

# Case Study Narrative

## Partnering with Community Organizations to Develop a More Equitable, Patient-Centered Measurement System



*Powered by*  
ATW Health Solutions



### **Authors**

Karen Frazier, PhD; Mary Lavelle, MS; Rebecca Fritz, BA; Nefertiti OjiNjideka Hemphill, PhD, MS; Desiree Bradley; Muhammad Khanan Chaudhry, BA; Nykia Rutledge, BA; and Knitasha V. Washington, DHA, MHA, FACHE.

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

# Table of Contents

<b>3</b>	Introduction
<b>6</b>	Indigenous Lifeways: "Telling our own story"
<b>14</b>	Asian Health Coalition/Center for Asian Health Equity: "If we're funded for something, that's a win for our entire community"
<b>21</b>	The National Birth Equity Collaborative: "Taking a step back and being there for what they need"
<b>28</b>	Summary
<b>29</b>	References
<b>31</b>	Acknowledgements

# Introduction

For measurement to advance equity and meet the needs, priorities, and values of all patients, including those who experience disparities in health care and health outcomes, patient-centered measurement (PCM) must be community-led. Community Organizations (COs) have a deep understanding of the experiences and needs of their communities, and have established longstanding, trusting relationships with those communities.

To understand the experiences of CBOs in developing and using health care measures, we conducted case studies with three organizations working to advance health equity among their communities. These organizations were also, in some way, (1) collecting data in their work to advance health equity or (2) engaging with health care measurement. Through these case studies, we explored the following research questions:

**1**

**What are the primary projects or initiatives the organization is involved in?**

**2**

**What populations do these initiatives serve? Which of those populations experience health disparities?**

**3**

**How does the organization advance health equity through their projects or initiatives?**

**4**

**What metrics/data does the organization collect or monitor related to their projects or initiatives?  
What are the organization's vision, goals, and needs related to capturing metrics or data?**

**5**

**What connections do these organizations see in their work between health equity and health care measurement?**

## Case Selection.

A total of 29 community organizations working to advance health equity that also may collect data or be involved in health care measurement were identified. From that list, interviews were conducted with 15 organizations and three were selected to participate in a case study. The team selected organizations for inclusion in case studies to represent a diversity of experience in measurement work and populations served (e.g., Indigenous, Black, Asian). The three organizations selected were Indigenous Lifeways, the Asian Health Coalition (AHC), and the National Birth Equity Collaborative (NBEC). Table 1 highlights characteristics of the three case study organizations.

**Table 1. Case Study Organization Characteristics.**

Characteristic	Indigenous Lifeways	AHC	NBEC
Communities served	<ul style="list-style-type: none"> <li>Indigenous communities in Gallup, NM and surrounding areas including Navajo, Zuni, Hopi, and others</li> </ul>	<ul style="list-style-type: none"> <li>Asian American, Asian Immigrant and Pacific Islander communities</li> <li>Black immigrants of African descent (including Nigeria, Haiti and other Caribbean nations)</li> <li>Latino populations experiencing similar disparities</li> </ul>	<ul style="list-style-type: none"> <li>Black birthing people in the United States and transnationally</li> </ul>
Use of data	<ul style="list-style-type: none"> <li>Collects data for internal program evaluation</li> </ul>	<ul style="list-style-type: none"> <li>Collects survey data to understand the needs of their diverse communities</li> <li>Collects pre- and post-program data for individuals enrolled</li> </ul>	<ul style="list-style-type: none"> <li>Develops and validates health care measures</li> </ul>
Roles of staff interviewed	<ul style="list-style-type: none"> <li>2 leaders at organization and partner organization</li> </ul>	<ul style="list-style-type: none"> <li>2 leaders at organization</li> </ul>	<ul style="list-style-type: none"> <li>4 researchers</li> </ul>
Documents reviewed	<ul style="list-style-type: none"> <li>Indigenous Lifeways website</li> <li>McKinley Mutual Aid Facebook Page</li> <li><i>USA Today</i> <a href="#">news article</a>, “‘Still killing us’: The federal government underfunded health care for Indigenous people for centuries. Now they’re dying of COVID-19”</li> <li><i>The Guardian</i> <a href="#">news article</a>, “Native American groups capitalize on record donations to confront chronic hardship”</li> <li><i>New Mexico In Depth</i> <a href="#">news article</a>, “Mutual aid groups rushed to the rescue during COVID-19”</li> </ul>	<ul style="list-style-type: none"> <li>Asian Health Coalition website</li> <li>Center for Asian Health Equity website</li> <li>Centers for Disease Control and Prevention, <i>Morbidity and Mortality Weekly Report</i> <a href="#">article</a>: “Community-Based Services to Improve Testing and Linkage to Care Among Non–U.S.-Born Persons with Chronic Hepatitis B Virus Infection — Three U.S. Programs, October 2014–September 2017”</li> <li>University of Chicago, <i>The Forefront</i> <a href="#">news article</a>: “CARES program makes strides to increase colorectal cancer screening in Cook County”</li> </ul>	<ul style="list-style-type: none"> <li>National Birth Equity Collaborative website</li> <li><i>International Journal of Environmental Research and Public Health</i> <a href="#">article</a>: “The Cycle to Respectful Care: A Qualitative Approach to the Creation of an Actionable Framework to Address Maternal Outcome Disparities</li> <li>National Quality Forum <a href="#">report</a>, “Maternal Morbidity and Mortality Measurement Recommendations Report”</li> </ul>

