WHITE PAPER

Centering the Consumer Voice in Health Equity: Healthwise Consumer Advisory Board on Maternal Health

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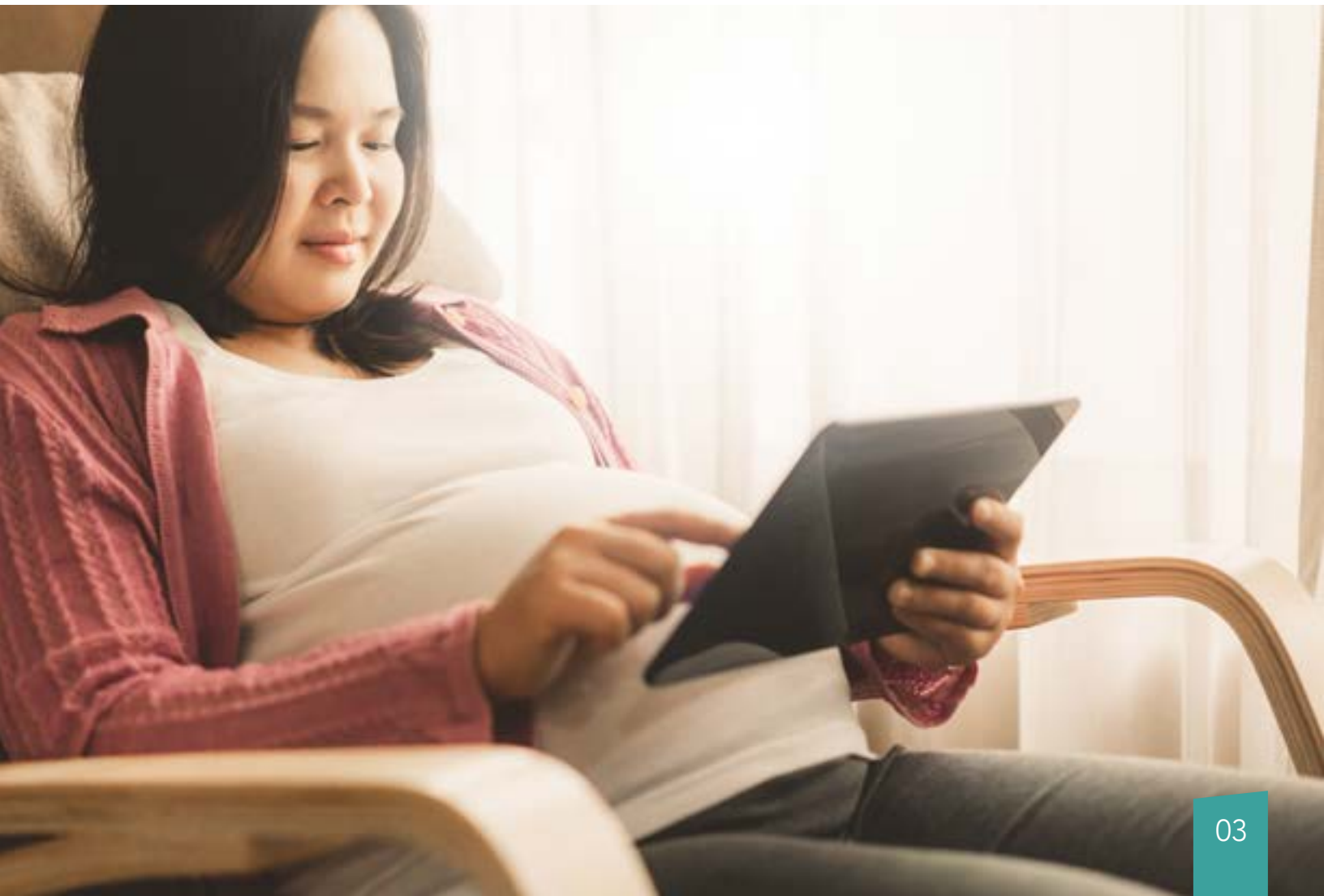
INTRODUCTION

Healthwise has set the standard for health education since 1975. Nonprofit and independent, Healthwise is a trusted resource for health information, technology, and services that help people make better decisions and improve health outcomes. To help us do this, we continuously strive to strengthen our relationship with consumers and better understand their needs. In 2022, Healthwise established Consumer Advisory Boards (CABs) as another way to receive feedback from community members. The purpose of a CAB is to hear directly from consumers on a given topic about their healthcare and lived experiences, their needs related to health information, and their feedback on Healthwise education.

