

Theory of Change for an

EQUITABLE PATIENT CENTERED MEASUREMENT ECOSYSTEM

That Supports an Advanced
Healthcare System

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This project summary is not intended to represent the individual voices of any of the organizations listed here.

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Introduction

Eliminating disparities will require an extensive examination of the health care measurement ecosystem. Grave health and healthcare disparities continue to plague minority patient populations in the United States. National healthcare clinical quality measures that have been in use for more than two decades have been a catalyst for change, driving improvements in quality and patient outcomes. However, Black and Brown patients continue to experience worse outcomes than White patients—a fact highlighted by the COVID-19 pandemic. The people and processes involved in developing our current healthcare measurement system have allowed us to achieve levels of quality once thought unreachable. Yet if we wish to make healthcare outcomes more equitable, we must consider new ways in which the healthcare measurement system can drive improvements in quality for all patient populations. A re-examination of the healthcare measurement ecosystem—that is, the people and processes involved in developing, endorsing, selecting, implementing, and using healthcare metrics—is a necessary step toward promoting a more equitable and patient-centered healthcare delivery system: the Advanced Healthcare System (as defined in the theory of change).

The current healthcare measurement ecosystem includes stakeholders and structures that develop, endorse, select, implement, and use measures to guide care delivery, as well as systems that reinforce accountability for the quality of healthcare delivery. This ecosystem is provider-centric: Researchers and providers typically develop measures which are endorsed by the National Quality Forum (NQF) or other professional organizations as important, reliable, valid, and feasible; payers and health systems select measures for specific programs or purposes; health systems and providers collect, aggregate, and report data; and payers, providers, and health systems take action in response to measurement results.

Efforts are underway to shift the healthcare measurement ecosystem to one that is patient-centric instead, focusing on what is most important to patients and caregivers.



Invitations for patients to partner in the measure development process have been slowly increasing, in part because of organizations like the Patient-Centered Outcomes Research Institute (PCORI). Created and funded by the Affordable Care Act, PCORI requires its researchers to partner with patients and other stakeholders throughout the research process, including defining research questions and determining the research approach. Additionally, organizations such as NQF include patients and caregivers in the process for endorsing healthcare measures.



These are important steps toward creating [patient-centered measurement](#)—that is, measurement that is patient-driven, holistic, transparent, comprehensible, timely, and co-created in partnership with patients and caregivers—but they must be improved upon. Our team's work to date has shown that patients' and families' perspectives and priorities are different from—and often more holistic than—those of researchers, providers, and payers who have traditionally been involved in establishing the healthcare measurement ecosystem.

A review of existing frameworks for patient-centered measurement demonstrates a lack of evidence that diversity, equity, and inclusion were sufficiently examined and intentionally organized within the measure development structure. For example, today there is no requirement for assessment of performance based on a population in the measurement evaluations process; specifically where there have been attempts to identify performance gaps (i.e., social risk trials and risk adjustment projects). Additionally, while some patients, families, and caregivers have begun partnering with measure development teams, efforts by researchers and healthcare delivery systems have failed to adequately include diverse communities and populations in their processes. The same lack of diversity exists among the experts, funded research teams, and measure developers who lead this work.

Decades of advocating for and practicing patient and family engagement throughout the healthcare system have made healthcare delivery more patient-centered, but they have not made it more equitable. Crossing the Quality Chasm, a 2001 report by the National Academy of Medicine, laid out six aims for healthcare: to be safe, effective, patient-centered, timely, efficient, and equitable. More than 20 years later, the healthcare system has fallen far short of its aim to be equitable. In its 2018 National Healthcare Quality and Disparities Report, the Agency for Healthcare Research and Quality (AHRQ) noted that Black and Indigenous people of color receive worse care in about 40% of national quality measures.



In healthcare, what gets measured gets improved. As was historically the case in clinical trials, there has been a lack of minority participation in efforts to develop patient-centered measurement. The current approach mimics a "one size fits all" design to determine performance and quantify outcomes. Furthermore, the people and processes involved in this work have not undergone significant change in decades and do not reflect or address the needs and experiences of all patients, specifically communities of color. Until the people and processes that drive healthcare's measurement ecosystem become more diverse and inclusive, the healthcare system will continue on its current trajectory and health disparities identified by AHRQ and others will persist.