### **Data sources.**

Data sources included individual or group interviews with 2-4 members from each organization or a partnering organization. For two organizations (Indigenous Lifeways and AHC) we conducted two individual interviews of 60 minutes each. For NBEC, we conducted one 90-minute group interview with four members of their Research and Strategy Team. In addition, analysts reviewed the organization's website and any other documents related to the organization's use of data or involvement in measurement work (e.g., journal publications, reports, or news articles).

### **Action framework.**

We developed the interview guide and planned to prepare our case study narratives according to the Centers for Medicare and Medicaid Services' [Disparity Impact Statement](#) (DIS). The DIS is a framework to help health care organizations develop an action plan for advancing health equity. The steps include: (1) identifying health disparities they want to address and priority populations experiencing those disparities, (2) defining the goals they want to achieve, (3) establishing a health equity strategy, (4) identifying resources, and (5) monitoring and evaluating their progress. However, during the interviews, we found that this action framework did not resonate with participants. The DIS is intended for organizations who are attempting to initiate a new program that will advance health equity within an organization whose mission may not be grounded in advancing health equity. In contrast, for the case study organizations, advancing health equity has been foundational to all their work since the beginning of their organizations. Each case study narrative loosely follows the DIS action framework in that each describes the populations served, their approaches to advancing health equity, how the organizations know the needs of their communities, and their use of data. Each narrative also describes interview participants' vision for health care measurement.

# Indigenous Lifeways: "Telling our own story"



Indigenous Lifeways is an Indigenous woman-led organization working to restore health and balance for the Indigenous communities and the environment in and around Gallup, New Mexico. They address the generational trauma and historical disparities experienced by these communities through traditional Indigenous knowledge, respectful land-based practices, ceremonies, and a deep understanding of the dynamics and peoples of their communities.

They do this by centering around the needs of the community and leading initiatives to meet those needs in way that is holistic, culturally appropriate, and grounded in Indigenous tradition and ceremony.

Because all aspects of life are interconnected, all Indigenous Lifeways programs play a role in improving the health and well-being of the community. This organizational story describes how Indigenous Lifeways advances health equity in their community through the initiatives they develop based on an intimate understanding of the community's needs. It also examines how the organization collects data in a culturally appropriate way to inform its work and envisions health care measurement in the Indigenous community.

*"There's a certain way to help Indigenous people. From what we've experienced, [the help we have received has] never been aligned with what our community's needs were." -L-1*



**Indigenous Lifeways understands and responds to the needs of its community.**

Indigenous Lifeways was born out of the work of the Southwest Indigenous Uranium Forum which began in 1987 as an organization that participated in local, national, and international convenings to raise awareness about and advocate for environmental justice related to the impacts of uranium contamination on Navajo lands. The Southwest Indigenous Uranium Forum worked directly with the community to advocate for environmental justice, and they recognized a need for further education on the history and impacts of uranium mining on their lands. To address this need, the Southwest Indigenous Uranium Forum developed an annual fellowship program—the Social Justice Fellowship Program. Initially, this program provided resources for and built leadership capacity among those exposed to the health impacts of radioactive uranium from decades of mining in the region. Over time and in response to the needs of the community, the fellowship program evolved to address issues beyond uranium contamination, incorporated participants beyond those directly affected by uranium, and created a separate group for women—the Indigenous Women’s Working Group (IWWG)—to address violence against women and femicide in the indigenous community. In 2016, Indigenous Lifeways officially became a nonprofit organization.

*[To] have access to more healthy food...we're identifying farmers and how we can help them get more resources... [We teach] rainwater catchment—different ways to harvest water—healthy soils, composting, and so on... [Indigenous Lifeways is] doing the Indigenous Women's Working Group for healing...We was taught the importance of making moon water during the full moon, and how to pray with that and pour it into the garden... Traditional food is soul food for healing... it's nourishment, spiritually and physically. Emotionally too.” -L-2*

**Community is relational.** For Indigenous Lifeways, community is defined by relationships that have developed over time and across generations, whether with individuals or through partnerships with community focused programs. These relationships are rooted in their “*kinship system*” which connects Indigenous people through a familial relationship. The director of Indigenous Lifeways has been developing these relationships since she was a 14-year-old youth advocate. Through these relationships, the organization has a deep understanding of the health disparities impacting the community and what is needed to advance health equity. This understanding of the community’s needs drives all their programs.

