Partnership for Change

Equitable Healthcare Measurement

That Supports Community Voices, Systems, and Partnerships

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1. Executive Summary

The U.S. healthcare system is currently provider-focused and lacks the meaningful insight of patients and community organizations (COs) in nearly every aspect of its operation including healthcare measurement. The development of measures centered around the culture, lived-experiences, needs, and wellness goals of patients and communities are key to improving our nation's overall health. Therefore, they should be at the center of the healthcare measurement system in equitable partnership with measures developers, researchers, hospital systems, healthcare providers and government agencies. To better understand how to accomplish this partnership, COs from across the 5 U.S. regions were interviewed. The organizations provided a wealth of insight and recommendations for system-level changes across the health care measurement ecosystem. The COs also described the structural inequities, historical trauma, and exploitation experienced within their communities, and the harm imparted by the current healthcare measurement system on marginalized communities and communities of color. The organizations explained that to resolve these issues, a holistic approach to measurement will be needed. One that embodies equitable partnership through shared decision making between COs and healthcare measurement leadership. Working together with communities brings to the forefront the lived experiences that directly impact health outcomes and allows for the identification of healthcare measures that are meaningful to communities and promote health equity and change. This report elevates community voices to the forefront of healthcare measurement, illustrating the importance of centering healthcare and its measures around patients and communities.
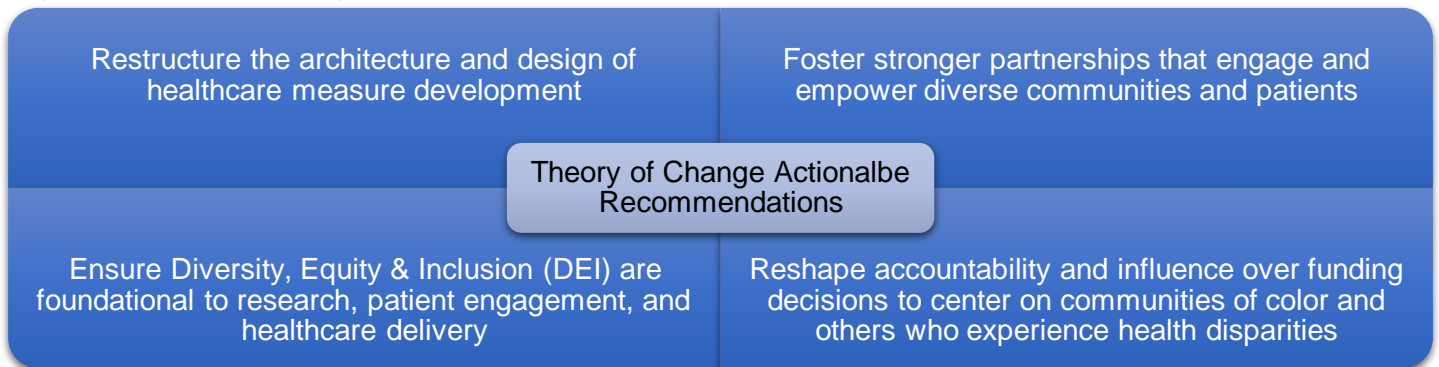
2. Key Findings

- Current funding structures within US hospital systems incentivize sickness and reward patient intake over wellness outcomes, which trap communities hardest hit by health disparities in a perpetual cycle of illness not captured by the healthcare measurement system.

- Historical trauma within marginalized communities and communities of color persists unaddressed and directly impact patient-provider trust and community and patient participation in the healthcare measurement system.

- Healthcare measures are largely quantitative and do not capture the context that drive the numbers, supporting the need for development of a system to systematically collect qualitative data.

- Cultural and community practices like storytelling are ignored by the current healthcare measurement system, resulting in an information gap that fails to capture the relevant experiences and metrics that inform downstream health outcomes.

- Current measures focus on weaknesses of communities rather than their assets. Community organizations are the experts on the assets and needs of communities and require a leadership role in shaping healthcare measurement to reflect the culture and values of communities.

- For communities, equitable partnership entails priority and emphasis on community voices in decision-making with key stakeholders within the healthcare measurement ecosystem and is the only way forward for development of healthcare measures that lead to improved health outcomes.

- The gap in accountability for systems change among government, funders, providers, and researchers must be resolved to ensure effective quality improvement that will promote health equity and reduce disparities in health.

- Additional resources are needed by community organizations to build capacity to engage in sustainable healthcare measurement work, and require flexibility in utilization and operation, in place of rigid guidelines, to best serve community needs.

3. Introduction

The Equitable Healthcare Measurement project builds upon the findings presented in the _Theory of Change for an Equitable Patient-Centered Measurement Ecosystem that Supports an Advanced Healthcare System_ whitepaper, funded by the Robert Wood Johnson Foundation (RWJF). The Theory of Change asserts the need for a closer examination of the healthcare ecosystem to address inequities and transform measurement by gathering and responding to communities' perspectives on their healthcare needs. Within the healthcare system, measurement is a powerful tool for quality improvement. However, the existing approach to measurement does little to address the impacts of structural racism, social determinants of health and other systemic barriers that impact patient and community wellness. Instead, the healthcare measurement and delivery systems focus payment structures on aggregate outcomes; make limited efforts to identify upstream factors that drive disparities; offer little accountability for population health management; and offer no accountability for equitable health outcomes, major health disparities, and structural racial inequities. As a result, patients, families, and caregivers experience an uncoordinated, inequitable healthcare delivery system. As such, the Theory of Change whitepaper identified the four actionable recommendations displayed in Diagram 1.

Diagram 1: Theory of Change Actionable Recommendations

Restructure the architecture and design of healthcare measure development	Foster stronger partnerships that engage and empower diverse communities and patients
Theory of Change Actionalbe Recommendations	
Ensure Diversity, Equity & Inclusion (DEI) are foundational to research, patient engagement, and healthcare delivery	Reshape accountability and influence over funding decisions to center on communities of color and others who experience health disparities

Central to these recommendations are the need to uplift community voices and address how diverse community participants play a role in equitable healthcare measurement. The American Institutes for Research (AIR)'s _Getting to Equitable Patient-Centered Measurement: Summary of Sharing Lessons Learned About Patient-Centered Measurement_ produced from pilot projects linked to the Theory of Change work, documents a series of lessons learned about engaging in measurement with teams that included patients and caregivers. As outlined in the Theory of Change whitepaper and shown through AIR's lessons learned, community voices are essential to patient-centered measurement and must be coupled with Diversity, Equity, and Inclusion (DEI) for true success. This project expands upon the Theory of Change by considering how a roadmap for equitable patient-centered measurement could look if it incorporated community experiences, expertise, and utilized the mediums such as narratives and visual storytelling that many communities use to communicate. Developed in conjunction with this report, are two additional resources, a case study narrative and call-to-action video. Respectively, they provide a more in depth look into how communities experience healthcare measurement and work to raise awareness on the need to create more opportunities for partnership between CFOs and current healthcare measurement ecosystem stakeholders. Collectively, these resources outline the changes needed from the perspectives of communities and provide a guide for equitable community partnership.