Methods

This examination of how we can expand the healthcare measurement ecosystem to become patient-centered and equitable uncovers key insights and valuable lessons shared by some of today's most credible clinicians, researchers, system leaders, payers, patients, families, community leaders, and organizations. A comprehensive review of the data collected for this research has informed a proposed theory of change focused on the people and processes involved in the healthcare measurement ecosystem. Increasing the uptake of patient-centered measurement and ensuring that diversity, equity, and inclusion become core practices embedded within the measurement ecosystem can ultimately shift the power dynamics to create a more equitable ecosystem that is patient and community owned and driven.

To explore this notion, we conducted data collection and interviews guided by the following study questions:

- 1) How do we develop the practice of patient-centered measurement to achieve equity? That is, how do we ensure that the teams who develop, select, implement, and use measurement are informed by patients and caregivers? How do we assure that measurement systems identify disparities and support their elimination?
- 2) What is the path to shifting the power of measurement from solely professional interests within healthcare to include the interests of patients, families, and their communities?

To develop a theory of change, our team drew on key insights from interviews with more than 50 stakeholders representing patients and caregivers, measure developers, funders, community partners, and healthcare and academic executives. Interviewees highlighted ways in which the current healthcare measurement ecosystem falls short of the goal of guiding patient-centered and equitable care delivery, including the following:

- An over-reliance on professional expertise without regard for lived experience, which is equally important in informing measure development processes
- A provider-centric measurement ecosystem, which guides decisions about what measures to develop; shapes the development process; and informs decisions about endorsing, selecting, and implementing measures
- A paternalistic culture characterized by power imbalances that further inequities, including the following:
 - o Uni-directional processes with limited information exchange or involvement for those experiencing inequities
 - o Homogenous partnerships that do not recognize the experiences of communities of color
 - o A reliance on universal processes that do not recognize the value of participation by diverse people and communities
 - o A lack of accountability for measuring or resolving disparities

Results



Study participants described the healthcare measurement and delivery ecosystem as one that focuses payment systems on aggregate outcomes; makes limited effort to identify disparities; offers little accountability for population health management; and offers no accountability for equitable outcomes, major health disparities, and racial inequities. As a result, patients, families, and caregivers experience an uncoordinated, inequitable healthcare delivery system.

Interviews also surfaced four major areas of focus that, if addressed, can expand the healthcare measurement ecosystem to become more equitable, and can ultimately support a more equitable healthcare delivery system:

- Restructure the architecture and design of healthcare measure development
- Foster stronger partnerships that engage and empower diverse communities and patients
- Ensure diversity, equity, and inclusion are foundational to research, patient engagement, and healthcare delivery, and
- Reshape accountability and influence over funding decisions to center on communities of color and others who experience health disparities.

These areas of focus have shaped the theory of change proposed in this paper. If we are to bring about long-term systemic change in the healthcare measurement ecosystem, specific actions must be taken to address these areas of focus.

The key to success is to drive a shift in power dynamics, moving from a provider-centric measurement system to one that is patient-centric and uses data and information that are deemed important by patients who represent all communities. Table 1 outlines the four elements of our theory of change and provides a summary of learnings and recommendations that can create the necessary conditions to make the healthcare measurement ecosystem more patient-centered, diverse, equitable, and inclusive.

Table 1: Theory of Change for an Equitable, Patient-Centered Measurement Ecosystem That Supports an Advanced Healthcare System

Theory of Change Element 1: Bi-Directional Measure Development Process
 Restructured architecture and design systems for healthcare measurement specifically address inequities and unintended consequences to drive inclusion and accountability.

" We have to fix ourselves first—we need to address the structure of our healthcare providers/system."

- Measure developer

"Traditionally we only look at outcomes measures. This is inadequate. Outcomes measures are often not accurate and beside the point, whereas a process measure is more meaningful."

