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# Principles for Making Health Care Measurement Patient-Centered

American Institutes for Research

Prepared for:  
Robert Wood Johnson Foundation  
Gordon and Betty Moore Foundation  
California Health Care Foundation

APRIL 2017

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April 2017

American Institutes for Research



AMERICAN INSTITUTES FOR RESEARCH®

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## Acknowledgements

Support for this project was provided jointly by the following organizations:

- Funded in part by the by the Robert Wood Johnson Foundation.
- Funded in part by the Gordon and Betty Moore Foundation.
- Funded in part by the California HealthCare Foundation.

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

### About the Project Team

The project team for this effort was led by the American Institutes for Research, with contributions from the Integrated Healthcare Association and Patients' View Institute.

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## Executive Summary

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. It also requires that the needs and concerns of other key stakeholders such as health care providers, health care organizations, payers, insurers, and policymakers are considered, allowing for increased information flow between stakeholders; improved partnership; and shared responsibility and accountability for outcomes.

Five principles for patient-centered measurement were developed with input from a multidisciplinary group of stakeholders that included patients. These principles describe the essential elements and characteristics of patient-centered measurement. As a group, the principles augment and complement each other to inform a vision of measurement that reflects what patients say they need and want. The principles require that patient-centered measurement be: patient-driven, holistic, transparent, comprehensible and timely, and co-created with patients. Adhering to these five principles of patient-centeredness will improve the ability of measurement to drive meaningful change toward better health, better care, and lower costs.

### Five Principles for Patient-Centered Measurement

*Patient-centered measurement is:*

1. **Patient-driven:** Patients' goals, preferences, and priorities drive what is measured and how performance is assessed.
2. **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.
3. **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.
4. **Comprehensible and timely:** Patients and other stakeholders get timely, easy-to-understand data to inform decision-making and quality improvement.
5. **Co-created:** Patients are equal partners in measure development and have decision-making authority about how data is collected, reported, and used.



## Introduction

In a high-performing health care system, measurement drives progress towards safe, effective, efficient, timely, equitable, and patient-centered care. Measurement helps identify areas for improvement, evaluate what works in making changes, and promote accountability. It informs how health care is paid for and how resources are allocated. And, as patients and families are asked to take more active roles and assume more responsibility for their health and health care outcomes, it gives them information to make more informed decisions. In working towards better care, better health, and lower costs across the health care system, effective measurement is key.

The challenge comes when considering how to define “effective” measurement—and from whose perspective. As the field of health care measurement has evolved in scope and complexity over the past decades, it has done so in ways that reflect researcher, clinician, payer, and policymaker priorities. As a result, there is a critical gap. Current measurement approaches are not patient-centered, and often do not align with patient and family preferences and values. Patients are not involved in meaningful ways in decisions about what to measure, how to measure it, and how to report and use the resulting information. Patients are the subjects of health care measurement as opposed to decision makers and drivers of change.

When this happens, we run the risk of providing information that is not useful to inform patients’ health care decision-making. We spend resources measuring, and potentially incentivizing, aspects of health and health care that do not resonate with patients. And, we overlook opportunities to drive progress toward better care, better health, and lower costs in ways that align with patients’ values.

## Defining Patient-Centered Measurement

**Patient-centered measurement** is therefore a critical component as we work to meet the needs of the people at the center of our health care system.

### Definition of Patient-Centered Measurement

*“Health care measurement driven by patients’ expressed preferences, needs, and values that informs progress toward better health, better care, and lower costs.”*

In this definition, the term “**patient**” refers inclusively to people who receive health care services; family members, friends, and other caregivers; and any consumers of health care. It is important to remember that patients are diverse in demographics, experiences, needs, perspectives, and values. The term “**health care measurement**” refers to any type of health, health status, or health care-related measurement. The use of the word “measurement” is intentional and indicates a focus beyond developing measures. Patient-centered measurement involves partnering with patients to decide what we measure, how we measure it, how we report the information, and how we use the results of measurement.