4. Methods

A search was conducted to identify community-based organizations (CBOs) in the United States that engage in health equity and measurement work. The criteria for CBOs were expanded to Community Organizations (Cos), to include CBOs, Federally Qualified Health Center's (FQHCs), and Technical Assistance (TA) organizations. The initial combined

list of 29 CO candidates from across the five regions (West, Midwest, Northeast, Southwest, and Southeast) of the United States were contacted, fifteen of which were interviewed to provide their insights surrounding the capacity, needs, and goals of COs to support co-created measurement within the healthcare delivery system. Qualitative data was captured via focus groups and interviews. An inductive and deductive approach to thematic analysis strategy provided by Braun & Clarke (2006) was utilized. Themes (e.g., central, and sub-themes) were identified during the process.

5. Findings

Overview

Through interviews and focus groups with more than fifteen-organizations, our team spoke with twenty-one community leaders and staff from a diverse group of COs serving communities of color and marginalized communities from across the United States. The conversations provided rich insights into patient-centered care, equity, measurement, and community needs. Across the twelve themes (storytelling, race/cultural sensitivity, patient-centered healthcare measurement, data, financial structures within healthcare measurement systems, community, social determinants of health, structural racism, medical mistrust, accountability, shift of power/change, and capacity building) that emerged from these data, interviewees highlighted ways that **current measurement systems and practices cause harm and fail to address needs within marginalized communities**. When asked to discuss their perspectives on patient-centered health care measurement, DEI in healthcare measurement, partnership with measurement stakeholders, organizational role, community connection, and supports, resources, tools and platforms needed for measurement work, they called out necessary changes to drive equitable measurement, and the role communities themselves must play in making those changes (see Appendix). We discuss each of these elements of interviewees' insights with an emphasis on their recommendations for investments and changes to policies and practices necessary to build an equitable measurement system.

Current Measurement Practice: Gaps and Failures

Interviewees described many ways in which the current healthcare measurement system causes harm to marginalized communities; most prominently, by failing to address their needs and priorities. Interviewees called out the harm they experience when stakeholders from across the healthcare ecosystem exercise the power of ignoring what they don't want to hear. This happens when government agencies and researchers spend tax dollars on extensive measurement efforts, then bury results in dense, inaccessible reports, or don't report some data at all. It happens when evaluators and health systems interpret metrics and make improvement recommendations without any input from the communities most affected by the measured processes and outcomes. It happens when health systems and insurers own, control access to and profit off patients' health data. And it happens when the power to make decisions based on metrics does not rest with those who are best positioned to design and implement solutions – those who are most proximal to the problems.

Interviewees emphasized the ways that current healthcare measurement systems – as with almost all other aspects of the U.S. healthcare industry – ignore the long history of exploitation, neglect and trauma marginalized communities have experienced through interactions with the healthcare system. For example, the two decades of efforts to address patient safety that began with the watershed To Err is Human (2000) report have consistently framed patient safety failures as arising from inadvertent harm, without recognizing the history of intentional harm inflicted on Black, Indigenous, immigrant and other marginalized communities over decades of American healthcare delivery. Patient safety measures and improvement initiatives implemented widely across the U.S. focus on medical errors and avoidable complications resulting from systems failures (Agency for Healthcare Research and Quality, 2019). While these efforts have led to major gains in patient safety across the U.S. population (Eldridge et. al., 2022), these efforts neither acknowledge past intentional harm perpetrated against nor address long-standing health disparities within communities of color. Current patient safety measures also largely ignore the harm patients from marginalized communities experience through everyday interactions with healthcare providers and systems that lack cultural sensitivity and accountability to the communities they serve.

Interviewees called out harms such as microaggressions, disrespect, racial and ethnic biases, and communication failures that arise when providers don't speak the preferred language of the

communities they serve. They noted that patient experience of care surveys and other quality measures don't ask about these negative experiences even though they directly affect health outcomes. Interviewees also called out marginalized communities' hesitancy to complete experience of care surveys, report problems, or participate in research or improvement efforts because doing so triggers intergenerational trauma accrued over decades of interaction with what one interviewee called a "predatory" system.

Interviewees emphasized that current measurement systems' over-reliance on individual-level outcomes ignores inter-generational effects and the social conditions that drive them. This hides one of the most pervasive effects of systemic racism and marginalization, while also overlooking potentially transformative impacts from systems change efforts. When measurement doesn't account for intergenerational effects, opportunities for making lasting improvements across whole communities go unrecognized and often fizzle out for lack of funding. And when measurement ignores the social conditions that drive health disparities (whether measured through individual or community-level outcomes), we miss opportunities to address root causes of those disparities. Interviewees also noted that focusing solely on individuals during their interactions with the healthcare system – that is, a focus on "patients" rather than whole people or communities. Doing so ignores individual and collective strengths, values, assets, and goals. As one interviewee described the lure of quantitative data for those who hold power, "…we like to focus on measures because then we can de-humanize…we don't necessarily remain in touch with what's happening because we assign a number to a face."

Interviewees stressed ways that over-reliance on quantitative metrics renders invisible their communities' cultures, assets, and values, particularly when those metrics reflect what matters to leaders within White-dominated healthcare, policymaking, and funding institutions. They emphasized that numbers alone are not enough to understand the health and wellbeing of their communities (or any communities) and that reductionist measurement strips local and cultural context from their healthcare experiences and outcomes. The Urban Indian Health Institute, part of the Seattle Indian Health Board, has called such practices "data genocide" (Urban Indian Health

Institute, 2021). They point to unequal distribution resources during the COVID-19 pandemic as an example of how Indigenous communities are harmed when data used to distribute resources do not reflect, or even acknowledge, Indigenous people or cultural identity.

Finally, interviewees noted that overreliance on data serves as a tool for procrastination, a way to stay stuck in the planning and studying phases of change efforts without acting to meaningfully improve health and wellbeing within marginalized communities. Investments to gather, improve or analyze data also typically flow to already well-resourced organizations for technology and professional services most often delivered by White-dominated organizations that lack local community context. In addition, even when measurement or improvement experts ask members of marginalized communities for input or invite collaboration, they often fail to adequately compensate community members and often devalue lived experiences while prioritizing professional degrees in decision-making. One interviewee recounted such an experience, "I came across a publication from our scale work...not one community-based organization was one of the co-authors of that. So, everybody got fed, got valued. But not us, our voice, used, taken and exploited to value and prop up other people's careers, but not our own."