- Clinical researcher



- Measurement becomes patient-centered when patients and caregivers representing diverse populations inform decisions about what we measure, how we analyze health metrics, and how we evaluate healthcare performance.
- Showing that the healthcare system values the health of all populations requires granular information that provides context, such as pairing outcome measures with process measures and disaggregating data.
- Ensuring diversity, equity, and inclusion within the architecture and design of patient-centered measurement demands that all measures be stratified at least by race, ethnicity, gender, and language. Measure performance differs across different populations, and a measure alone cannot tell you why. Stratification is a first step toward identifying and addressing disparities.
- We cannot improve what we do not measure, which means that our measurement system must more clearly extrapolate inequities that result from variations in healthcare delivery from the disparities seen in health outcomes. Measuring performance at the policy, systems (organizational), and individual levels, and in terms of outcomes and processes, is critical to demonstrating and exploring disparities. For example, stratifying public and transparent COVID-19 data by race and ethnicity promoted discussions that guided researchers to not only understand these disparities but to begin working to remove them.

- Get the data right. Clean up existing data and measures to improve quality and use. Most importantly, improve quality and accountability in the collection and reporting of data on race, ethnicity, gender, and language; sexual orientation data; and social determinants of health (SDOH) data. Additionally, an acceleration of efforts to train and educate about patient self attestation is necessary collecting race and ethnicity data.

- Redesign the measurement infrastructure. We must restructure the methods and leaders we use to develop, test, implement, validate, and evaluate measures. Additionally, we must change the format in which we report data.
 - o Include patients, families, and caregivers in redesign efforts, from design and implementation through to evaluation.
 - o Create accountability systems to affirm the diversity and inclusion of patients throughout the process.
 - o Restructure the way in which we perform reliability and validity testing in order to understand measures' performance among vulnerable populations.
 - o Increase workforce diversity, including the recruitment of people from marginalized communities.
 - o Give communities more pronounced voices in the leadership process for ensuring equity in patient-centered measurement. Understand what communities value most and how to partner with them.
 - o Create practical tools to guide measure developers and quality improvement experts in supporting the redesign.
- Start telling the disparities story using data. Stratification should be commonplace to make opportunities for improvement more transparent.

See [Rush University Medical Center's 2018 Health Equity Report](#) for an example of how we can shift the culture of healthcare using transparency, reporting, and storytelling.

Theory of Change Element 2: Expand Partnerships to Promote Diverse, Inclusive Systems
 Diversity, equity, and inclusion are recognized as foundational to research, measurement, patient engagement, and healthcare delivery.

"Institutional leaders have not wholeheartedly supported this work. All too often researchers are not authentically supported in this work."

- Funder

- Currently, measurement is primarily driven by researchers. There was a consensus among interviewees—including measure developers—that the types of problems researchers look to solve may not necessarily align with the needs of all communities. Patient-centered, equitable measurement requires upstream work to ensure that healthcare measurement is built on partnerships with diverse patients, families, and caregivers, including through all stages of design, endorsement, adoption, and implementation.

"Biggest part is having patients and families as part of those measurement teams and really being in leadership roles and being fully supported and compensated in those roles."

- Patient/family engagement subject-matter expert



- Funders must drive accountability for diversity and inclusion among the people who shape measurement—especially the researchers assigned to develop, endorse, test, and implement measures—and in the processes and infrastructure that support this work.
- Patients are best positioned to determine whether care and outcomes align with their values, preferences, and needs. Future work must acknowledge that quality-of-life issues (as recognized by researchers, clinicians, and other stakeholders) may vary among diverse populations.
- The design of our value-based healthcare system may unintentionally widen gaps in disparate health and healthcare outcomes. Payers play a significant role in this process because they influence the value assigned to measures and have the decision-making authority to influence the use of particular measures. How payers choose measure developers—and which measures to develop—matters. Various funder considerations affect the healthcare measurement ecosystem, including how measures impact diverse populations, the ease of data collection, and the burden of producing measurements.