Because it is a new concept, we find it helpful to also clarify what patient-centered measurement is not. First, patient-centered measurement is not about assessing the patient-centeredness of care. It is about measuring health care quality, safety, value, outcomes, and patient experiences of care in ways that reflect—or center on—the needs and values of patients. Second, patient-centered measurement is not just about developing and using measures reported by patients, such as patient-reported outcomes (PROs). Rather, it involves considering patient-centeredness not only in measure development, but also data collection, data reporting, and decisions about how measures are used. And finally, while patient-centered measurement recognizes and emphasizes the importance of patient preferences and values, it does not ignore the needs and concerns of other key stakeholders such as health care providers, health care organizations, payers, insurers, and policymakers. With patient-centered measurement, there is increased information flow between stakeholders; shared responsibility and accountability for outcomes; and improved partnership around common goals. In turn, this improves the ability of measurement to drive meaningful change toward better health, better care, and lower costs.

## Principles for Patient-Centered Measurement

The question at the heart of patient-centered measurement is: “How would health care measurement look different if it reflected what patients say they need and want?” To begin answering this question, we have developed five principles for **patient-centered measurement**.

### Five Principles for Patient-Centered Measurement

*Patient-centered measurement is:*

1. **Patient-driven:** Patients’ goals, preferences, and priorities drive what is measured and how performance is assessed.
2. **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.
3. **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.
4. **Comprehensible and timely:** Patients and other stakeholders get timely, easy-to-understand data to inform decision-making and quality improvement.
5. **Co-created:** Patients are equal partners in measure development and have decision-making authority about how data is collected, reported, and used.

Developed with input from a multidisciplinary group of stakeholders that included patients,<sup>1</sup> these five principles describe the essential elements and characteristics of patient-centered measurement. Taken individually, each principle represents an important aspect of patient-centered measurement. As a group, the principles augment and complement each other to inform a vision of measurement that reflects what patients say they need and want.

Below we describe each principle in more detail, including examples of how to translate the principle into action. These examples are not intended to be comprehensive or prescriptive. They provide a starting point for stakeholders to think innovatively and creatively about how to apply these principles to any measurement effort. They also represent immediate actions to advance patient-centered measurement.

## Principle 1: Patient-driven

*Patient goals, preferences, and priorities drive what is measured and how performance is assessed.*

Patients have priorities related to health care quality, costs, and outcomes that often differ from what health care providers, health care organizations, researchers, insurers, and policymakers view as important. The “patient-driven” principle is about partnering with patients to determine how measurement is used and applied to patients’ health and health care. This means that patients’ needs, goals, perspectives, and values—as expressed by patients themselves—inform decisions about what we measure, how we assess health outcomes for individuals, groups of patients, communities, and populations and how we evaluate health care performance (e.g., related to payment, reporting, and quality improvement).

Examples of translating this principle into action might include:

- **Working with individual patients to identify meaningful outcomes for their care**—for example, health care providers or organizations tailor what it means to have “good” care outcomes based on individual patient priorities, identify measures (including PROs) related to a patient’s priorities, and use these patient-preferred measures to track progress.
- **Working with groups of patients who share the same diagnosis or disease to identify measures that are most relevant for specific conditions**—for example, health care providers, researchers, or insurers ask patients with cystic fibrosis which symptoms, experiences, or outcomes are most important to assess, monitor, or consider in evaluating new treatments.
- **Customizing community and population health measurement approaches based on patient input**—for example, public health departments or policymakers work with community members to identify which measures are most meaningful to track in diagnosing community health status and identifying health service needs.

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<sup>1</sup> For more about how the principles were developed, see Attachment 1.