These vast arrays of harms cited across community organizations as well-known points of failure for the current healthcare measurement systems, continue to persist unresolved. Measures exist for the purpose of improvement and must be expanded and revised to include the concerns and experiences of those directly affected and heaviest hit by health disparities and marginalization.

Changes to Healthcare Measures to Build Community Trust and Prevent Future Harms
Interviewees emphasized that acknowledging harm is as a necessary first step toward building trust between marginalized communities and healthcare providers, leaders, or other stakeholders. They underscored that healing requires those who have experienced harm and those who caused harm to together face the past, build trust, and move forward in a different way. With respect to measurement, this means ensuring that measures of healthcare quality, safety and equity acknowledge past harm, hold stakeholders accountable for current harm and failures, and that all healthcare stakeholders

acknowledge the harm caused by measurement itself.

As examples of acknowledging and repairing harm, interviewees emphasized the need to hold health systems and providers accountable for providing culturally sensitive and equitable care by measuring patients' experiences of disrespect, microaggressions and bias. They also insisted on accountability for providers to deliver compassionate care to all patients, for providers and health systems to recognize that everyone has a right to excellent healthcare, for officials to take action to address health disparities, and for insurers to make their budgets, profits, and health plan coverage public. This means using measurement to create incentives for systems to close health disparities gaps by addressing root causes of those disparities and developing competencies and policies that ensure equitable care delivery. Interviewees contrasted such use of measurement to current policy which they described as incentivizing health systems to profit off inequities. As one interviewee described, *"we don't pay for health, we don't pay for wellness, we don't pay for equity, we pay for sick[ness]."* Another interviewee put it more bluntly, *"People make money on our issues; they don't really want our people to [recover]."*

Despite 20 years of widespread quality measurement efforts across healthcare, many measurement efforts still fail to examine or report health disparities by race or ethnicity, in part due to incomplete data. The National Committee for Quality Assurance reported that in 2019, a large majority of commercial health plans lacked race and ethnicity data for more than half their members, while a substantial proportion of Medicaid and Medicare plans also lacked complete race and ethnicity data for their beneficiaries (Harrington et al., 2021). These data gaps block even the most basic examination of racial and ethnic health disparities among most of the American population with public or private insurance. Even when data on health disparities are available, the persistent nature of these disparities attests to the inadequacy of reporting alone as a health equity strategy. For example, the Agency for Healthcare Research and Quality (AHRQ) recently published its 19th annual healthcare quality and disparities report. In that time, AHRQ reports that health disparities improved (meaning a narrower gap between quality measure scores for racial and ethnic minority populations compared to the White

population) for fewer than 10% of measures across all racial and ethnic groups (range 2% to 10%) (Agency for Healthcare Research and Quality, 2021; Plott et al., 2021).

Since 2020, measure developers, policymakers and other stakeholders have devoted more attention to individual-level measures of health equity (State of Rhode Island Department of Health, 2022; RAND Health Care, 2021) and strategies for using measurement to advance equity. Examples of system-level measures of equity are far fewer and earlier in development. In its Guide to Racial and Ethnic Equity Systems Indicators (2021), Strive Together defines system-level equity indicators as, *"a measurement (both qualitative and quantitative) that reveals inequities in how resources, decision-making power and opportunities are distributed to inform policies and practices within institutions, organizations and programs that are interdependent and/or related."* The guide proposes a set of individual- and system-level indicators to drive equity in educational opportunities (the guide's focus) alongside adjacent measures that address factors influencing education, such as housing, health, food security, inclusive communities, and the legal system. While not focused specifically on health equity, this guide offers an example of a holistic approach to measurement that balances quantitative data with qualitative information, examines both individual and system-level outcomes, integrates social determinants of health and incentivizes addressing root causes of inequities.

Interviewees also wanted to see measures that assess how well providers, health systems and insurers are meeting patients' goals and needs and addressing social determinants of health that drive communities' health outcomes. Such goal-directed measures offer one way to address the tension between desire for standardized measures and the need for flexible measures tailored to local context, both called out as important by interviewees. Recent efforts to develop person-driven outcome measures (Mohanty et al., 2022) offer one avenue for assessing and incentivizing goal-directed care while allowing flexibility for each patient to determine what's most important to their own health. Implementing such measures will require changes to both clinical practice (to discuss patients' goals in a culturally competent and respectful manner) and quality measurement (to document goals and assess progress toward them).

Interviewees emphasized the need for a broader understanding of measurement – one that includes stories alongside data, reflects local traditions and context, and addresses mental, emotional, spiritual, economic, and racial needs in tandem with physical needs. This contrasts with current healthcare quality measures which rely almost exclusively on quantitative data, most of it generated and owned by healthcare systems, insurers, or government agencies. Measures that rely on patient-generated data, such as responses to experience of care surveys, place burdens on patients by asking them to complete surveys when and how (e.g., via mailed or phone surveys) it's convenient for health systems, not for patients themselves. Typical response rates below 50% attest to the lack of relevance and inconvenience of these methods. To incentivize addressing root causes of health inequities, interviewees called for measuring the social conditions that influence individual and community health.

In contrast, current measurement practice typically ignores these conditions, or uses them to risk adjust measure scores to avoid penalizing providers or health systems for delivering care to patients with higher levels of social risk for poor health outcomes (National Quality Forum, 2021). However, doing so essentially excuses these stakeholders from addressing health disparities or the root causes of systemic racism, economic deprivation and intergenerational marginalization that cause them (Sheingold et al., 2021).

Shifting Power Towards Equitable Healthcare Measurement Processes
To mitigate harm caused by measurement practices and policies, interviewees called for transparency throughout the entirety of the measurement process, not only in reporting end results (where transparency is also frequently lacking). This means making each stage of the measurement process open, inclusive, and collaborative, from the earliest stages of defining why to undertake measurement, through developing and selecting measures, collecting, and analyzing data, making sense of what measure results mean and ultimately acting in response to those results. Interviewees noted the importance of frequent, easy-to-understand information communicated in visual as well as written form.

However, interviewees emphasized that sharing information alone is not enough; a truly equitable measurement process requires partnership, shared power and ultimately community leadership. This dovetails with recent work by ATW Health Solutions to develop a Theory of Change (2021) achieving equity measurement. With support from the Robert Wood Johnson Foundation, the team interviewed more than 50 key informants, representing healthcare executives, funders, measure developers, researchers as well as many patient advisors and community-based organizations. These stakeholders identified several key strategies for fostering an equitable, patient-centered measurement ecosystem. These included building partnerships among researchers, measure developers and patient communities who experience health inequities; integrating patients and caregivers representing diverse communities throughout measure development, endorsement, and use; creating accountability systems to affirm diversity and inclusion of people with lived experience throughout measurement processes; and ultimately diversifying the measurement workforce. We discuss communities' roles in equitable measurement in greater detail in the next section.