- Build trusted partnerships and use trusted partners. We must do more to dedicate sufficient effort and resources to ensuring that the partnerships we advocate for are equitable, and to make the case that diverse experiences are essential to creating a safe, effective, efficient, timely, patient-centered, and equitable healthcare system.
- Ensure that trusted partners from communities of color and diverse backgrounds—such as Black, Hispanic, and lesbian, gay, bisexual, transgender, and queer (LGBTQ+) communities—are front and center in leading the work.
 - o Measurement teams and patient-engaged researchers often partner with patients and families who do not represent a diversity of lived experience; they tend to represent the experiences of White and middle- to upper-middle-class Americans. Or when persons of color are present tokenism exists. We must acknowledge that the experiences of these White patients and families do not represent those of Black, Latinx, Indigenous, or LGBTQ+ patients.
 - o Similarly, we must acknowledge that the experiences of those in power are not the same as the experiences of those who are not in power. Healthcare professionals, researchers, and funders must recognize their power and defer to patients' and families' needs, values, and preferences.

We must highlight stories where partnerships with diverse community members have driven the success of research projects, such as [2CEERIAS](#), which used "promoters" to educate people who live in south Chicago about stroke signs and symptoms to improve patient outcomes.

Theory of Change Element 3: Educate All Levels About What Works

Disparities are not new and have been well examined. It is important to surface the best lessons we have learned through an environmental scan, meta-analysis, and widespread dissemination of findings and best practices.

"Sharing of best practice. There are lots of lessons learned that are gone undissemintated or lacked in dissemination."

- Measure developer

"Training must occur [and] both have to be trained for the interactions that occur when patients are engaged."

- Funder

" We have to build the capacity of the patient ... but equally as important is building the capacity of the physicians and the nurses."

- Community leader

- Education is power. We must develop and implement a systematic approach to learning, based on best practices, at all levels including measure developers, researchers, providers, patients, administrators, funders, and payers.
- It is important to showcase specialty areas where this work has been done in order to inspire others, and to share lessons learned from prior work and research.
- Researchers and measure developers alike seek funder direction to support new ways of scaling and demonstrating the validity of measures that matter to diverse communities and patients. A connection to the community is essential to drive improvements in sustainable outcomes and must be nurtured.
- Flexibility in research and design, as well as in measuring implementation, must be built in upfront and tailored to meet the needs of all communities. Researchers and measure developers can be taught how to accomplish this to ensure diverse representation of the communities for whom the measures are most applicable.

- Educate, educate, educate. Funders must lead by example. This includes developing a systematic approach to requiring education in diversity, equity, and inclusion, with recommendations for best practices in patient engagement and equity strategies. It is equally important for this work to be led by people of color and/or those who represent disenfranchised communities, and to create intentional feedback loops led by persons of interest.
- Share what we have already learned for broader application. In the past two decades, considerable effort has been devoted to understanding equitable opportunities in healthcare. We must showcase existing pockets of excellence, such as the Ryan White Program (HIV) and the End Stage Renal Disease Kidney Donor Program.

We must make use of existing structures to provide education to all stakeholders, including entities such as the [Centers for Medicare & Medicaid Services Office of Minority Health](#) and the [Small Business Administration](#).

Theory of Change Element 4: Equity Accountability - A Systematic Approach

The lack of focus on equity is tied to a lack of systems accountability. Ensuring accountability at all levels of measurement requires accountability for who does the work of measurement (the people) and accountability for how that work is managed and evaluated (the process).

"What matters is at the most fundamental level, in terms of inclusivity and diversity, if you're starting at the very front end of the research process, we need much greater diversity and inclusion, but it's not that people don't understand that we need diversity, we need mechanisms and tools that will ensure that inclusion occurs."