Healthwise partners with the Savvy Cooperative to recruit community members for CABs based on eligibility criteria we establish around a given topic. For this CAB, we also partnered with Grapevine Health, a data-driven patient engagement company that creates and digitally delivers culturally appropriate health education content to help close care gaps for underserved communities.



BACKGROUND

In 2020, the maternal mortality rate in the United States was almost triple that of other high-income countries. The U.S. averaged 24 deaths per 100,000 live births, and among those deaths, the mortality rates for minorities were much higher compared to maternal mortality rates for white women. For American Indian and Alaska Native women, mortality rates were twice as high, while mortality rates for Black women were three times higher than those of white women.

This Consumer Advisory Board (CAB) engaged with community members about maternal health. Our goal was to better understand patient and community member experiences during and after their pregnancies and how to best support them with health education content. Healthwise also developed patient-facing materials on this topic, along with plans to obtain feedback on these materials. Our maternal health education includes information on how systemic racism impacts maternal health outcomes and encourages people to advocate for themselves.

METHODS

Savvy Cooperative recruited participants using demographic requirements and screening questions developed by Healthwise and Grapevine Health.

Eligibility criteria for the CAB included:

- Identifying as a person of color.
- Having sought maternal health services in the last three (3) years for either prenatal checkups, childbirth, or postpartum care.
- Having experience as a Medicaid enrollee, public option insurance coverage, Women Infants and Children (WIC), Supplemental Nutritional Assistance Program (SNAP), Electronic Benefits Transfer (EBT), and/or being uninsured.
- Experienced challenges with access to care due to socioeconomic barriers or social determinants of health (SDOH) like food insecurity, housing, transportation, or financial insecurity.

In addition, ideal participants sought support for themselves. The only exclusion criterion was previous professional involvement in the healthcare system. Savvy Cooperative provided Healthwise with a list of 18 participants, which Healthwise narrowed to six participants.

These are the demographic breakdown of the six participants:

GENDER: 6 female

AGES: 20-30 (4), 30-40 (2)

ETHNICITY:
- 4 Black/African American
- 1 Asian
- 1 Hispanic/Latino

LOCATION:
- 4 urban (inside of a large metropolitan city)
- 2 suburban (outside of a large metropolitan city

NUMBER OF CHILDREN:
- 5 with 2 children
- 1 with 1 child

HEALTH INSURANCE BREAKDOWN:
- 5 on Medicaid
- 1 on employer-sponsored health insurance

Before the group discussion, Grapevine Health conducted one-hour individual pre-interviews with the participants. The purpose of the CAB pre-interviews was to address concerns, build rapport, answer questions, and align participants on the purpose, goals, and objectives of the CAB meeting.

Savvy Cooperative coordinated participant schedules. At the beginning of the sessions, the group reviewed ground rules with emphasis on the expectation of full participation throughout the meeting.

FINDINGS

Each CAB participant participated willingly and consistently throughout the advisory board meeting, offering perspectives, insights, and feedback. The following notable themes emerged about maternal health, access to healthcare, and trusted health information.

Pre-Interviews

General observations and feedback

FINDING PROVIDERS IS DIFFICULT

Finding providers is difficult, but it's even harder if the preference is for a Black, female doctor. People sometimes rely on social networks and social media crowdsourcing to identify providers. For some, provider racial concordance is a high priority because they feel they're more likely to be heard and taken seriously by their provider.

FEELING UNHEARD, IGNORED, AND MARGINALIZED IS COMMON FOR THEM

One person described feeling stereotyped by the provider when questioned about abuse in the home, which she believed to be based on her race and appearance.

INTERNS AND RESIDENTS NEED TRAINING

Two people reported negative health experiences associated with students and residents in training who they described as intimidated by them. When discussed further, it was unclear if the fear and reluctance to provide care was socially or racially motivated or a function of training and lack of confidence.