*“When we say community, we're not just talking about the community members and the people that live there. We're talking about all these programs that are within our community [run by Native people]. It's really broad when we say community, because I see them as my aunties, I see them as my sisters, my uncles, my grandpas that are out there really doing the work.” -L-1*

*“We try and be as responsive to the community as we can. If there's a program that we have within Indigenous Lifeways, it's only because the community had that there was a need for it. We never push anything that is not for our community and something that our community does not want.” -L-1*



**Programming is guided by the community's needs.** All Indigenous Lifeways' work is grounded in a holistic approach to the person, land, body, and environment as well as a recognition that to advance health equity among their community their voices must be centered.

*"We need to bring ownership to the land that we have, the food that we have access to. We need to take ownership and make decisions that are for our people. Instead, [it is] reversed—we have politicians and leaders that are going against what we believe as a community."*

*-|-|*

To take ownership of their community, land, resources, and health, the organization grounds all their programs in ceremony and traditional Indigenous ways of thinking. With that foundation, they plan their initiatives by examining the needs of their community and developing a program and curriculum for a few months to start. Based on verbal or written feedback from participants, they adjust their approach.



## **Qualitative data collection allows the Indigenous community to share their own stories.**

To understand how well specific programs are serving the community, Indigenous Lifeways has collected data from program participants in the form of surveys, written qualitative data, and town halls. They have found that survey or quantitative data is less effective in allowing their community to tell their own story because of its format (closed-ended questions) and typical mode of administration (online or via telephone). Rather, offering participants the opportunity to share their stories qualitatively—either in writing or verbally in a group setting—has allowed the community to express their needs in a way that is familiar and comfortable to them.

For example, as a part of the McKinley Mutual Aid network, Indigenous Lifeways has used surveys to capture the experiences of the community during the COVID-19 pandemic, including documenting the impacts of the pandemic and the *“lack of equitable access to the basic necessities.”* However, many of the people in their community do not have internet or telephone access. This meant that those experiencing the most dramatic disparities would be excluded from representation in the survey. Indigenous Lifeways is exploring options for future in-person administration of the surveys at local and regional markets to ensure individuals without phone or internet access could be included.

In addition, when evaluating their Literacy Spheres initiative, Indigenous Lifeways initially administered pre- and post-test questionnaires to participants and decided that collecting survey data was not *“giving a real voice to the participant”* to communicate how well the programs worked. As an alternative to closed-ended question survey data collection, Indigenous Lifeways decided to incorporate the Indigenous tradition of storytelling into their Literacy Spheres evaluation. They found that by collecting qualitative data through open-ended questions, participants could share meaningful information that helped the organization plan activities that would meet their needs.

“[Storytelling] is just our natural way of communicating because as Indigenous people, it's just our oral histories and ... When we're able to let them naturally communicate in the way that they were brought up, it really shifts into more of a storytelling, qualitative data collection instead of quantity like '70% of them, they agree to this statement.'” –L-1

One interviewee also pointed to the richness that could be collected through the more personal approach of gathering data face-to-face. She shared the story of a middle schooler who communicated detailed reactions to a program she participated in when they were talking, but when the interviewee asked her to write her thoughts down, she wrote a single basic sentence, “*The podcast presentation was boring.*” In addition, the McKinley Mutual Aid town hall participants shared their appreciation for the two-day virtual meeting that allowed providers and community members an open forum to share what they had experienced during COVID and explore solutions. Where others have failed to represent the experiences of the community faithfully or accurately, participants valued being able to tell their own story. Community members have told Indigenous Lifeways they need more town halls to be able to tell their own stories.



*“[They told me] we need more of these. We need more ways of us telling our own story. It's usually the Navajo Nation telling our story, the president, and it's completely different from what we're experiencing.” –L-1*

### **Existing health care data does not consider holistic, historical experiences of the Indigenous community.**

When thinking about the relationship between the Indigenous community and health care measurement, interviewees pointed out that existing health care data does not reflect the holistic experience of the Indigenous community. For example, one survey captured data about access and barriers to health care within the Indigenous community, with questions asking about experiences of domestic violence, access to transportation, or access to running water. However, none of the questions explored the historical traumas that form the basis for the health disparities that Indigenous communities experience.

*“When we really talk about health care, especially from an Indigenous point of view, we really have to talk about any historical traumas that we in the past have experienced, because that has been passed down.” –L-1*

Health care measurement, then, must take into account the holistic experience of the Indigenous community. For example, it must account for the historical trauma of forced enrollment of Indigenous children in boarding schools, the abuse that occurred at those schools, and devastation of environmental contamination from the mining industry (e.g. high rates of cancer among the community). As one interviewee shared, *“everything has been destroyed because of these industries.”* In addition, health care measurement should reflect the present circumstances of the community including a lack of jobs, lack of access to food and other necessities, and reliance on the underfunded Indian Health Service which does not have the resources to provide needed care to the community.