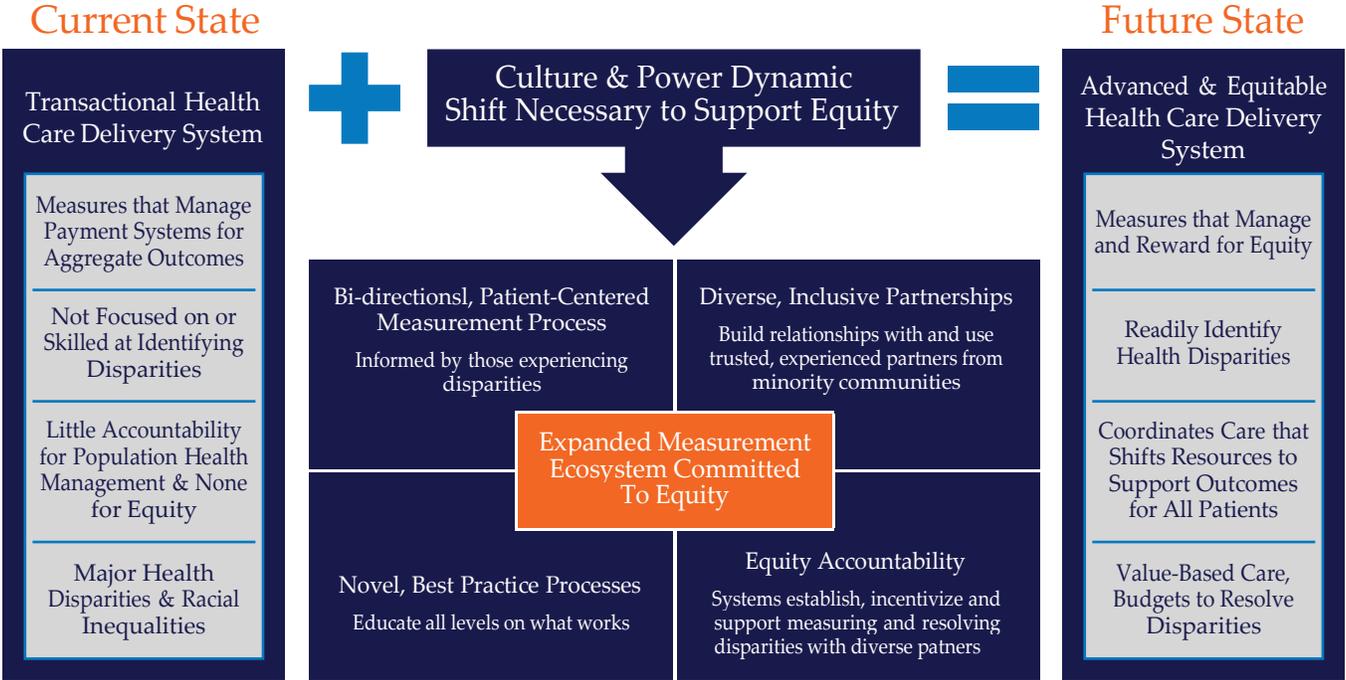
- Funder

- Shifting the paradigm will require changes to the thought processes of all stakeholders. Systems of accountability must be put in place to ensure that conflicting goals and objectives do not disrupt the integrity of equitable, patient-centered measurement.
- We must restructure the players, data, and requirements (i.e., development, endorsement and use) that do not require assessment and analysis of the impacts on populations, either episodic (i.e., point in time) or longitudinal.

- Incentivize the creation of more equitable systems and outcomes.
- Reconsider and reconstruct "what we pay for." To be intentional about the work moving forward, funders must be bold about how and who we prioritize. A system of checks and balances is needed to monitor what is researched, evaluated, and paid for so that these decisions align with the needs, values, and preferences of all patients.
- Dedicate more funding to diverse partners representing communities of interest who can lead this work. The architecture of measure development and research must become nimble and flexible enough to enable minority communities not only to become involved, but also to lead.
- Create a mechanism for funders to hold partners accountable for their intentionality in the work. Interviewees identified a lack of checks and balances to ensure intentionality as a common concern. Organizations often identify equity as a fundamental value in their patient-centered work but fail to create systems that demonstrate the presence and intent of equity, diversity, and inclusion in the design and throughout the continuum of their work. There are many ways to hold organizations accountable, including using a diversity rubric to evaluate who gets funded for measurement-related projects.

