WHITE PAPER

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

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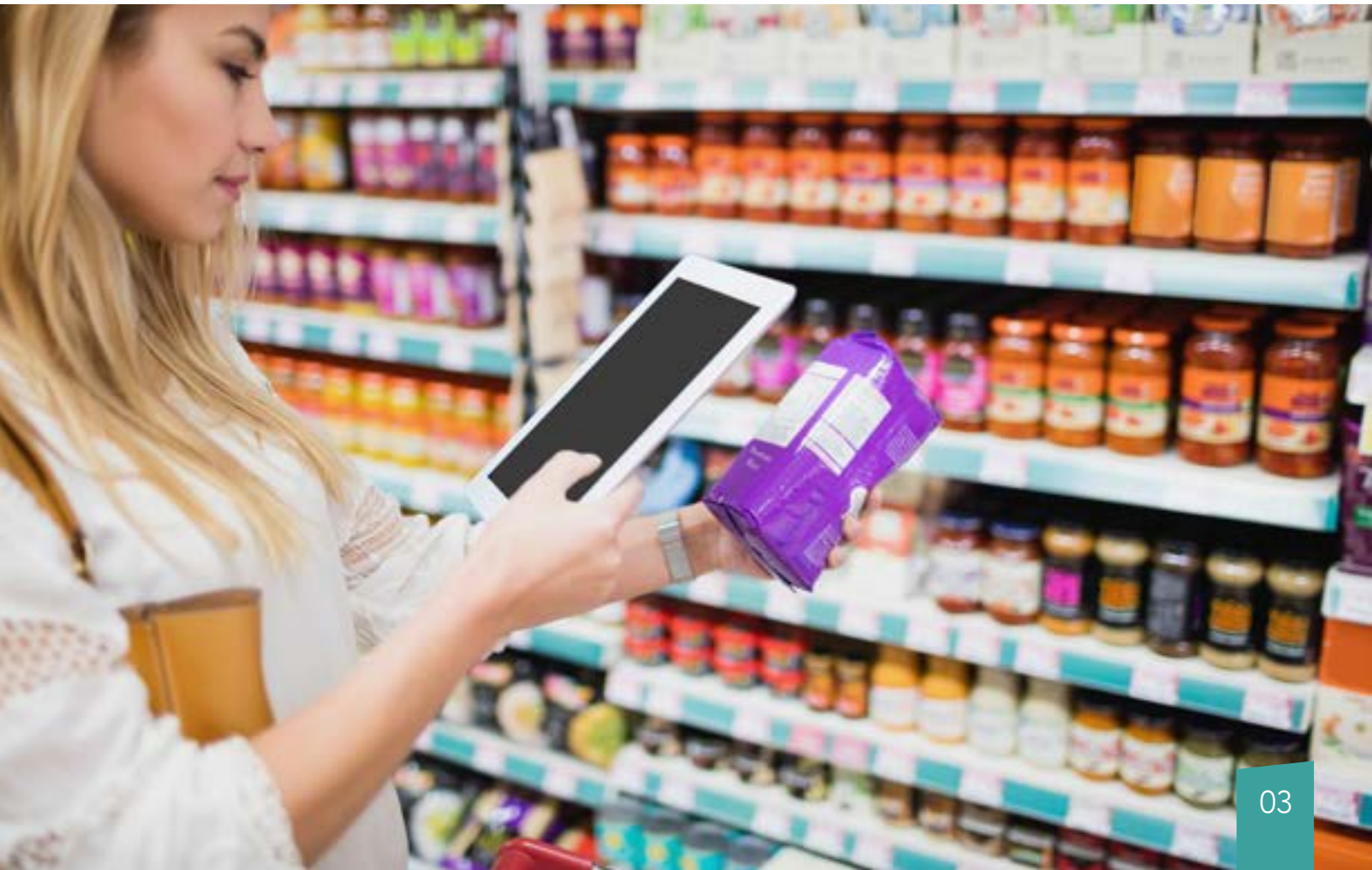
INTRODUCTION

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 health decisions and improve 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 so we can understand how their health care journeys and the health information they receive impact their lived experience.

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.



> "Food pantry quality is not fresh. It's day old and leftovers they couldn't sell."
>
> CAB participant

> "I have been getting cheap meat at the grocery store as long as it is not dangerous."
>
> CAB participant referring to potentially spoiled meat

BACKGROUND

In 2022, almost 13% of American households were considered food insecure (The USDA defined food insecurity as the limited or uncertain availability of nutritionally adequate and safe foods, or limited or uncertain ability to acquire acceptable foods in socially acceptable ways).That's 44.2 million individuals, including 13.4 million children. Not only are people not getting the food they need, but a recent study showed that food-insecure families had 20% greater total health care expenditures than food-secure families.