## Principle 2: 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.*

Health care measurement is frequently siloed based on medical specialty, care setting, or health condition. In addition, it tends to emphasize problems and illness as opposed to prevention and wellness. Measurement that focuses on fragmented, problem-based health care is not meaningful or useful to patients. The “holistic” principle is about recognizing that patients: (1) want to experience the health care system as a whole, not as a series of care settings; (2) are more than just collections of health symptoms, conditions, and diagnoses; and (3) spend only a small portion of their lives as patients. This means that measurement considers the whole person, including patients’ journeys over time, experiences across care settings, and lives within and outside of the health care system to provide a more complete picture of health care quality, value, equity, and patient / population health. To be effective, measurement must also be sensitive to the differences among patients in regards to their characteristics, health needs, preferences and values, and pay particular attention to the needs and preferences of vulnerable populations.

Examples of translating this principle into action might include:

- **Assessing experiences and outcomes across care settings and patient-defined episodes of care**—for example, health care organizations, measure developers, or insurers develop measurement approaches that assess maternity care experiences, outcomes, and costs as a bundled whole from pre-conception to post-delivery.
- **Capturing information across the patient’s life course to provide a comprehensive, historical view of experiences and health**—for example, researchers or health care organizations use continuous and integrated measurement to develop a better understanding of patients’ experiences and outcomes as they move through pediatric, adult, elderly, and end-of-life care.
- **Developing measurement approaches that emphasize health and wellness as opposed to disease and sickness**—for example, insurers or health care organizations measure the extent to which patients with chronic health conditions are able to stay healthy (based on their own health goals) and avoid interactions with the health care system.
- **Integrating information from within and outside of the health care system to create a more complete picture of community and population health**—for example, researchers and health care organizations integrate information from health care providers, employers, health and wellness organizations, schools, social service organizations, and community organizations (as deemed appropriate by patients) when conducting community needs assessments.

## Principle 3: Transparency

*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.*

Health care providers, insurers, and payers often have access to data about health care outcomes, quality, and costs that is not available to patients or the general public. Moreover, patients lack clear, understandable information about the types of data collected and used to guide health care decision-making at the individual, population, and policy levels. The “transparency” principle is about increasing visibility into the health care system, providing patients with equal access to information and shared knowledge about how that information is used. This means that information about health care outcomes, quality, costs, and patient experiences of care is shared in ways that patients can understand and use, and that patients understand how performance information is used for improvement and payment.

Examples of translating this principle into action might include:

- **Providing patients with access to and control of their personal health data**—for example, health care providers or insurers develop mechanisms such as OpenNotes by which patients can access or input information about their health history (e.g., diagnoses, medications, allergies, surgeries), input and track their health numbers (e.g., weight, blood pressure, blood sugar), and assess their health status and outcomes over time.
- **Reporting data related to care costs, safety, and quality that has not traditionally been shared**—for example, health care organizations publicly report data about adverse events at care facilities or collect and report individual patient comments about quality of care, or insurers provide patients with accurate information about out-of-pocket costs in advance of specific procedures.
- **Sharing information about how performance measures are used to assess and incentivize health care providers**—for example, policymakers or insurers provide patients and the public with plain language information about value-based purchasing, including which measures are used to assess performance and why.

## Principle 4: Comprehensible and Timely

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

Much information about health care outcomes, quality, costs, and patient experiences of care is not available to the public in ways that are understandable, usable, or accessible at key decision points. The “comprehensible and timely” principle is about ensuring patients and other stakeholders—including health care providers and organizations—have understandable and timely data to inform health care decision-making and drive quality improvement. This means that patients have information they can understand, interpret, and use in accordance with their

preferences at the time it is needed. It also means that health care providers and organizations have access to timely, action-oriented data to inform rapid-cycle quality improvements that align with patient values and preferences.

Examples of translating this principle into action might include:

- **Providing patients with “on-the-spot” data for educational or decision-making purposes**—for example, insurers develop tools that allow physicians and patients to immediately access and discuss cost and quality data related to different treatment options.
- **Developing personalized data reports based on individual patient preferences**—for example, measure developers, insurers, or health care organizations develop reporting tools that enable patients to learn about, select, and weight quality measures based on experiences and outcomes that are most important to their health goals.
- **Using real-time data collection and reporting**—for example, health care providers or health care organizations use mobile or web-based technology to collect point-of-service data from patients that is used in real-time to inform quality improvement.