Leading by example, the State of [Illinois increased its investment in violence prevention and trauma recovery services by \\$10 million in 2020](#). The state has developed a program to create opportunities for community-based organizations in this space, and has ensured that the work will be informed by and will align with the needs of regional and local communities and counties in the state.

Figure 1: Summarizes each of these elements of the theory of change, and illustrates how changes to the people and processes involved in the healthcare measurement ecosystem can inspire change toward a more advanced and equitable healthcare delivery system.



- Healthcare measurement ecosystem includes the people and processes involved in developing, encoding, selecting, implementing and using health care metrics.
- Patient-centered measurement process is one that is co-created in partnership with patients and caregivers and measures developed are patient-driven, holistic, transparent, comprehensible and timely.

Discussion

Changing our current healthcare system (a transactional healthcare delivery system) to become an advanced and equitable healthcare delivery system requires changes to the people and processes that are traditionally involved in that system. The theory of change identifies a systems approach to overhauling healthcare delivery and models for measuring performance in order to make them more patient-centric and equitable. Shifting the culture and power dynamics of our current healthcare measurement ecosystem will require us to forge an infrastructure that promotes the following four elements of change: (a) bi-directional learning, education, and communications; (b) diverse partnerships; (c) the sharing of innovative best practices and processes; and (d) accountability.

Changes to healthcare measurement alone will not result in improvements in equity, but changing the way in which healthcare measurement is conducted across the ecosystem can make a meaningful difference. Making healthcare measurement more equitable and patient-centered will require a system that more readily identifies disparities. At present, it is difficult to identify disparities because quality measures are reported in aggregate. To disaggregate this information, health systems must have accurate, patient-level, demographic data. But it doesn't end there, ensuring diverse voices are leading efforts to guide the reconstruction of the measured ecosystem is imperative. It is also imperative that diverse voices are leading efforts to reconstruct the measurement ecosystem. We recognize that embedding diversity and inclusion and stratifying data are just the first steps on the path toward implementing evidence-based practices that result in the elimination of disparity. But that exploring how we identify social determinants of

health, measure institutional racism and implicit bias are necessary to advance toward the desired future of a more patient-centered and equitable health care delivery system.

Our research found that within the context of measurement, having a system with accountability is the most important condition for guiding greater equity and patient-centeredness. Pervasive disparities must come to an end, along with the continued lack of Black and Brown representation in the national conversation around measurement, performance improvement, quality improvement, patient engagement, and disparities. To solve a problem, those who are most affected must be adequately represented in—and must guide—efforts to find the solution. Almost every major organization in the United States, in healthcare and beyond, has made goodwill commitments to advance diversity, yet the results remain dismal. Funders, researchers, measure developers, healthcare delivery systems, and performance and quality improvement efforts must establish bold goals supported by strong accountability to drive meaningful change. This change must begin by elevating the many unheard voices within ethnic minority communities and ensuring proper feedback loops. The Advanced Healthcare System must manage, incentivize, and reward improvements in equity using these approaches, within a continuous quality improvement framework. Consistent and transparent exposure of disparities across the healthcare continuum—and the intersection between those disparities and other challenges such as structural and systemic racism—will prompt changes and improvements in patient care and in health and healthcare outcomes.

Appendix

Equality and Patient-Centered Measurement: Thematic Analysis

High-Level Notes and Summary Discussion Points

Key Messages

- Patient and Family Engagement (PFE) Subject-Matter Expert (SME): "We need to get on the front end of the problem (i.e., disparities), we need to go upstream."
- Funder SME: "When we measure diabetes or we measure hypertension, it's a clinical number that people are looking at: Is the average hemoglobin A1C less than it is under control? That would be under control. Right, and then there'll be these fierce debates about whether it should be 9 or ... it should be 10, so there's all this stuff that goes on around that kind of a clinical measure, which is necessary, but not sufficient."
- Measurement SME: "Sharing of best practice. There are lots of lessons learned that are gone undissemated or lacked in the dissemination."
- Funder SME: "What matters is at the most fundamental level, in terms of inclusivity and diversity, if you're starting at the very front end of the research process, we need much greater diversity and inclusion, but it's not that people don't understand that we need diversity, we need mechanisms and tools that will ensure that inclusion occurs."
- Clinical Research SME: "Traditionally we only look at outcomes measures. This is inadequate. Outcomes measures are often not accurate and besides the point, whereas a process measure is more meaningful."
- Measurement SME: "We have to fix ourself first—we need to address the structure of our healthcare providers/system."
- Funder SME: "We need to evaluate what we are paying for and why. Then what measures work based on what we should be paying for."
- Equity SME: The pervasive existence of race and racism has made it fundamentally difficult to do this work.