Diverse Partnerships
Interviewees made clear that measurement that drives equity must itself be equitable. Only when there is equity in who develops and selects measures, collects, owns, and interprets data, and acts in response to metrics will measurement be capable of making healthcare more equitable. This means that communities who experience racism and other forms of marginalization must be partners in all measurement efforts – and the change efforts informed by measurement– so they can tell their own stories.

Over the last several years measure developers and policymakers have increasingly recognized the importance of measuring what matters to patients and communities, and of partnering with patients and caregivers throughout measurement efforts. With support from the Robert Wood Johnson Foundation, the American Institutes for Research developed, and pilot tested a set of guiding principles for patient-centered measurement that reflects what patients say matters most to their health and well-being (American Institutes for Research, 2017). This work showed that partnering with patients and family caregivers throughout all aspects of measurement

(from development through testing, implementation and use) is necessary to ensure that measures reflect what matters to patients and are used in ways that ultimately benefit patients and their communities (Robert Wood Johnson Foundation, 2020). More recently, the National Quality Forum in its 2021 strategic plan called for more consistently engaging patients and families throughout measure development (National Quality Forum, 2021) and the Centers for Medicare and Medicaid Services (CMS) developed a toolkit for how to engage patients and families in measure development (Rainmakers Strategic Solutions, 2022).

While these efforts represent a big step forward, interviewees made clear that patient and family engagement in measurement alone is not sufficient. To develop a system of equitable measurement, the patients and family members who partner in healthcare measurement work must represent marginalized communities and must have decision making authority. Diversity of patients and caregivers' partners has not yet received adequate attention within the measurement field, although some other systems transformation efforts have worked to build partnerships with patients and caregivers who have lived experience with racism and marginalization. For example, a group of community champions with lived experience of health inequities who partnered in the 100 million Healthier Lives initiative developed a toolkit to help organizations work toward more equitable partnerships (Community Commons, 2020).

Systems Accountability and Community Leadership
Interviewees stressed, too, moving beyond partnerships to create systems that route accountability back into the hands of the communities. One interviewee summed this up: *"We don't need contract care consultants coming in to manage our hospitals, we need home-grown leadership."* They underscored that healthcare measurement won't ensure health system accountability to communities without community oversight. This aligns with recent work by the American Institutes for Research, which published a set of five principles for using shared measurement to align healthcare, public health and human services with communities' priorities and needs (Hilliard-Boone et al., 2022). These principles include using measurement to create accountability to communities for addressing root causes. The principles also emphasize that accountability

requires sharing power by ensuring community members have decision making authority throughout the measurement process, including defining why and how to use measurement. Ultimately, interviewees emphasized that achieving equitable measurement requires community leadership.

In one example of community-led measurement, Native Coast Salish communities from the state of Washington developed and piloted a set of Indigenous Health Indicators to reflect aspects of community health important to their people (Donatuto et al., 2016). These included community connection, natural resource security, cultural use, education, self-determination, and resilience. In a second example, a group of youth advocates in Chicago's South Shore neighborhood, a predominantly Black community located near the University of Chicago, collected data from residents about the community's needs and assets and their vision for a more equitable future (Free Root Operation, 2022). They integrated this quantitative and qualitative information into a report developed by and for South Shore residents highlighting how they defined key elements of a thriving community, including accessible housing, transportation, education, leisure, and healthy resources. Partnering with communities to incorporate these measures illustrates the importance of community-led healthcare measurement systems and the increased capacity for change.

Investing in Community Capacity to Lead Equitable Measurement
Interviewees were clear: policymakers, insurers and philanthropies that typically fund measurement efforts must make investments to develop capacity and support staffing within CFOs so they can partner on and lead measurement efforts. One such example is the Patient-Centered Outcomes Research Institute's investment to develop research fundamental training (2021) to prepare patients and other stakeholders to engage in research. The Urban Institute's Elevate Data for Equity project (2022) highlights several other examples of training to enhance community capacity for using data, including a Neighborhood Leadership Training program in Kansas City that taught residents how to use a locally developed health data platform to advocate for community health improvements.

To avoid perpetuating measurement practices that harm marginalized communities, representatives of

these communities must be a part of – or lead – training development and delivery. For example, the New York Times recently featured Indigenous scientists' efforts to train more data scientists within their own communities as a necessary step toward data sovereignty (Imbler, 2021; Rainie et al., 2017). In addition to training, interviewees called out needed investments in technical assistance, technology, staffing and workforce development. Communities have clearly articulated what the research evidence continues to show, which is that the current healthcare measurement system falls drastically short of capturing the relevant factors that impact their overall health and wellness. Equitable healthcare measurement requires a shift in power dynamics and communities are ready to engage within leadership roles to ensure the accuracy and integrity of improved and positive healthcare measurement systems, processes, metrics, and outcomes.

6. Discussion

Across organizations the conversation around healthcare measurement consistently triggered experiences of deeply rooted trauma, silencing, marginalization, and exclusion from the healthcare measurement process. Communities articulated the need for shared power in measurement development, healthcare systems accountability, provider training and funding allocation. Interviewees discussed the importance of incorporating cultural practices such as storytelling and shared narratives into how healthcare metrics are captured and reflected in the types of measures developed. The importance of holistic measurement was repeated again and again, emphasizing what research shows about social determinants of health and the impact of lived experience on health outcomes. The findings in this report illustrate that marginalized communities suffering the most from health disparities, rightfully, hold little faith in the current healthcare system and the metrics that it employs. The system has been resigned to a failure in the minds of communities, as it not only perpetuates a cycle of sickness and systemic racism; it also acts to harm through the lack of wellness, quality care, and resolve that its inadequacy denies communities.

Despite the neglect, communities articulated a genuine interest in a shifting of power and a leadership role within the healthcare measurement process and ecosystem. Interviewees also described equitable healthcare measurement as a restoration of balance and a sharing of power, between communities and the healthcare system. They articulated the distinction between inclusion in the process as an "advisory member" versus that of a "decision maker," with the latter being necessary for true equitable partnership. The importance of community leadership is grounded in the expertise of lived experience. Interviewees stated repeatedly throughout each interview session that the system cannot capture what it does not know or understand, meaning communities and patients are the experts on their needs and experiences, and must be a part of the measurement process and overall healthcare goal setting. Inclusion of community voices in the healthcare measurement process has the ability to improve cultural awareness within the healthcare system and among those that use the system including, patient care providers, payers, government agencies, funders and current measure developers. This sensitivity is key to the reflection of community values and preferred outcomes within the healthcare measurement system.

