Knowing It When I See It: Listening to Community Members About What It Means for Systems to Align for Their Health and Well-Being

> " I would like for someone who [has] needs to be able to walk in a mental health center and not have to wait 3 months before they receive adequate services. That's how you know a community is changing, when holistically they are able to get all of their needs met... Everything that I need should be within my community because that's how my community thrives. (Chicago, IL) "

What was the purpose of the community listening sessions?

The goal of this project is to develop a set of stakeholder-driven principles for systems and communities to use measurement as a tool to align decisions, policies, and practices toward equitable health. These actions should reflect and address the needs and priorities of the communities served and the effects of institutional policies and practices that have historically created inequitable outcomes for excluded or marginalized groups.

To that end, we listened to community members to learn more about their experiences with systems and services and understand what is most important to them about what it means for systems to work together toward a common goal. To incorporate their perspectives, we conducted community listening sessions in six diverse communities: Asheville, North Carolina; Boston, Massachusetts; Denver, Colorado; Chicago, Illinois; Jackson, Mississippi; and Wenatchee, Washington.

This summary provides high-level takeaways from the sessions to inform the Delphi process.

Who participated in the community listening sessions?

We wanted to hear from persons who have first-hand experience navigating multiple systems within their community. Initially, we planned to hold six in-person listening sessions with six to eight participants in each session in March 2020. Due to the coronavirus pandemic, we switched to smaller virtual groups and delayed the groups until July and August 2020. Our partner, Community-Campus Partnerships for Health (CCPH), is a nonprofit organization that works to promote health equity and social justice through partnerships between communities and academic institutions. CCPH engaged community partners in

six different communities to host virtual, 1- to 2-hour listening sessions with four to six community members participating in each session by phone or Zoom.

- Chicago, IL (Community Partner: Healthy Washington Heights)

- Jackson, MS (Community Partner: Jackson Medical Mall)

- Wenatchee, WA (Community Partner: CAFÉ)

- Boston, MA (Community Partner: Multicultural AIDS Coalition)

- Asheville, NC (Community Partner: Asheville Buncombe Institute of Parity Achievement)

- Denver, CO (Community Partner: Colorado Black Health Initiative)

Communities were selected to ensure variation in perspectives related to geographic location; geographic setting (urban, rural); and citizenship status (U.S. citizen, immigrant).[1]

What did we hear from community members?

What does *community* mean to you?

Participants' definitions and perceptions of *community* varied across the listening sessions. Participants commonly defined their community in either geographical or social relationships. When defining their community geographically, participants' scope varied greatly from apartment building or neighborhood to the city and county level. Participants also defined *community* based on the social and cultural connections they have with others, particularly in our sessions with two different immigrant community members.

> *My community, well, I see myself straddling communities, actually. I don't know if that's, that's the kind of a response, but I belong to the Nigerian community, the African community and then African-American community. I see myself straddling at least these three communities here in Massachusetts. I think that's, that's the second one. The third one, what does community mean to you? Well, there's a general way I see community. First as a place where I can be human, talking the way I see where I can be, be able to see myself human behavior, functioning as a human being in the community in general, rather than being alone.* (Boston, MA)

> *I live in Washington Heights in Chicago. It is considered urban, African-American community. What I love mostly about my community...we have the ability to organize and come together, to celebrate one another and also supporting one another in different ventures. I would describe my community as predominantly African American. But within that, I live in a community where there's a lot of elders, a lot of retired teachers and public servant workers, so they take a lot of pride in the community. . . . Chicago is a block-by-block type of a city. So no one block is the same, but I've created . . . I think in the space of where I am, it's my little happy place.* (Chicago, IL)

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[1] We did not ask participants their citizenship status. However, we chose two communities because the community partner worked with immigrants and non-citizens, and we wanted to include that perspective in this activity.

When I think about this community, I think about celebration because they're always finding ways to celebrate this community, finding ways to engage one another, to build community and relationships, and I really appreciate that about this community. There are a lot of hard-working seniors in this community that are working tirelessly to make sure that this community keeps its historically Black legacy. So, I appreciate that about this community, and I am privileged to sometimes be able to work along with those seniors and other community partners. What does community mean to me? Community means to me, a place where you can feel safe to just be you, and to be able to support one another in challenging times, and also the ability to be able to freely express whatever gifts and talents that you might have in order to elevate and benefit your community. (Asheville, NC)

Well we have Officer Bob come from district one to our meetings and talk to us and we're asking him specific questions. He gives us the broad [information], all of district one. And I think that encompasses part of the North side as well. And we're like, 'Well, sorry, but we don't really care what's going on over there. We're just concentrating here on [their neighborhood]. . . .' And I sometimes think that makes our leaders uncomfortable, that we're asking them for specific questions. We don't want broad overall. We know the broad overall. We want you to narrow it down and make it specifically about this community and what it is that we can do and the questions that we have. (Denver, CO)

How would you like to see your community improve?

Participants identified many systems and services that they would like to improve in their communities in the short and long term.