*"It's been practiced recently to ask, do you feel safe at home? Domestic violence. That should not only be physical domestic violence but domestic violence as, living by a uranium mine waste. That's domestic violence because you're bombarded daily with radioactive particulates. Do you feel safe at home?...No, I don't have any food. No, I don't have any running water. Those need to be in the measurements, because it's a major disconnect....They treat everybody the same, and there needs to be more questions that capture that information." -L-2*

*"When you ask an Indigenous person, "Do you rely on IHS?" That's the biggest determinants that they lack so much more services than the average person...we have to travel hours to get any type of basic needs. When we rely on something that barely has any resources, your health and the health conditions and your family unit, it's really hard to say what the outcomes will be." -L-1*

# Asian Health Coalition: “Whenever we are funded, that’s a win for our entire community”

This organizational story describes how the Asian Health Coalition (AHC) advances health equity in local communities by focusing on community-based research, public policy/advocacy, training, and community engagement. One programmatic area includes fielding linguistically and culturally adapted versions of Chicago’s annual health survey to Asian and other immigrant communities they serve. Through the data collected from this survey, AHC identifies health disparities within their communities and then—in partnership with local CBOs—develops and implements community-based programming to mitigate the demonstrated health disparities.

*“What we try to do is find a hole, find where there’s a gap in services to the community or a gap in knowledge about health disparities impacting Asian communities. We try to find that gap, and then we find funding to help address it.” –A-2*



**The AHC and the University of Chicago partner to form the University of Chicago Center for Asian Health Equity (CAHE).**

AHC was founded in 1996 as a coalition of community-based organizations in Chicago to advance health equity among Asian communities in the region. In 2015, the AHC partnered with the University of Chicago to launch CAHE, an innovative community-academic partnership.

Grounded in the principles of community-based participatory research, CAHE bridges the research strength of the University of Chicago with the community capacity of the AHC. The university pursued the partnership because it understood the value of partnering with diverse communities in research and training. CAHE provided the university with an opportunity to formalize their relationship with a deep network of Asian CBOs. Partnering with the University of Chicago offered AHC a unique opportunity for expanded research and dissemination, collaborative funding, and student participation in their work to advance health equity. As one interviewee described, they were able to “*get into bigger markets in larger conversations.*” Currently, CAHE has trusting relationships with over 25 local CBOs and over 50 CBOs nationwide. CAHE’s work includes projects and programs across the Midwest and, within that portfolio, AHC is primarily responsible for the programs and initiatives in the Chicagoland area. As the only academic-community partnership serving diverse Asian communities in the Midwest, CAHE has brought significant recognition to both the University of Chicago and the AHC.

*“While the Asian Health Coalition does do research, the partnership has allowed them to do expand their capacity for interdisciplinary research. In the community some people have described [the Asian Health Coalition] as a super coalition. We didn’t used to be that way, but because of this partnership starting in 2015, we have grown and have been able to have greater impact on health disparities effecting our communities.” –A-2*

While AHC and CAHE function as one, this narrative is specifically focused on AHC’s local work in Chicago. Since CAHE was formed, AHC has broadened the populations they serve to include other vulnerable communities in Chicago that experience health disparities such as Black/African immigrants and Hispanic/Latinx communities. These groups experience many of the same health disparities as the Asian American, Asian immigrant, and Pacific Islander populations.

## **AHC and CBO partners work together in a reciprocal relationship.**

AHC and their CBO partners have a mutual appreciation for and reliance on the strengths that each brings to the partnership. AHC works closely with their CBO partners to address community members' needs by building capacity through culturally competent and language specific health education and health literacy programs, outreach materials (translated into the appropriate languages), training CBO staff to implement the programs, and providing technical assistance to support program implementation. To advance health equity through these programs, AHC ensure that they are designed—with their CBO partners—to meet community members where they are. For example, AHC's diabetes program (All One Community) is strategically designed to be delivered in the home to eliminate the barrier of traveling to a clinic. When developing and implementing culturally appropriate and relevant programs like this, AHC recognizes that the intimate knowledge that their CBO partners have of the community members and the trust that they have built among the community is essential to advance health equity.



*"I would not be able to do what I do without them (the CBOs). They're the ones that the community knows and trusts and they know the culture, they know the different nuances, they know the language. By being open to all of that, that's how I'm able to have a program in 18 different languages, tailored for multiple different ethnicities, able to effectively reach all these different populations." –A-1*



At the same time, to fund this work AHC passes more than half of their funding straight through to their community partners, while also building capacity among CBOs to increase their ability to partner in research and program implementation efforts to support the needs of their community.