This Consumer Advisory Board (CAB) engaged with community members about food insecurity. Our goal was to better understand how patients and community members understand and perceive food insecurity and how to best support people with food insecurity through health education content. Healthwise has developed patient-facing materials on this topic and aimed to obtain feedback on these materials.

METHODS

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

The CAB group was made up of six participants. The demographic breakdown of the six participants is shown below.

GENDER:

3 female

2 male

1 male/nonbinary/ transgender

AGES: **(1)** 20-30, **(3)** 30-40, **(1)** 40-50, **(1)** 50 and above

ETHNICITY:

- 2 Black/African American
- 1 White/Caucasian
- 1 American Indian or Alaska Native, White/Caucasian
- 1 Hispanic/Latino
- 1 Native Hawaiian, Pacific Islander, Other, Black/African American, Asian

LOCATION:

- 4 urban
- 2 suburban

HEALTH INSURANCE BREAKDOWN:

4 on Medicaid

1 on Employer-sponsored health insurance

1 does not have health insurance

Prior to 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 through the advisory board meeting, offering perspectives, insights, and feedback throughout. The following notable themes emerged.

General Thoughts About Food

Participants widely recognized that food access affects overall health, energy, and mental health. One person said that it's hard to get through the day without the right food and that not accessing the right foods leads to sickness.

Feedback and Suggestions About Food Insecurity

PERCEPTIONS

The phrase "food insecurity" and the general topic is highly stigmatized, and the reasons for this should be discussed more openly. Participants felt the term food insecurity sounded like a deficiency or an eating disorder and was hurtful, but they were unclear about another term that might be more appropriate. Some had not heard the term before the Savvy invitation. Participants felt society should discuss the social and geographic factors that create and sustain food insecurity. Specifically, society needs to better understand food insecurity, including answers to questions like "Why do food deserts exist?" and "Who created them and why?"

Someone said people are really suffering and food insecurity is disgraceful.

No one expressed difficulty getting to the grocery store. People are resourceful about "stretching" food; strategies include eating less and skipping meals.

Participants said that expanding food pantries doesn't solve the long-term problem because food pantries are too limited and don't address the root cause of food insecurity, which is poverty. Food pantries are primarily great for situational or acute issues.

Participants felt comfortable talking to doctors about food insecurity if they perceive there is no judgment. However, they said doctors overall are not proactively inquiring about food insecurity and that these discussions are most often initiated by social services. Participants suggested healthcare providers should collaborate with politicians and demand support for people with food insecurity. They said healthcare providers should also have resources readily available for patients but believe physicians are often uneducated about associated support services.

One person suggested receiving social services is stigmatizing because these services are "only offered to poor people."

> "Food insecurity is shameful and embarrassing. It sounds like a disease or disorder and gives you a bad feeling."

> "'Food insecurity' is evocative but makes me feel defensive."

> "Society acts like it's a failure in responsibility."

CAB participants

> "Receiving social services is stigmatizing because these services are only offered to poor people."
>
> CAB participant

POLITICIANS AND POLICYMAKERS

The group also felt policymakers have an important role to play in addressing food insecurity. The topic must be destigmatized, and people should refrain from blaming people with food insecurity for their plight. Policymakers should address poverty as the root cause of food insecurity and should also address affordability and access to nutritious food. Some participants felt politicians should talk openly about food insecurity and why food deserts exist because the food access problem must be addressed at that level. Another person mentioned that the cost of food must be addressed.

One participant offered a suggestion to activate resources like 211 and Ombudsman offices for food insecurity. Overall, participants felt more support systems are needed to address food insecurity.

FOOD BANKS AND PANTRIES

There was robust discussion about food banks and pantries because all participants heavily rely on these services. The group believed food banks, pantries, farmers markets, and co-ops should solicit input from the people they serve through things like regular community meetings. Due to the stigma associated with patronizing food pantries, participants believe food pantries should also offer mental health support.

A consistent challenge with food banks is the need to queue for long periods, because of the risk of food running out once they get to the front of the line. A few participants mentioned frustration with beans as one of most common food items.

Some felt food banks do not collaborate or communicate effectively with each other and with the people they serve. The group described significant redundancy in the types of food offered across food organizations. They believe food service organizations could expand their capacity to serve more people if their offerings were better streamlined and coordinated to complement each other.