Summary Themes

- Measurement should not only consider the continuum of healthcare but also the lifecycle of any disease state, including external factors of influence such as social determinants of health (SDOH).
- It is important to measure things that help us understand how to help patients make decisions, including but not limited to SDOH.
- There is a need to showcase specialty areas where this work has been done, and to share lessons learned from prior work and research.
- The current definition of "what matters to patients or what patients value" does not explicitly cite who participates in the process.
- Patients relate to and care more about the process. Process measures are within the realm of control and are connected to legitimate activities that can be changed.
- The one-size-fits-all approach to measurement no longer works in this large, diverse, and changing environment.
- Measurement architecture must be redesigned to ensure that concepts of equity, diversity, and inclusion are included across the continuum of the work, including development and testing.
- A tremendous effort is needed to streamline current measures and expedite the inclusion of measures that eliminate gaps in data and information.
- There are opportunities to learn from and scale programs that have had to apply equitable methodology throughout their work. For example, the Ryan White Program recognizes that HIV disproportionately affects people of color, people of varying sexual orientations, and people with mental illness. It is important to scale what we have learned in these pockets of excellence.

Key Messages

- PFE SME: Biggest part is having patients and families as part of those measurement teams and really being in leadership roles and being fully supported and compensated in those roles, and so the force ball scale pilots launched...
- Funder SME: "What matters is at the most fundamental level, in terms of inclusivity and diversity, if you're starting at the very front end of the research process, we need much greater diversity and inclusion, but it's not that people don't understand that we need diversity, we need mechanisms and tools that will ensure that inclusion occurs."
- Funder SME: "We struggle with how we would scale this work across all patient populations."
- Community SME: "We have to build the capacity of the patient, but I think ... And more so, so... Well, not even more so, but equally as important is building the capacity of the physicians and the nurses and the reception."
- Community SME: Barriers to seeking care include "mistrust in the healthcare system, misconception of hospital 'grade,' i.e., this hospital is bad and won't give good service."
- Equity SME: Data is key. Knowledge is power.
- Health Delivery SME: "Nobody's getting paid to do this work."
- Funder SME: "Training must occur on on all levels and not merely for the interactions that occur when patients are engaged."
- Funder SME: Funders must more wholistically need to change their organizational cultures to authentically
- Researcher SME: Difficult for PIs [principal investigators] to act on the input from stakeholders and patients. We all too often are under the pressure of getting the research out that we create.
- Funder SME: "Institutional leaders have not wholeheartedly supported this work. All too often researchers are not authentically supported in this work."

Funder SME: Equity is still seen as a novel "idea."

Summary Themes

- Patients, families, and caregivers must be included in the process, from conception and design through to implementation and evaluation.
- Accountability is needed to ensure diversity and inclusion throughout the continuum of measurement work, from development to implementation.
- It is important to share information about where people can go to learn about hospital quality and educate them.
- Broader measures can be implemented that look at processes at the organizational level and align them with community values.
- There should be a national focus on the collection and use of data on race, ethnicity, and language.
- A significant level of effort is required to improve REaL data collection by focusing on improving data collection quality.
- Data need to be more easily available and accessible (without the burden of cost).
- Leaders must understand the close alignment and ... connecting the dots with the equity lens across all facets of the work.
- It is important to demonstrate how the contributions of patients provide new perspectives on equity measurement and feed into the decisions that states and other organizations are making today and will make in the future.