*Then we're able to give those funds, pass them straight to our community partners. We see ourselves as not only funding us. If we're funded for something, we feel like that's a win for our entire community." –A-2*

To build capacity, AHC provides access to an asynchronous virtual training program on topics such as motivational interviewing; strategies for conducting outreach, educating community members, and making referrals; cultural competency; and health topics (e.g. vaccines, hepatitis, diabetes). In addition, AHC holds monthly collaborative meetings where CBOs and AHC staff can learn from one another and discuss skills and strategies on topics related to challenges they encounter with program(s) they are implementing. AHC invites clinical partners to these meetings to give the CBOs the opportunity to begin to develop trusting relationships with the clinical community to ultimately support CBOs in connecting community members with a medical home. In addition, AHC has built capacity for program implementation among organizations for implementing health equity programs. For example, a few years ago there were no CBOs serving Black/African immigrant populations in the Chicagoland area with the capacity to partner with AHC. In response, a staff member identified the existing leaders and organizations serving that community and worked with them to build their capacity to work with AHC. At the time of these interviews, they have been partners for about two years.

**AHC understand the needs of their communities by using disaggregated data.**

AHC identifies the needs of their community through community and partner input, evaluation data from their existing programs and initiatives, and the disaggregated population level data collected through the Chicago Immigrant Health Survey. This survey originated to address the lack of data collected from Asian communities in the Healthy Chicago Surveys administered by the Chicago Department of Public Health. The Healthy Chicago Surveys collect racial and ethnic demographic data in broad categories (e.g., Asian, Black), masking

differences between the many distinct Asian ethnic groups that comprise these categories and that AHC serves. In addition, the surveys have had a low response among the Asian population. For example, a prior year saw only 18 responses received from respondents self-identifying as Asian. Disaggregated data is particularly important because data reported in aggregate masks disparities and hinders work to advance health equity. AHC saw that the data was insufficient to determine what health disparities their communities were facing. They pursued funding and worked closely with their partner CBOs to adapt the survey—culturally and linguistically—to collect more detailed information on the needs of the diverse Asian and Black/African immigrant populations in Chicago.



*"What we said is, 'Listen, we don't know how to do it better, but we have a connection with the community, with other nonprofits like ourselves, and we really want to do this right. We really would like to find out because the Chicagoland area, and the Midwest area has the fifth largest Asian population in the country.'" -A-2*

AHC worked with their CBO partners to translate the surveys, make cultural adaptations (e.g., remove sensitive questions), and include additional questions they felt were important to capture (e.g., mental health, substance use, hepatitis B, COVID-19). AHC used separate links for each survey version and worked with CBOs to administer the survey in waves, opening and closing the administration and outreach by one CBO at a time. In addition, each survey asked respondents where they had heard about the survey, providing data analysts additional information to help them assess the respondent's ethnic group. With this information, AHC was able to disaggregate the data to understand the disparities each community was experiencing.

*"The Filipino population had a different survey link than the Chinese population. The Rohingya population had a different survey than the South Asian group. If you think about it, it's not rocket science. Some people say we can't get the data disaggregated, but you can, if you just utilize what you have in front of you." –A-2*

Ultimately, AHC was able to administer surveys to nine different ethnic communities in multiple languages. Their current total responses are around 3,000 completed surveys. Administering the adapted surveys in this way allowed AHC to identify specific needs of their diverse communities, and to help them develop programs and initiatives to address those needs.

*"That's health equity right there because we're providing the voice of our community partners, and we're receiving population-based data from the actual population." –A-2*

### **Health care measurement must be culturally specific.**

For AHC, health care measurement must disaggregate data beyond the existing racial categories. The current categories do not capture the varied disparities experienced by specific ethnic groups.

*"A third of [the Asian population] are limited English proficient...If you are taking a survey of English speaking, American born Chinese people, you're not looking at the health indicators of the Chinese community. You're only looking at the indicators of those who are educated and can read your survey." –A-2*

*“The main challenge that we see is getting [individuals] into the clinic, getting them to trust Western medicine, the medical systems... A lot of things they're collecting just isn't important ...Take that little bit of time to really connect with the community, find out what's happening. I've heard time and time again—because of the color of their skin or because of their ethnicity or because of language barriers—they get different qualities of care and that's not okay. There needs to be measurements that are culturally inclusive, that are not just, 'Okay, we're ticking a box.’” –A-1*

In addition, for AHC existing measures do not focus on the experiences or outcomes that are most important to their communities. To address this, measurement must be culturally specific and reflect the needs of the specific community being measured. This requires stakeholders involved in measure development to meet communities where they are. They must go to the communities, engage with them, understand the context of their health care experiences, outcomes, and disparities, and then work with them in their own environment.