## Principle 5: Co-created

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

Most work to develop measures and determine how they will be publicly reported and used is done without meaningful involvement from patients. Patient involvement in this realm has typically been relegated to interviews or focus groups, or public comment after development decisions have been made. The “co-created” principle requires equal partnership with patients at all stages of developing measures, determining how they will be reported, and deciding how the information is used for improvement initiatives and policy. Co-created means patients have a clear role, early and ongoing involvement, and shared power and responsibility for decision-making. This foundational principle of patient-centered measurement drives progress toward all other principles.

Examples of translating this principle into action might include *partnering with patients* in:

- **Creating measure concepts, developing measure specifications, and testing measures**—for example, measure developers or policymakers partner with patients to determine which aspects of care should be assessed, the most appropriate data sources and population targets, and changes needed after testing to improve the measure.
- **Evaluating measure endorsement criteria**—for example, organizations that endorse or certify measures meaningfully engage patients in the process of reviewing existing or newly proposed endorsement criteria to ensure reflection of patient and population perspectives and values.



- **Developing public reporting initiatives**—for example, researchers or policymakers partner with patients to determine which structural, clinical quality, patient experience, and cost measures are most important to report along with how and to whom they should be reported.
- **Identifying measures for use in accountability programs**—for example, insurers or policymakers partner with patients to determine which domains of quality are important for use in value-based purchasing or testing alternative payment models.

## Conclusion

Transforming measurement will require innovative approaches and partnering with patients in meaningful ways to develop measures, collect and report data, and make decisions about how to use measures. When translated into action, the five principles of patient-centered measurement transform measurement to reflect what patients say they need and want. With combined efforts across all stakeholder groups—patients, patient advocates, researchers, measure developers, policymakers, health care providers and organizations, insurers, and others—we can drive progress toward better care, better health, and lower costs in ways that align with patients’ values.

## Attachment 1. Patient-Centered Measurement Principles—The Path to Development

The five principles for patient-centered measurement were developed through a collaborative process marked by research, public input, and stakeholder brainstorming and discussion. A key event in this process was a facilitated meeting of stakeholders in September 2016, which we refer to as a convening.

### Preparing for the convening

Prior to the convening, we conducted an environmental scan and interviews to identify previous and current work related to patient-centered measurement. We then solicited input from patients and family members via three public deliberation sessions about how health care measurement could best capture what matters to them. In general, participants in the public deliberations expressed deep frustration with the health care system, describing it as difficult to navigate, lacking transparency, and inadequately focused on patients' needs, preferences, and goals.

#### Public Deliberation Themes

##### **The public felt information and measures were lacking in the following areas:**

- Navigating and understanding insurance
- Predicting and comparing out-of-pocket costs
- Understanding quality of care and care experiences across a broad spectrum of topics (e.g., wait times, error rates, and care coordination)
- Understanding health care provider credentials and continuing medical education
- Having open access to personal health information and medical records

##### **The public expressed that “health care measurement” should:**

- Focus on what matters to patients
- Provide information in a way patients can understand and use to manage their own health and health care
- Take into account patient goals and preferences for health and health care
- Provide accurate cost and quality information together, using high quality data
- Involve patients, families, and communities in the process of developing, selecting, and evaluating measures
- Be conducted and/or monitored by an independent, unbiased third party

We then shared the public deliberation findings with five health care innovators to gather ideas about how to drive progress toward more patient-centered measurement. We asked interviewees to consider principles that might guide measurement to be more patient-centered, and to identify short and long term implementation strategies. Overall, interviewees noted the need to re-orient our current health care system, describing it as fundamentally designed around the convenience and control of health care providers, rather than patients.