As highlighted above and across previous reports, equitable community partnership is central to systems change in the healthcare measurement process. According to interviewees a major part of that shift results from the enactment of leadership accountability and continuous evaluation of process. Communities stated loud and clear that they are uninterested in symbolic progress and continuation of the perpetual planning phase. To the contrary, communities are demanding meaningful change that will bring about healthy communities, increase health equity, improve health disparities, and build lasting trust and equitable partnerships between the healthcare systems and communities.

Future work should include the sharing of the findings within this report with members of the healthcare measurement ecosystem and CFOs to promote equitable partnership for change through a learning collaborative designed to stimulate dialogue and understanding between stakeholder groups. Additionally, CFOs should engage in coalition-building around equitable healthcare measurement to elevate community voices, systems, and partnerships. Finally, next steps should also include engagement of both stakeholder groups in the development of a strategic plan to promote

meaningful systems change within equitable healthcare measurement.

7. Conclusion

Healthcare measurement should not cause harm but does in many marginalized communities as illustrated by the interviewees in the contents of this report. Attenuation of these effects can only be accomplished by a holistic systems change approach, which involves the inclusion of communities as equitable partners within the healthcare measure system. Understanding the lived experience of healthcare system users outside of their health care visit is truly critical to developing solutions that are designed to address the whole individual and not just the disease. Therefore, in the same way that comprehensive care is important, so is comprehensive measurement and it requires an increase in cultural sensitivity, training, humility, and competency among members of the healthcare measurement ecosystem. Interviewees across all the participating COs expressed a willingness to engage in equitable partnership with measures developers for the purpose of co-creation to support their respective communities. This report is a call-to-action for members of the healthcare ecosystem to engage in equitable partnership for systems change and create a measurement system that leads to optimal health, safety, and wellness for all.

8. Limitations

A major limitation of this project was timeline, which impacted time available for partnership building with community-focused organizations around health care measurement, recruitment, and data collection. A second limitation is the opportunity to speak directly with community members from each organization. Most participants work within CFOs, however, speaking directly with community members may have provided additional insight into community needs and relevant metrics.

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Appendix

Voices from the community

Central and Sub-themes

Analysis of the interviews and focus group sessions identified several central themes (e.g., story-telling, social determinants of health, capacity building, medical mistrust, race/cultural sensitivity, patient-centered healthcare measurement, data, community, accountability, structural racism, and shift of power/change, financial structures within healthcare measurement systems) and sub-themes. These reflect the issue areas raised by interviewees when asked to discuss their perspectives on patient-centered health care measurement; DEI in healthcare measurement; measurement partners; organizational role and community connection; and supports, resources, tools and platforms needed for measurement work.

Storytelling
Subthemes: media

One interviewee described storytelling through art, film, photography, podcasting, and oral storytelling as powerful ways to re-tell marginalized communities' stories and combat stigma and discrimination. In addition to traditional research methods, storytelling can highlight a community's wealth of culture, shed light on a community that is otherwise stigmatized, and empower community members. The interviewee anticipated how communities' stories could be used by researchers and measurement developers to better understand communities' challenges and health needs and to improve healthcare measurement.

> *"There are so many folks in my community that are afraid or feel ashamed or have that stigma and they can't speak for themselves...There's so much negativity that can be said about my community, but there's also so much good and wealth that we have in our community that is often not spoken about."*

Using storytelling to give space and voice to community members can also help researchers and measurement developers further understand and assess a community's health through its history and social determinants. Interviewees suggested capturing the intergenerational impact of disease in the form of in-depth stories and using social media to communicate the health inequities that communities face. Often, those outcomes are exacerbated when examined by race.

"Involving the community through oral storytelling, beyond surveys and quantitative ways of thinking, is a quality way to engage families 'long term.'"

"I think that really humanizes the whole experience, when we're able to be like, let's really evaluate this person's experience, they gave this response... they send in a video or they send in an audio recording of what happened that day, and any type of complaint or experience. How their insurance was billed out or how they have to pay, or how their medication was given to them, or how the nurse treated them, or the doctor. So much can be changed if we really are able to be more responsive to those types of experiences."

"Looking at intergenerational trauma, if we're able to look at that as not just an individual, but it's the long-term generational impact of illnesses of disease in the family, I really think like when we're able to get really in-depth stories, then we're able to really get the experience and the real front line how it is when you're in that world."

"I believe in using current platforms to get at what we need to get at… maybe make regular two to three-minute videos that are impactful, that are through social media streams that people can just click on to get information and education real quick where my five [year] old could understand like, oh wow! But if I'm Black, it's even worse, right?

Race/Cultural Sensitivity
Subthemes: bias and discrimination in healthcare systems

The lack of cultural knowledge and sensitivity among healthcare providers was continually highlighted by interviewees across multiple organizations. Interviewees discussed the need for cultural provider training to improve patient-provider interactions and communication. Interviewees explained how lack of understanding leads to bias, which directly impacts healthcare seeking behavior, patient experience, and quality of care. Topics such as languages, community history, and racial micro-aggressions were identified as areas for improvement.

"[If] you're not proximate to the communities and you don't understand the why of communities that suffer from disparity and inequity, then how can you really work through a process that actually is measuring real outcomes?"

"The purpose of that [project] is to create a black woman community-led process, creating a patient-reported experience measure and quality improvement process that holds hospitals and providers accountable to disrespect,

racial micro-aggressions and those other things that just totally sour somebody's experience. The least they can do is sour an experience, and the worst that they can do is create these bias dynamics where lives are at stake, where moms and babies are dying because of this neglect. This disrespect is a kind of overall impact of bias, that is not measured and is never included in payment systems."

"If you as a provider, feel like there's something else to address on top of what the patient wants to address, then you can take a lead on that, but minimizing someone's language or someone's pain because of whatever biases you have, it makes it difficult for these patients to come forward, and I know some patients feel like they're stuck with their providers, because of the insurance that they have, so they're just defeated, and they don't go to the doctors again, and so they end up getting sicker."

"It's about understanding all of these different factors that go into that patient and also being able to effectively communicate with that patient. Really being able to listen and

hear and meet the patient where they're at. Understanding that they live in a food desert, they can't access [healthy] types of foods or they're not the ones that are the cook in the family. So, they don't have that influence on how much sodium they eat, or what they're eating."

"I think we need training centers for folks to have more skills on how to be a community organizer and be engaged, and be culturally aware, and know the histories of the community. It's different in each community, and the history and the impacts are so different. We need folks that are trained to have that relationship building between community frontline grassroots organizations and professional healthcare professionals."

"So, if we're gonna lead a patient-centered measurement tool, you gotta lead with race, because if we can solve for health disparity around racial lines, everybody else benefits from it. If we can focus on the least and the most marginalized, like we need to, I feel like that's what measurement tools begin to look like when you have a true focus on the margins

Creating better tools to measure patients' lived experiences in healthcare and patient-selected healthcare outcomes, is essential to not only equitable healthcare measurement but also more equitable healthcare systems. When patients feel as though they are not understood by their healthcare provider, they are less likely to seek care, which can result in worse health outcomes. Despite the significant impact that discrimination and lack of racial and cultural sensitivity have on patients' experiences, these factors are often not measured and considered when investigating non-clinical indicators that contribute to health.