*“We already know the phrase, ‘Your ZIP code is more defining of your health than your genetic code.’ I would like for there to be more focus on that so that community is also a health indicator...These are non-tangibles. They're hard to quantify. Researchers kind of stay away from them, but they really have an impact... So we try to figure out what people's life is, look at what they're doing every day. How do you spend your day? How do you spend your weekend? What services do you come to your community partner for? Oh, you like to come on Fridays just for lunch so you can talk about how things are going with your family. So that's a mental health opportunity. They don't call it that. It's lunch on Fridays with these other 50 women.” –A-2*

# The National Birth Equity Collaborative: “Taking a step back and being there for what they need”

NBEC is a Black woman-led organization that works to improve birthing outcomes by addressing structural and interpersonal racism and inequities in maternity care. NBEC was founded in 2015 to address rising infant mortality rates among Black and Brown populations and—in response to the disparities experienced by Black birthing people—quickly expanded its mission to include addressing the maternity care experiences of birthing people and their babies. NBEC staff work towards enacting structural and cultural change toward health equity and reproductive justice via different avenues, including research, policy, advocacy, communications, training, and technical assistance. This organizational story describes how NBEC centers people and communities in their measurement work by developing trusting relationships with and investing in community-based organizations (CBOs) and by adopting equitable organizational practices and structures to support the work of advancing health equity.

The U.S. is the only industrialized nation in the world where maternal mortality is rising. And, the U.S. has nearly the highest maternal mortality rate among high-income countries. Each year, approximately 700 American women die during pregnancy, childbirth or subsequent complications. — *Forbes*, August 2021

**Even when accounting for social determinants, Black women are still dying at 2.5 times the rate of their white counterparts.**



*“Centering patients is a value or principle that we abide by. So, each team—whether it’s policy, research, transnational, or administration—we all center patients differently, but we’re centering patients.” –N-1*

### **Communities drive NBEC’s measure development process.**

NBEC’s Research and Strategy Team runs the Respectful Maternity Care Initiative, partnering with CBO leaders and other stakeholders to center patients in health care measurement work related to birth equity. With funding from federal, academic, and philanthropic organizations, NBEC developed a framework for respectful maternity care and a companion patient-reported experience measure (PREM), all driven by the knowledge and expertise that CBO leaders have of their communities. NBEC is currently partnering with CBO leaders to create a framework for birth equity measurement, which will be used to define a set of variables and guidelines for the development of measures of birth equity.



NBEC’s measure development process follows standard steps: holding focus groups with impacted patients, identifying measure constructs, identifying survey questions for those constructs, creating new questions as needed, conducting two rounds of a modified Delphi process, and validating the measure. However, their approach is distinct in that NBEC partners with CBO leaders in all aspects of the measurement development and validation process to center patient and community needs. For example, when developing the PREM for respectful maternity care, CBO partners drove content development, led data collection, and supported data analysis.

*"We developed a facilitator guide and honed it in partnership with the CBO groups, and the CBOs helped co-facilitate [the groups] and sample the participants. They really led the data collection aspect of that phase of the research...[To analyze the data] we developed a framework of how we conceptualize the themes and a framework for the Cycle to Respectful Care, both of which came from [the CBOs]...They helped us organize the thinking. The cycle to respectful care is actually based on a framework that one of our CBO leaders pointed out." -N-2*

**Co-creation with communities is possible because NBEC has built caring and trusting relationships with CBO partners.**

NBEC is able to co-create measurement with CBO leaders because they invest deeply in their relationships with partners, as one researcher shared, *"our philosophy is not just doing research on people but investing in communities."* NBEC views themselves as a resource for CBOs and is committed to ensuring their partners have the support they need to sustain their work in the community and partner in research. NBEC uses their infrastructure, expertise in research methods, and experience with grant-writing to submit grant applications to funders. They are then able to invest much of the funds they receive in CBOs



*"Where the work is really getting done."* CBOs that are chronically underfunded and do not have the resources to build organizational infrastructure (e.g., financial or administrative support) are often overlooked to participate in research activities. Through a partnership with NBEC, these overlooked organizations *"get tagged to play in the game."* As CBOs are brought into research activities, they are able to build power within their organization to drive research and measurement activities. As described above, CBO leaders led the data collection activities to develop a PREM for respectful maternity care and they played a key role in the analysis. On another project, NBEC is building capacity among partners by training patients and other stakeholders on how to partner in patient-centered outcomes research.


*"If we get a \$5 million grant, \$3 million of that we're going to figure out a way to invest in our CBOs or other thought leaders who don't necessarily have PhDs and master's degrees to elevate them so that when the research is done, they have the tools and economic resources to continue that work because they are the experts." –N-2*

NBEC also supports their CBO partners by ensuring that the research process and funding requirements do not cause harm to the CBO leaders or their community. When working with funders, staff are asked to *"recognize their power"* when requesting what they need and CBO partners are encouraged to do the same. For example, NBEC finds that working with outside organizations often brings with it a *"sense of urgency"* (a characteristic of [white supremacy culture](#)) that does not allow for space to collaborate with CBO partners while recognizing their many competing demands. To ensure that the process does not cause harm to their partners, NBEC communicates to outside organizations about their needs for time and resources and stands firm. This may mean delaying deliverables, expecting equitable funding, or requiring that a group of funders organize their funding such that NBEC's administrative burden is minimized.

