patient-centered implementation approach and be ready to make significant revisions to the original measure.

6 **SUPPORT A FLEXIBLE APPROACH TO MEASURE DEVELOPMENT.**

It is important to support and encourage a flexible approach to measure development and implementation for it to be patient-centered. This includes creating time and space to work through decisions. For example, when preparing research proposals, teams can build a schedule that will allow time for ideas to shift and change. Additionally, institutions must encourage and support flexibility in patient-centered work. For example, institutions can provide access to resources such as file-sharing platforms and ensure timely payment without burdensome paperwork.



FOR MORE INFORMATION ABOUT THIS PROJECT

Visit www.air.org/PCMPilots



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Support for this project was provided by the Robert Wood Johnson Foundation. The views expressed here do not necessarily reflect the views of the Foundation.



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