The group made several observations about food pantries that should be addressed, including the following:

- Food pantries are great at giving food, but there is no standardization.
- A person must learn specifics about each site and what kind of food each site offers.
- Participants like that the food pantries don't require IDs to access services because, if desired, people can maintain anonymity.
- Most food pantries are not well-stocked and don't have enough food to meet demand.
- Some food pantries have expired food.
- The meals are not tailored to medical needs.
- It is rare to find high-quality food.
- The limited food variety is discouraging. A few participants expressed fatigue with rice, pasta, and beans.
- Most fruits and vegetables offered are "at end of their life span."
- Open hours vary across food pantries, making it difficult to track when pantries and food hubs are open.
- It is inconvenient to line up for food. Some people expressed frustration with queuing at the back of the line only to arrive at the front and find all food had been distributed.

STATE AND LOCAL GOVERNMENT

The group noted how local and state governments respond to food insecurity. Some believe cities are not proactive enough in supporting community gardens or offering support for people to learn about and grow their own food. They also believe there's tremendous food waste, and that this issue is not well-addressed. In a pre-interview, participants mentioned food waste because they believe local laws contribute to food waste.

Health Information

PERCEPTIONS

The CAB discussion included questions about interest in and access to health information.

General reactions to health information that participants have received through the healthcare system include:

1. The health information is often too vague and needs to be targeted to the user with information on local resources.
2. Too often, doctors don't admit lack of knowledge about available social resources related to food and nutrition. Consequently, participants turn to Google and online search engines.
3. Some resort to search engines because healthcare providers "refuse" to believe patients or dismiss symptoms.
4. People have trouble finding helpful information at the moment they need it.

SOURCES OF TRUSTED HEALTH INFORMATION

Participant-trusted sources of health information include:

1. **Online communities.**
These can help with practical information doctors may not know, such as personal accounts of people's experiences.

2. **Google searches.**

3. **Pamphlets.**
The pamphlet information needs to "speak" to them and immediately attract their attention. For example, a food insecurity pamphlet should say, "This is what food insecurity is, and if you have food insecurity, here is what you do."

4. **Emergency rooms.**
However, ERs are not always readily available to them.

5. **Healthcare providers.**
The group had mixed views about health information from providers. Some participants shared that their trust in health information from a doctor was contingent upon their trust in the doctor, whether or not the provider made them feel comfortable, and whether they perceived the provider to be judgmental or condescending.

> "It would be great if I could get text messages and emails tailored to what I need rather than generic information."

> "Their language is too medical, too dense."

> "I also would rather them be proactive with sending me info rather than waiting for me to ask."

CAB participants

"You gotta take what you can get."

"I'd like some vegetables and not just big bags of beans."

CAB participant perceptions of food pantries

SOLUTIONS

The group felt that it's important to discuss food insecurity but also felt the word "insecurity" was stigmatizing. Participants offered several ways to address food insecurity:

- Improve food pantry food variety tailored by need.
- Reduce or eliminate food waste.
- Implement policies to outlaw or penalize food waste.
- Adjust food distribution policies to maximize the number of people able to access the benefit.
- Account for net rather than gross income when considering eligibility.
- Enable WIC access beyond women, infants, and children.
- Offer home food delivery from food pantries.
- Shift food pantry hours to improve convenience and expand offerings.
- Increase food variety at food pantries. For example, offer bread, milk, and more vegetables, and swap butter for margarine.
- Offer milk for lactose-intolerant people since "Lactaid is expensive."
- Make policy changes to support income needed for adequate food support and access.
- Increase Facebook and social media support groups and make it easier to find these communities.

OPPORTUNITIES FOR HEALTHCARE ORGANIZATIONS

This feedback from CAB participants can help healthcare organizations more effectively reach patients with health-related social needs while addressing health equity concerns. CAB participants felt some healthcare professionals don't provide adequate health information, and what they do share may not connect them to local resources.

Here are some strategies:

1 Support providers in actively discussing food insecurity and nutrition.
Providers may not understand what roles they can play or what support to offer for addressing social needs like food insecurity. For example, they could include eligibility information for local social benefits. This information is often not readily available to consumers, and providers who share it can build trust and improve social care outcomes.

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 service resources.

3 Provide education content.
Make sure the content uses nonjudgmental language that speaks about food insecurity with compassion. For example, the education could use language like "You may be experiencing economic hardship," which implies the social circumstance may not be the fault of the individual. Make sure clinicians know what health education is available for patients, and encourage them

4 Offer actionable education content.
Ensure the content encourages people to ask for help or offers ways to make the social need conversation more comfortable for both the provider and the consumer.

Healthwise Health Education

Healthwise's health education is shaped by consumer feedback and developed following 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. For example, we've recently added SDoH-focused content sets that specifically cover topics like "Learning About Getting Help With Food," and "Learning About 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 food insecurity, visit our website.

If you're interested in collaborating with Healthwise on health equity initiatives like 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