*"We can voice what we want and need and if people want to work with us then they have to meet us where we are. We're not going to devalue our partnerships or people with lived experiences. We're going to center them. If that means we get pushback from funders and we push back on them, then that's what we have to do." –N-1*



“Finally, all NBEC staff have lived experiences of systemic and interpersonal racism. The experiences that NBEC staff and Black birthing people and communities share means that they “*all speak the same language,*” facilitating trusting partnerships. These partnerships often emerge organically through interconnected spaces and existing networks of people and organizations who are already doing similar work to advance health equity. In addition, because of the way NBEC works with their partners, the partners trust that NBEC is “*doing this work and it’s not a façade*” meaning that they are not superficially talking about health equity without being committed to doing the hard work to dismantle racism.



“This is ancestral. Our ancestors did this work. Now people have a name for it: community organization or community power building reproductive justice, birth equity...People of color, specifically Black women, Black families, Black communities, they’ve always been connected. They’ve always thrived and they’ve always handled it. When I think about these partnerships, they’re organic... As people of color, we’re always connected with our community. If we’re not, we find ways to be connected, because we cannot do this work alone. –N-1

**NBEC adopts equitable organizational practices and structures to support the work of advancing health equity.**

NBEC’s commitment to centering patients as they work toward dismantling structural and interpersonal racism in maternity care also requires a different way of working as an organization. For example, rather than instituting an organizational hierarchy, NBEC has organized themselves non-hierarchically so that they can continuously reflect on their processes and remain flexible to advance the work of health equity. The benefit of this structure is that when staff or partners identify something that could be improved, the organization can adapt quickly and create a needed structure or practice. In a recent instance, NBEC realized that to be sure they center the community in all their organization’s activities—not just those related to programming or research—they needed a new structure. They created a “Community Power Building Team” that will allow dedicated staff to focus on developing trusting partnerships, collaborating with, and centering their partners in all NBEC’s activities and decision-making.

*“It’s not like you wait 10 years to see a change that people before you have been trying to do. Change happens in real time at NBEC.” –N-1*

"In addition, NBEC supports their commitment to dismantling structural and interpersonal racism in maternity care by valuing staff for *"who [they] are beyond [their] resume."* NBEC recognizes that the work they do is emotionally draining and intellectually demanding. To protect the mental and emotional health of staff and ensure they can sustain this type of work long-term, NBEC has a self-care program that includes days off when needed, a yoga program, virtual happy hours, and cooking classes. In addition, staff have adopted practices to care for each other such as asking how they can help one another or encouraging each other not to monitor email while on vacation. Because staff are treated holistically and are supported and protected by their leadership, the organization operates based on relationships of trust.

*"We show up as our full selves because we can trust each other. There's not a lot of spaces where I can show up as my full self and not feel like someone's going to exploit me for it...We see the entirety of our colleagues' experiences as an asset, as beautiful. Then also protect them." – N-2*

**Community-driven measurement means researchers taking a step back.**

For NBEC researchers, current health care measurement cannot advance health equity in maternity care because current measures assess the most extreme outcomes that are important to health systems, payers, and clinicians (e.g., death, C-sections, etc.), but do not reflect the outcomes that are most important to patients. In addition, the existing approach to measurement does not identify or address the root causes of a given outcome, nor does it capture disparities in experiences or outcomes. Finally, the current system of accountability around measurement does not lead to structural changes.



"When we look at maternity care, we're not taking into account everything prior to pregnancy or what's happening around pregnancy that's affecting the outcome. Is it transportation? Is it not having food? Is it not having employment? Is it having intimate partner violence? All the measures in maternity care disregard that because they don't know how to deal with it. So they just rather measure what they can do. "Okay. We can do something about C-sections." But can you do something about referrals to CBOs? Can you do something about a support system? Can you do something about resources and funding? And that that's the problem. Measures are only created for stuff that we feel like we have solutions for, not for what we really need to be worrying about." -N-1

NBEC researchers are practicing and advocating for community-driven measurement in which researchers step back and listen to people and communities and invest in CBOs as partners, helping them to recognize their power by training them to take a lead in measurement work.

*"Community-driven measurement means taking a step back and being there for what they need... Instead of you figuring out what the solution is, ask the people that are experiencing the outcome what solution will help them?... Community-driven measurement will include trainees, maybe curriculum development, where we can give tools to community partners so that they can do this work. What does a modified Delphi process look like? What are cognitive interviews? Let's train community organizations so that they can do this work and then they can choose measurements that they feel are valuable. You'll be so surprised to see what comes out." -N-1*

# Summary

Participants from all organizations pointed out that the current approach to health care measurement does not capture outcomes that are important to their communities and does not reflect the historical, structural, and interpersonal racism that lead to health disparities. As a result, health care and community organizations cannot use measurement to identify and address those factors that will improve patients' care, experiences, and outcomes. In addition, measurement cannot serve as a tool to identify and address root causes of disparities and advance health equity.