## The convening

For the convening, we brought together 55 people representing a wide range of health and health care perspectives (see Attachment 2). Thirteen patients, caregivers, and patient advocates constituted the largest group. We also had representation from payers, researchers, clinicians, health care organization leaders, purchasing groups, policymakers, and funders.

During the convening, we asked participants to creatively reimagine health care and measurement through the lens of patients' needs and preferences. Participants discussed key themes from the public deliberation sessions, and built upon these themes to create a vision of measurement that is patient-centered. Through both small and large group discussions, we asked participants to engage in a collaborative exchange of ideas, focusing on opportunities and possibilities. Participants were tasked with identifying what is working well now in health care and health care measurement, imagining how things could be different, and developing ways to drive progress toward a new vision of measurement.

To develop the principles for patient-centered measurement, we divided convening participants into small teams and asked them to identify key elements or defining characteristics of measurement that is patient-centered. Participants did so by completing the statement, "Measurement is patient-centered when..." We compiled responses from each of the small teams, condensed and grouped them thematically, and reflected a synthesized list of principles back to participants for reaction and feedback. Overall, participants were pleased with the draft principles for patient-centered measurement and primarily suggested clarifications, expansions, and refinements.

## Finalizing the principles

After the convening, we analyzed participants' thoughts, ideas, and questions as captured in pages of notes and dozens of flip charts. We used the participants' suggestions, along with handwritten edits and notes participants made on copies of the draft principles, to further refine the principles. We shared the principles again with convening participants in a draft report and solicited additional comments and suggestions. Lastly, we further condensed, clarified, and simplified the principles to highlight the most important elements of patient-centered measurement.

## Attachment 2. Convening Participants

| Name                       | Organization <sup>2</sup>   |
|----------------------------|---|
| <b>David Andrews</b>       | Georgia Regents Medical Center  |
| <b>Cynthia Barginere</b>   | Rush University Medical Center  |
| <b>Laura Batz Townsend</b> | Louise H. Batz Patient Safety Foundation                                |
| <b>Arlene Bierman</b>      | Agency for Healthcare Research and Quality (AHRQ)                       |
| <b>Marc Boutin</b>         | National Health Council   |
| <b>Kevin Bozic</b>         | Dell Medical School at The University of Texas at Austin                |
| <b>Katherine Browne</b>    | Constellation Consulting  |
| <b>Jim Chase</b>           | Minnesota Community Measurement   |
| <b>Alicia Cole</b>         | Patient Advocate  |
| <b>Darren DeWalt</b>       | University of North Carolina – Chapel Hill                              |
| <b>Chris Duke</b>          | Altarum Institute   |
| <b>Hala Durrah</b>         | Patient Advocate  |
| <b>Kat Esser</b>           | Center for Care Innovations   |
| <b>Ted Eytan</b>           | Kaiser Permanente Center for Total Health                               |
| <b>Lori Frank</b>          | Patient-Centered Outcomes Research Institute (PCORI)                    |
| <b>Jennifer Fronzaglia</b> | Vitals  |
| <b>Dominick Frosch</b>     | Palo Alto Medical Foundation Research Institute (PAMFRI)                |
| <b>Mindy Hangsleben</b>    | HHS IDEA Labs initiative  |
| <b>Chris Hass</b>          | Mad*Pow   |
| <b>Mark Hornbrook</b>      | Center for Health Research, Kaiser Permanente                           |
| <b>Stephen Hoy</b>         | PFCCpartners  |
| <b>Ann Hwang</b>           | Center for Consumer Engagement in Health Innovation, Community Catalyst |
| <b>Julia Kim</b>           | U.S. Department of Veterans Affairs                                     |
| <b>Rebecca Kirch</b>       | Patient Advocate Foundation   |
| <b>Ariel Klein</b>         | Castlight   |
| <b>Sarah Kucharski</b>     | Stanford Medicine X   |
| <b>Kevin Kumler</b>        | ZocDoc  |
| <b>Joseph Kvedar</b>       | Connected Health, Partners HealthCare                                   |
| <b>David Lansky</b>        | Pacific Business Group on Health (PBGH)                                 |
| <b>Alan Manning</b>        | Planetree   |