Patient-Centered Healthcare Measurement
Subthemes: patients as experts of their experiences, integration of the patient voice in measurement

Across organizations, interviewees called attention to the importance of transforming care and measurement to be more patient-centered. Interviewees shared that providers' often disregard the patient voice instead of collaborating with them to ensure that they are meeting patients' needs and molding care based on what patient's value.

"We need to have patients do the metrics, not a provider, but before we get to the metrics, providers should be able to listen to the patients. The next question is, what is it that you really want? So based on what you want, that will be what a provider gives to them. Then, we will go back as a provider to measure the services that we provided from what the patient wants. That is what we call the patient centered [care]."

"I think [patient centered] would actually ask them what their

measures are, and not to use that word measures, but from a real view, spiritually, emotionally, mentally, economically, racially. How do we build that and stop trying to establish a number on a scale."

"Being able to make [care] patient-led would make huge strides in that diversity and inclusion, and then additionally, in terms of measurement."

According to the interviewees, a journey to patient-centered health care measurement will require the health care system and its providers to foster effective communication with patients, listen to and elevate their voices, and integrate their input into measurement processes and health care delivery. Within this, it is important for providers to understand that patients are the experts of their lived experiences.

"Community is the expert, I'm the expert, I know what I need, I got no problem telling you what I need, however, let me tell the person what I need that could bring about the change. Put me in that room."

Data
Subthemes: representative healthcare metrics, data systems

Current healthcare metrics rarely incorporate patient experiences or perspectives, and therefore lack the outcome measures most relevant to patients. This gap in representation constitutes an absence of relevant indicators to

help guide the health care system toward meaningful metrics that can inform the development of effective solutions. Additionally, the lack of disaggregate data also plays a role in the needs of individual communities getting lost during the measurement process. The inclusion of community voices and individual experiences in addition to numerical health data are paramount to understanding the relevant factors that mediate health. Interviewees from across organizations describe this and highlight the importance of co-measurement creation with communities and note that the healthcare system prioritizes financial profit over the development of systemic structures to ensure that existing measures are inclusive of vulnerable populations.

"You're asking us about needs, but you also have to write down what are our assets? Where is our power? Everybody on this call is transforming lives, changing systems daily, we could all tell you 150 people that we saved their life. That doesn't show up on the data. And when you think about a patient, you're thinking about their vulnerability, their weakness, and their needs. You're not measuring the assets, the resiliency, the effectiveness. We talk about bright spots, no matter how bad the data is, there is always success stories. And we don't measure those. We're looking at only one side of the coin."

"There's a story to the numbers, right. There's context versus if you just get…at the number. But what about the complications of having a morbidity experience at birth? What does that mean for that family? Looking further into interviewing people…their partners? …how does life change? …it's not just a singular event…I think that measurement doesn't get at that…so that's something we're trying to do better as we're developing these measures. How do we make

space…to follow the guidelines that people say is 'worthy' of a measurement."

"In Maine, we have a data system that for a long time just looked at averages, and that was not helpful really at all, and so there's a new bill in the legislature right now to

disaggregate all that data so that it is looking at race, it is looking at a variety of different things, but it is focusing on the people that need the most attention and not just averaging things out."

"Sometimes I feel like what happens is that we like to focus on measures because then we can de-humanize, and we don't necessarily remain in touch with what's happening, because we assign a number to a face."

"Okay, so when we give you collective data quantitatively, then that doesn't include everybody, 'cause our measures suck. Then we have these focus group interviews, and you say, yeah, that's not enough, 'cause you know we can't get a p-value. Then we do both, and [the response is] okay, thanks so much. You've just confirmed what we knew, we'll talk about it. So, when we talk as a group, we're constantly sitting in the plan cycle. We never move to act. Because we, in my opinion, [do not] wanna move from our capitalistic view."

"I think the Maslow's hierarchy of needs kind of things, anything where there is food, shelter, safety, anxiety, I think that's a data point that could easily be measured. Do you have this? Are you experiencing these things? So perhaps something like that could be helpful, so that you get the individual's perspective about the larger concern. The community concerns."

Financial Structures Within Healthcare Measurement Systems
Subthemes: funding restrictions, allocation of funding, budgeting limitations, eligibility, compensation

Across organizations, interviewees expressed similar sentiments of frustration and the need for changes related to systemic financial structures within healthcare measurement systems. They described challenges associated with securing and maintaining grants and other programmatic resources as well as the lack of accountability and oversight from funders and the government to ensure equitable practices and incentivize outcome-driven approaches. They articulated the redundancy of having to continually make the case for funding support in communities hit hardest. Also highlighted were issues in funding priorities, illustrating examples where patients and communities were second tier to more frivolous hospital system investments. Interviewees also provided constructive feedback, offering recommendations for how funders could better support organizational work and improve the current funding system and processes, and how hospital systems could better support patients and community needs.

"Wish there weren't so many restrictions on how funding is allocated or barriers to the budget, because then it will allow us to give even more resources to communities and people that we work with."

"So how about we take that message to the decision makers. It has to hit their pocket. Maybe we think about from a federal perspective, legislatively, if you are a healthcare system and you don't improve your metrics for [a] population, you're not

gonna be allowed to bill at this level. I would love to believe that we could transform people and teach them about equity and get them to love each other, but there are some people that they only care about money."

"Because we don't pay for outcomes, we pay for outputs. We pay for people walking through the door. We don't pay for health, we don't pay for wellness, we don't pay for equity, we pay for sick.

Community
Subthemes: Partnerships, expertise, role in measurement, exclusion

Across organizations, interviewees emphasized the importance of having healthcare leadership from the community. Naturally, community members are well-positioned to understand the challenges of communities and identify their health needs. Given this, community leaders and organizations are highlighted as key groups that can partner with workers of the healthcare system to guide approaches and execute solutions to address community needs.

"Why do we always have to make the case when we know this is important? I think… the systems need the tools to better work with us so that they don't cause this harm and create more burden."

"Well, I definitely feel like we can shine a light to where the [community] need is."

"It takes intention…we check ourselves throughout the entire process, and it's like okay, [did] we run this by CBOs? Did we get black birthing people's experience? Did we get doulas? Did we get birth workers? Did we really make space for them? And if not, that means we keep going back until we have time to meet with them, and every little change we make, we go back. Is this what we said? We change it. Okay. And so, it goes through a lot of iterations."

Interviewees also explained the importance of incorporating authentic community relationship building throughout institutions and not only within DEI offices and community-focused departments. They also articulated how past measurement efforts used their voices exploitatively without acknowledgement or inclusion in the publication of that work.