Interviewees called for measurement that reflects their community's culture and individuals' holistic experiences, which includes culturally specific, disaggregated, community-level data. To produce this type of data, those involved in measurement work should work in partnership and co-create measurement with CBO leaders to develop measures that reflect the experiences and outcomes most important to that community. Effective partnerships are characterized by long-term, trusting relationships that are developed over time and include investments in the form of capacity-building, planning for long-term sustainability within the community, and shifting power such that communities are leading measurement.

These three organizations demonstrate that for health care measurement to function as a tool to advance health equity, stakeholders involved in measurement work should:

- Establish trusting, long-term relationships with CBOs, including investing deeply in them and their communities.
- Partner with CBOs in measurement activities (e.g., leading data collection efforts and analyzing the results).
- Adopt approaches to health care measurement that reflect the culture and needs of the community. For example, qualitative data collection and storytelling (verbal or written) may be more effective in some communities.
- Develop appropriate linguistic and cultural adaptations of data collection instruments to reach different communities.



# References



Asian Health Coalition. (2021). Retrieved August 12, 2022, from <https://www.asianhealth.org/about-asian-health-coalition>

Centers for Medicaid Services. (2021, March). *Disparities Impact Statement*. Retrieved August 12, 2022, from <https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Disparities-Impact-Statement-508-rev102018.pdf>

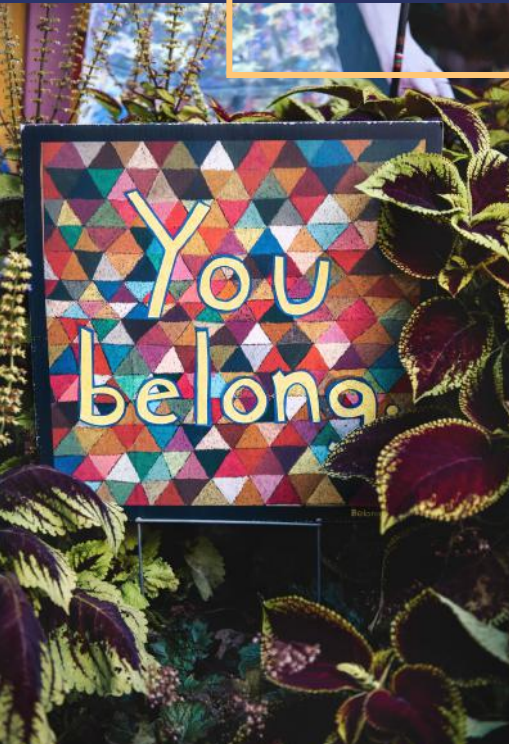
Centre for Community Organizations. (n.d.). *White Supremacy Culture in Organizations*. Retrieved August 12, 2022, from <https://coco-net.org/wp-content/uploads/2019/11/Coco-WhiteSupCulture-ENG4.pdf>

Indigenous Lifeways (n.d.) Retrieved August 12, 2022, from <https://www.ourindigenouslifeways.org/>

National Birth Equity Collaborative (2022). Retrieved August 12, 2022, from <https://birthequity.org/>



# Acknowledgements



# Community Organizations

Thank you to participating COs that shared their community's perspectives and experiences in this case study to promote equitable healthcare measurements.

Krystal Curley from Indigenous Lifeways in New Mexico

Fornessa Randal & Alia Southworth from Asian Health Coalition/Center for Asian Health Equity in Illinois

Kiara Cruz, Latasha Gatling, Carmen Green, Zainab Jan, and Susan Perez from National Birth Equity Collaborative in California

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

# American Institutes for Research

We would like to thank members of the American Institutes for Research (AIR) for their contributions to the project.

Author: Karen Frazier, PhD

Author: Mary Lavelle, MS

Author: Rebecca Fritz, BA

Author: Nefertiti OjiNjideka Hemphill, PhD, MS

Author: Desiree Bradley

Author: Muhammad Khanan Chaudhry, BA

Author: Knitasha V. Washington, DHA, MHA, FACHE

Author: Nykia Rutledge, BA

# ATW Health Solutions

Additionally, we would like to thank members of the ATW Health Solutions team for their design, development, and research on the project.

*The authors declare that they have no competing interests. All authors read and approved the draft project materials. Correspondence concerning this project should be emailed to both Dr. Nefertiti OjiNjideka Hemphill (Nefertiti.O.Hemphill@atwhealth.com) and Desiree Bradley (desiree.bradley@atwhealth.com) or addressed to ATW Health Solutions, 1132 S. Wabash Ave., Suite 304 Chicago, IL 60605.*