ACCESSIBLE MENTAL HEALTH RESOURCES ARE NEEDED

A few mothers discussed their need for mental health support. One described the cursory delivery of information and was discouraged by the lack of depth in the materials. One person recalled her distress during a birth experience that felt rushed and chaotic, but no one recognized her anxiety or offered to support her mental health. Another woman wasn't aware she could advocate for herself in a stressful hospital environment. She found out about self-advocacy online and later used this information to address her concerns with her care team.

TRUST IN PROVIDERS IS FRAGILE

A few women discussed a lack of confidence in their provider's decision-making. One mentioned attempts to learn more about doulas and gain access to their services to help as advocates in these situations. Some felt a loss of control when disagreeing with their provider about pain control and the need for a cesarean section (C-section). One person expressed concern about receiving inferior care from residents and cited an example during labor in which a resident improperly measured her cervix and did not recognize she was ready for delivery.

> "I saw the racial and social bias in the [hospital]. Once when I asked for something, they asked me if I was aware of the cost. I am pretty sure they wouldn't ask a white person or a rich person that question."

> "Some doctors talk over your head and others talk down to you."

CAB participants

Maternal health-specific observations and feedback

We asked: "The issue we're thinking about is why healthcare outcomes for mothers of color are so much worse than they are for white moms in this country when it comes to complications and even deaths related to pregnancy, childbirth, and the postnatal period. Do you have any observations or experiences you can share on why that might be?"

Most participants found doctors hard to find and access. The majority of pre-interviews touched on a shortage of "good" OB providers. When asked to define "good," most suggested it's linked to trust, cultural competency, and listening.

Most reported Black moms are not taken as seriously and that providers don't trust their version of symptoms and health experiences. Some felt their doctors believed they had higher pain tolerance than other races and that providers are too quick to select C-sections because it is more convenient for them. One mother said, "Doctors need to change their mind-set about us."

One person believed the Black/white maternal-health death disparity was due to the provider's trust in the mother.

The perceived lack of choice was raised by a mom who felt that all clinical decisions were being forced on her rather than in partnership with her. One mom said she has experienced it herself and that a lot of her friends—who are all women of color—said the providers provided white women with far more resources and opportunities.

Health information resources

When asked about sources for trusted health information, participants offered a range of sources including social media, the internet, word of mouth, and written materials from providers. Most preferred digital over paper educational materials. Some used pregnancy apps for maternal health information, but for most general health information the group turned to Google. Some also find providers through provider reviews.

A few participants suggested a need for mental health content. Although providers may ask about their mental health or explicitly ask if they feel depressed, the inquiry often feels rote, and there is no follow-up.

One person recommended provider offices send monthly email blasts about a variety of health issues. She believed most patients do not receive enough health information from doctors.

One person referenced health information she heard multiple times from different people, and one stated social media was a poor health information source. The remainder relied partially on social media and the internet for health information. One person relied on a family member, believing this person had more medical knowledge than her doctors. One person actively sought trusted health information from "people that look like me" and who delivered information without science and medical jargon.

The health information most received was via U.S. mail and was often not relevant. For example, a participant received information about general diabetes support programs during pregnancy, but she is not diabetic.

Some felt more health education materials featuring Black and brown people from different walks of life should be developed and made available. Materials should also be convenient to find and access.

> "Doctors don't go in-depth to see how you're really doing. They focus on tests and shots but don't ask personal questions about your well-being."

> "Encourage connection to doctors who look like us. The problems are about listening and believing us, so I am not sure. I have had doctors tell me I am wrong about my symptoms. A lot of the nurses are blockers. They are biased too and won't tell the doctors about our complaints. I think the content will help. It needs to be on social media. A lot of people think (social media) is a negative, but it can be used for positive things."

> "First, be sure you understand people's experiences. Then, even though you use doctors, you should use us too because we have been through things."

Pre-interview participant

CAB Discussion

The CAB participants participated willingly and consistently through the advisory board meeting. Each person offered perspectives, insights, and feedback throughout the meeting.

Access to healthcare and maternal health experience

Feeling unheard was one of the most prevalent themes from CAB participants. Most commonly, this is related to the development or awareness of a new symptom such as pain or discomfort. Often, people are unable to specifically articulate a concern, and this may be expressed as "I know something is not right," which may be easily dismissed by healthcare providers. Some also described this as feeling unsupported.