"I can give a real-life example really quick. We have an HR department, and our department is doing a presentation, and someone asked a question, when we talk about recruiting, where you're gonna recruit, and how are you guys are gonna build relationships with the HBCUS in the community and the

HR department immediately said, well the DEI department is gonna... I'm like, when you start to say, that's gonna happen over there, that is when we know the authenticity of how we're trying to get at the work, it's not gonna happen."

"We don't need contract care consultants coming in to manage our hospitals, we need home-grown leadership."

"There are reports and there is a publication, and I was sick to my stomach this morning, I was writing a publication for another project, and I came across a publication for our scale work that was funded by Robert Wood Johnson, not a one community-based organization was one of the co-authors of that. So, everybody got fed, got valued. But not us, our voice, used, taken, and exploited to value and prop up other people's careers, but not our own. Now, again, going back to the system operates with or without us, that's what it was designed to do, so they didn't have to put a lot of effort in taking our words and profiting from it, and not including us."

Social Determinants of Health
Subtheme: transportation, income, environment

Across organizations, social determinants of health (SDOH) were consistently highlighted as a missed context for many of the health conditions that are plaguing communities. Interviewees explained how built environmental barriers present challenges to achieving optimal health and wellness. They described barriers to accessing quality health care, through a lack of adequate transportation and economic resources.

"I do really feel like the number one determinant of outcomes are going to be found in that realm of social determinants. I do think it's one of the most important indicators, probably aside from income, [that predicts] how your health is going to be overall. If we could figure out a way to focus our attention and our resources as a community at large, I think that it's going to prove to help the most people."

"In Coos County, it would be easy for somebody to live 30 to 50 miles away from the doctor, and so if they don't have a car, or maybe they only have one car and a family, but that one family member took the car to work and now the other family members at home and they need to go to the doctor, what do they do? That's the type of thing where you have to look at the challenge. It's like, how many people don't have

private, reliable, personal transportation outside of a certain distance of the doctor."

"That's the biggest social determinant to health, is whether or not you've got the money so you can access this healthcare."

"And when you look at government budgets, you will see their priorities, right, small piece goes here, and a small piece goes there, so we start talking about access and people can't get here and there. What is the Department of Transportation doing?"

"You really have to come to the people, because they don't have access to vehicles, they don't have safe roads, unpaved roads. So, to really capture their experience and to measure what is happening as they're going to get healthcare

services, it's really hard, because some of them even their first language out there is Navajo. There are so many barriers for them to really get the story out and see what their needs are and what resources that they need."

"A lot of our people are not even living in homes, some folks are just living in busses, caves, cars, little shacks. Housing is a big issue..."

One interviewee explained the lack of initiative to address the SDOH in their community related to housing, neighborhood factors, environment, support systems, and access to healthcare facilities. In the interviewee's own community, known as Gallup, there are only 22,000 residents but 33 liquor establishments. These liquor establishments are primarily convenience stores that have ceased to sell gasoline and instead focus on selling alcohol to primarily Navajo and Zuni community members. The interviewee explained:

"When people are walking on the street, under the influence, there's a police van that will pick them up and take them to a center where they sober up, and then let them go again, but there's no treatment. So, they just let them go and it's like 26,000 people are picked up in a year in Gallup for being under the influence...and it's just a revolving door. People make money on our issues; they don't really want our people to [recover]. They don't go to the root causes of why our people are on the streets."

Also described were the environmental contributors to negative health outcomes that are not captured in the health care metrics.

"The evidence is all here. Yeah, the maps, the data is available in terms of cancer in Northwest New Mexico, [it's] high as compared to the rest of the state. You [can] overlap the cancer rates with the mining extractive industries."

"That layer of environmental justice, environmental racism, and looking at the whole picture of how we're targeted as a whole people through extractive industries, and how that just totally…destroyed our way of life pretty much through our water, our air, our earth, everything has been contaminated at this point. So, to find clean water, to find land that we're able to prosper off of, it's really hard to find that."

The experience of community suffering is tied directly to the conditions in which people live. These conditions influence health, and as such, are fundamental reasons why capturing lived experience is key to understanding what communities need to achieve optimal health and wellness and to eliminate health disparities.

Structural Racism
Subthemes: inequities for communities of color, bias

Across organizations, interviewees articulated the negative impacts of institutional racism on communities of color. Racism has been built into the healthcare system and has not only contributed to healthcare disparities but has also created barriers to understanding the healthcare needs of vulnerable communities of color. Listed below are interviewee quotes that contextualize the harms of the healthcare system towards marginalized racial groups.

"Our health care system is built off of whiteness and what that means in our country, and so if you are not directly proximate to the individuals that are suffering the most from our healthcare system, you're gonna continue to do what you perceive that they need from a care perspective."

"The health care system is built on white middle class culture, and anything that's not white and not middle class is the problem, so they are firing patients 'cause they missed appointments, and you have low-income, black and brown people who don't have transportation, who don't have funds, who... can't access the measly care that's there. But rather than fix that, we blame and make that the problem as if there's something wrong with the patient and spend money trying to fix a problem that they created. So, when it comes to patient voice and experience, it's not just asking and hearing, it's having a plan to use and change systems along the same time…"

"So, part of the scheme of the Federal government, and when you have United States constitution that's racist, and it

says that African Americans are only three-fifth human, and that...we are merciless savages, were not even human. So as long as we're operating under a racist constitution, all this advocacy and the work that we're doing, we're really not getting to the root cause. We're just working with symptoms and the signs, and racism...Yeah, we're talking about it now, but what are we gonna do about it?"

"You have to humanize the experience, because we already know that there are people in this world, [whom] don't look at us as human. They look at us as like machines or you know, some type of tool. So, to be able to get people's feedback to say, well, when I was in the hospital, I was disrespected in this way…and somebody else may not have felt like it was disrespect…even us being able to bring that to the forefront and say you're in this person's community and you're assisting them with something, that it's literally life or death. You have to change your implicit bias. You have to be able to say, you know what, I was wrong in the way that I was thinking."

Structural racism must be addressed by the healthcare system to change the harmful interactions that people of color have with the healthcare system. The design of the healthcare system in its current form creates experiences of suffering for those who are not white.

Medical Mistrust
Subthemes: exploitation, trauma, healing

One interviewee, who is a member of the indigenous community, discussed the deep sense of mistrust felt towards the United States healthcare system because of long, existing structural inequities, historical trauma, and exploitation as a marginalized population. These experiences are examples of why entire communities do not trust healthcare systems, providers, or staff.