<sup>2</sup> The organizations in this list reflect participants' employers at the time of the convening (September, 2016).

| <b>Name</b>                   | <b>Organization<sup>2</sup></b>   |
|-------------------------------|---|
| <b>Kym Martin</b>             | Patient Experience Council  |
| <b>Anna McCollister-Slipp</b> | Galileo Analytics   |
| <b>Lindsey Messervy</b>       | Business Innovation Factory   |
| <b>Mary Minniti</b>           | Institute for Patient- and Family-Centered Care   |
| <b>Jean Moody-Williams</b>    | Centers for Medicare & Medicaid Services (CMS)  |
| <b>L. Gordon Moore</b>        | Doctor.com  |
| <b>Garrett Moran</b>          | Westat  |
| <b>Deirdre Mylod</b>          | Press Ganey Associates  |
| <b>Debra Ness</b>             | National Partnership for Women and Families   |
| <b>Kathryn O'Callaghan</b>    | Food and Drug Administration (FDA)  |
| <b>Sally Okun</b>             | PatientsLikeMe  |
| <b>Charlotte Parent</b>       | New Orleans Health Department   |
| <b>Jeanne Pinder</b>          | Clear Health Costs  |
| <b>Wendy Prins</b>            | National Quality Forum (NQF)  |
| <b>Michelle Probert</b>       | General Dynamics Bath Iron Works  |
| <b>Raj Ratwani</b>            | National Center for Human Factors in Healthcare, Medstar Institute for Innovation                             |
| <b>Lygeia Ricciardi</b>       | Clear Voice Consulting  |
| <b>Eduardo Sanchez</b>        | American Heart Association  |
| <b>Lewis Sandy</b>            | United Health Care  |
| <b>Amy Sherwood</b>           | CedarsBridge Group  |
| <b>Leah Tuzzio</b>            | MacColl Center for Health Care Innovation, Kaiser Permanente Washington Health Research Institute             |
| <b>Nick van Terheyden</b>     | Dell Healthcare and Life Sciences   |
| <b>Veronica Vela</b>          | U.S. Department of Veterans Affairs   |
| <b>September Wallingford</b>  | Costs of Care   |
| <b>Saul Weiner</b>            | University of Illinois at Chicago Veterans Administration Center of Innovation for Complex Chronic Healthcare |
| <b>Kristin Carman</b>         | American Institutes for Research  |
| <b>Pam Dardess</b>            | American Institutes for Research  |
| <b>Kourtney Ikeler</b>        | American Institutes for Research  |
| <b>Mary Lavelle</b>           | American Institutes for Research  |
| <b>Heather Ma</b>             | American Institutes for Research  |
| <b>Rikki Mangrum</b>          | American Institutes for Research  |
| <b>Maureen Maurer</b>         | American Institutes for Research  |

| Name                        | Organization <sup>2</sup>         |
|-----------------------------|-----------------------------------|
| <b>Ellen Schultz</b>        | American Institutes for Research  |
| <b>Ela Pathak-Sen</b>       | Commotion UK                      |
| <b>Ginamarie Gianandrea</b> | Integrated Healthcare Association |
| <b>Jill Yegian</b>          | Integrated Healthcare Association |
| <b>Pat Mastors</b>          | Patients' View Institute          |
| <b>David Adler</b>          | Robert Wood Johnson Foundation    |
| <b>Tara Oakman</b>          | Robert Wood Johnson Foundation    |
| <b>Anne Weiss</b>           | Robert Wood Johnson Foundation    |
| <b>Susan Baade Song</b>     | Gordon and Betty Moore Foundation |
| <b>Beth Berselli</b>        | Gordon and Betty Moore Foundation |

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