Many expressed a desire for access to easily accessible, coordinated, nonjudgmental care but noted it's difficult to find or switch providers. Those with fewer resources had a much more difficult time finding the care they needed, and some wondered if the disparity was racially motivated.

Everyone in the group had at some point consulted Google and social media to find healthcare recommendations.

Specific health literacy needs included:

- Insurance literacy.
- Advocating for self and family.
- Healthcare navigation.
- Breastfeeding information.

Consistent, frustrating challenges that CAB participants mentioned were inexperienced hospital providers, insensitive doctors, and staff who were unhelpful or seemed to be suffering from burnout.

Health information

Members were asked to briefly provide general perspectives about health information. Their responses included the following:

1. The go-to source for health information was multichannel, including email, the internet, texting, and social media.

2. The overwhelming preference for content was through authentic voices and people with similar backgrounds.

3. Some appreciated printed materials to refer back to, but everyone consumed digital content. Digital content refers to any content consumed via a device regardless of the channel or source, such as online, social media, texting, or email. Of those who appreciated printed materials, they also appreciated digital, but some preferred digital only.

4. Participants preferred realistic graphics in the visual content. Realistic means real bodies over simplified animations or cartoons.

5. Most preferred content that pertained to them directly, rather than general information.

Sources of trusted information

For participants, trusted health information sources are email, friends and family, YouTube, and social media including Twitter spaces, Facebook, and Instagram. Some get health information from TikTok.

When searching online for trusted health information, CAB participants said they rely on reviews and clinician credentials, although some may not understand how to distinguish one credential from another. They also rely on repeatable information. For example, one participant said that if multiple sources confirm something is true, she is more likely to believe the information. Information found both online and in person via word of mouth is deemed more credible. One member reported being skeptical if the information was heard from only one source. If the information on social media lacks followers or likes or is from an unrecognized or unpopular source, the information is less believable.

OPPORTUNITIES FOR HEALTHCARE ORGANIZATIONS

This feedback from CAB participants can help healthcare organizations more effectively reach everyone with health-related social needs while addressing health equity concerns. More fully discussing options and involving patients in decision-making emerged as key themes.

Here are some strategies:

1 Support providers in sharing maternal health education with patients and encouraging patients to comfortably share information with providers.

One thing that can help build patient/provider trust and open these conversations is shared decision-making tools. These tools help patients better understand their options and be better equipped to discuss their preferences with their providers. These tools can cover pregnancy-related services and treatments such as the selection of a doula, epidurals, C-section, and alternative therapy.

2 Seek out and listen to consumer feedback.

To help the populations you serve, especially those with unmet social needs, you must understand their challenges and preferences. Then use that information to ensure education materials cover those needs—including support for accessing social services. Make sure your organizational plan includes a content monitoring and evaluation strategy. Use it to identify whether your organization or providers have missed opportunities to share tailored, effective content around maternal health.

3 Ensure the education content that your organization shares encourages people to ask for help.

Specifically around maternal health, use education that explains and empowers self-advocacy, covers how to file a complaint, and contains enough detail to help readers make informed, personal decisions. CAB participants also specified the need for better and more abundant, accessible information on maternal mental health and local mental health support.

4 Create an organizational social media strategy that includes evidence-based health information.

The CAB was clear about their multichannel preferences for consuming health information. Consider how to leverage a digital strategy to distribute content in new and better ways to more effectively address health equity concerns.

Healthwise Health Education

Healthwise's health education is shaped by consumer feedback, and it's developed using trauma-informed guidelines to promote empowerment and decrease shaming and blaming. Our content supports providers and patients with actionable resources that encourage conversations about both health conditions and the social factors that can affect health.

To learn more about Healthwise health education, how it's created, and how it can help with sensitive conversations like those around maternal health, visit our website.

If you're interested in collaborating with Healthwise on health equity initiatives such as health risk assessments, social determinants of health, quality measurement, and showing the value of trusted health information for population health, email Dave Foster, Healthwise Senior Director Consumer Strategy and Insights, at dfoster@healthwise.org