"It's a whole deep relationship that needs to be built, [in order] to get that real quality, even the quantity of feedback and evaluations. I think one of the biggest things that hold Indigenous people back from being a part of research is the historical trauma. The healthcare system has been predatory against Indigenous women and people of color in the 60s when women were being forced sterilized or unknowingly sterilized. It's just like a real kind of trigger for us when it comes down to collecting surveys and being a part of studies and talking to the Indian Health Service in the hospital, because we have that other layer of trauma."

"My nephew calls it "pimping poverty", and I don't know a better word, because our healthcare business model is built on this exploitation. If they didn't have all these sick, poor Black people and low-income people to exploit, their business model doesn't work. So, they keep it going, and it's intentional and unintentional and that's systemic."

To improve medical mistrust and reach Indigenous and minority communities exploited by the United States healthcare system: (1) it is critical to confront the past and bridge a conversation about how to move towards trusting providers and healthcare leaders; and (2) build a holistic approach for how the United States healthcare delivery system engages and better understands the culture and values of the communities they serve.

"When we go through healing, and we have that open discussion and really have the doctors there and the providers there with the patients and really talk as a community together [it] is so important."

"You know, it's been a predatory industry, healthcare, we're not seen as humans, we're just seen as dollar bills, so it's all capitalism that's driving this unequal set up."

Accountability
Subthemes: provider, hospital, local government, federal government, universities, payers, transparency

The issue of accountability was an overarching theme that surfaced in multiple interview sessions with community organizations. Accountable parties were identified as providers, Federal and local government, universities, and payer institutions also known as insurance companies. Interviewees highlighted the importance of holding these stakeholders accountable for providing high-quality, affordable, accessible, and equitable healthcare. Many interviewees stated that the lack of accountability within the healthcare structure plays a key role in preventing equitable health care and that adequate healthcare metrics will still fall short of community need without adequate oversight.

"I think that would be incredible if there's actually laws that are in place to have insurance and hospitals accountable for making sure we have affordable healthcare and that it's accessible. There has to be a limit to the cost."

"I'm looking at my own institution, and I can tell you the years of grant funding that they have got in the name of my community, Maywood, and our community is worse after 30 years and the millions and millions of dollars...the health is worse…the community is worse…and there is no accountability."

"I wanna see the budget. I don't wanna just see the numbers that you choose to share with me. I wanna see the publicly available budget on the part of the system that I'm involved with as a patient. That's one piece of accountability that comes up for me. The second is participatory budgeting at the start, not waiting till things are all messed up, and then looking at it at the end."

"And so I think one of the things that may be useful is to think through which particular positions or offices really need to have the most attention in order to get this into the act phase, because to your point, the information is being collected and then you go through that whole dance about whether or not it's enough data or... like you say, P value and so and so forth. And then once you do get it, it's like, okay, well, duly noted. Thank you so much. You can go back to your seat. And so, I'm really interested in how to get it past that person that tells you, thanks so much, you can go back to your seat

and get it to the person that needs to be able to make those decisions."

"Let's work with what's out there. What is Medicaid doing? What is Medicare doing? What are the health systems doing? What are the insurance systems doing, and where have they been?"

"I don't know who makes decisions. Who puts policy into place? I don't know who that person is. Honestly, I think the Board of Directors got to report to who? Who are the directors of the hospitals or universities? Who do they report to? Who are the board [members], are they community? Because I'd be on the Board of Directors of the university of whatever. Could I be there? I can help them out, on how to do this."

"Sure, but see, here's the other part of problem, accountability. Nobody is being held accountable, and the

process to hold somebody accountable, either A, doesn't exist, or B, is so costly that most people aren't gonna do it, or C, it's so complicated, most people aren't gonna do it."

"Committees are a waste of time. So, unless there is a task and action items can be formed and tracked, cause that's one of the things I did as community advisory council chair. I'd say, we're gonna have a tracker when we make a decision. It's going on the tracker or we're gonna follow it up every meeting to see if our decisions are being implemented. And if not, why not?"

"It's just like these community advisory councils (CAC), the only reason why we have the CAC is because the law says we have to. If there was no law, there'd be no CAC. Whether or not anything gets done, that's irrelevant."

Shift of Power/ Change
Subthemes: power dynamics, decision-making, action

Interviewees described the importance of shared power between healthcare systems and communities as a requirement for achieving meaningful change. They explain the importance of the 'decision maker' role and the need for the person in that position to be known to communities and willing to make the necessary changes to healthcare system regardless of how the decision will be perceived by other individuals with power. Additionally, interviewees pointed out the gap in knowledge that most decision makers possess when it comes to understanding patient needs, and the lack of acknowledgement that persons in those positions often have for the community's experience and perspective.

"The decision-maker has to have the guts to make decisions that will benefit people that are marginalized because those decisions would benefit everybody, but you gotta have the guts first. You can't be in positions and not make tough decisions because of the backlash that you're gonna get from people, and our government has been the biggest perpetuates of that narrative, if you will, when it comes to our community."

"And the problem with the government is, you have people who have the ability to make decisions, they have the

authority to the take action, but they don't have the knowledge that they need to make the proper decision."

"[We] just had an experience with a contract that has some conflict. When they ask for a community voice, we're there, and when they don't like what they hear, which is a total white move, nobody says nothing, and it's as if it wasn't spoken at all, and they only listen and respond to what they wanna hear. That's the power dynamic that happens and why the information doesn't get implemented."

"We look for win wins, and opportunity to share power. I'm actually gonna look for a realistic solution, so that we can find a realistic win-win to change the systems."

Capacity Building
Subthemes: community health representatives, mental health support, compensation

An interviewee highlighted the importance of allocating funding to train and adequately pay community health representatives (CHRs) to improve the work of their organization. CBOs are often understaffed, and their community health workers are underpaid and overworked. CHRs play a critical role in providing services to communities, so it is important to build capacity for CHRs to meet the needs of communities. Another interviewee discussed how capacity building also involves creating space for CHRs to support their mental health. This is necessary given that the work of CHRs can be both physically and mentally exhausting and potentially lead to burnout.

"The whole infrastructure is not even really there, so we do need funding, and the CHRs are extremely underpaid, extremely overworked. Some of them are even grandmas that are driving all day. Each CHR has maybe about one to

three maybe around four communities that they have to serve. Very rural communities that literally have no access to running water or electricity. It takes us a whole day, a whole 12-hour day, just to make a food delivery."

"So, speaking to what [my colleague] was saying earlier, this work is hard, and so we have…to ensure that we are also caring for ourselves, and it's like breath work sessions or yoga sessions, learning about nutrition, just having a little turn-up session. We have two self-care days a month. Like this work is very, very, very hard. It's literally about Black maternal mortality. And so, in order for us to be able to show up, engage with our community partners, do the work ourselves, have our lived experiences, that's something that we have prioritized at [our organization] that is just so so impactful and honestly necessary to do this work well…"

"How can we build our infrastructure to do more of this work where we're not wearing multiple hats

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