Improvements in education were discussed across all listening sessions. Participants from several communities identified their desire to have quality education opportunities available for all community members and noted seeing drastic differences in educational opportunities between their communities and others nearby. Participants from immigrant communities also noted the importance of adult education opportunities including English lessons and reciprocity for foreign degrees.

We know that education is not just for kids but also for parents. Supporting parents with language, some need elementary or high school certifications. We know that when people are educated, it helps them have a voice. It gives them the security they need to share their opinion. Knowing how their community works, knowing their rights, what they can do or not. Even shopping . . . I had a student that once gave a $100 bill and got change for a $20 one back, and they can't defend themselves. We should help the parents with the language so they're not taken advantage of. (Wenatchee, WA)

Another thing that will help that happen mainly is education and having more opportunities for everybody to go to school. I really did like that one, a little free college tuition because that's, they give, everybody had access to education so they can help themselves and help each other and help the community as a whole. (Denver, CO)

Other systems discussed by participants include the following:

- **Economic development:** Participants discussed hoping to have increased job opportunities for community members, jobs that provide a living wage, and more essential businesses (e.g., grocery stores, banks) and more Black- or Latino-owned businesses within their communities.

- **Community development:** Participants noted the need for more and better quality community recreation facilities (e.g., playgrounds, community centers).

- **Public safety:** Participants stated they wanted changes in the manner their communities are policed. Participants in some communities expressed the need for more respect from and a deeper engagement with community police to feel safe in their communities. Participants in another community discussed the need for increased police presence to be proactive with crime in their community.

- **Health care:** Participants expressed a need for more and better quality health care facilities in their communities. Also, community facilities should provide a full range of services that includes preventive and acute/trauma services—similar to wealthier communities.

- **Housing:** Participants in both rural and urban communities noted the importance of affordable housing.

- **Human services:** Participants wanted more coordination among services such as food stamps, housing assistance, and homeless shelters from community-based organizations and social service agencies. Jackson participants further elaborated about their wish for services to be provided in a way that does not penalize individuals for efforts to improve their situation (e.g., reducing aid as income increases). Rather, they expressed a need for services that genuinely provide aid to set individuals up for long-term success and independence.

- **System navigation:** Immigrant community members expressed the need for services that helped their communities learn about and navigate systems in the United States in a way that showed respect for their culture and experiences.

- **Senior services:** Some participants also envisioned more services for seniors that cross all systems, including access to quality health care, affordable housing, and reliable transportation.

> *Look, you have, at this point in time on your Sheriff's Department, you have one officer who is an investigator that actually comes to the African-American neighborhood, gets out of his car and hangs out and gets to know the people that he is actually trying to protect and serve. That is it. Where's your other officers? I'm like, 'He's doing this when he's not on a case. You have officers that are patrolling all day long; why are they not doing the same thing?' So I can tell you that the sheriff we had beforehand, I'm not going to say that he was involved a lot, but he made sure his officers were over here and getting to know the community. And so when the other sheriff that we had, we did have a lot more law enforcement coming over, hanging out in the community, just whatever, but now it's not there.* (Asheville, NC)*

> *In my community, I would like to see us as black people stick together. Not only when something goes bad but during the good times too. . . . I would like the police presence to be present more,*

before the accident happens, be present, be sighted. So we be able to live our life safer. There's already an epidemic where everybody's scared to touch each other, everybody's scared to come around each other, but at least we can be there for each other. (Jackson, MS)

Well I see everybody has a role to play and if you play your role, I think we'll be . . . everybody's role, we can't do the police's job. We can't do the drug side, we can't compete with the office side. The only thing we can do is try to stick together and try to stay together for the sake of our peace and our respect. Because some police officers don't show you respect. Some leaders . . . judge, polices, do not show respect. And how we would know if it gets better, is we just stick together. You just stay in the community; you see it in the community every day. (Jackson, MS)

Here's a hospital in [my community], and it's a relatively new hospital. It's only been there for about 10 years. But over in [more affluent community] is a very established hospital. It's been there for about 100 years. You would think that the newer hospital might be where you'd want to be, but the nurse-to-patient ratio at the hospital at [my community] is so far below what you're going to get out of care when you're over in the nicer suburb. Same thing with the number of services that are available out there. It's the ones that are going to be most profitable that get the dollars in the less affluent community. It's not the ones that are going to actually keep you healthy. (Chicago, IL)

Participants also conveyed a sense of responsibility at the individual or community level to improve their situations. Most communities described the importance of having community members come together to meet their needs. We observed a potential relationship between the level of need experienced by a community and its focus on individual remedies rather than systemic changes. Participants from communities where some people struggle to meet their basic needs focused more on the information needed to attain services to meet those needs. In contrast, participants from other communities where needs are relatively easier to meet were able to identify ways in which systems should be improved to enhance overall community well-being. Participants from immigrant communities further elaborated their desire to pool resources and address the needs of their communities due to both shared culture and the additional need to increase understanding of American systems and norms.

But I know one of the reasons, one of the things that helps with speaking up is we find that most of us as African immigrants, we have so many competing priorities. Most of us came here for economic benefits. And once that is not yet settled, all these other things are not priorities. Like engaging in the civic work and making policies...as long as our priority of economic benefit is not met with, we don't get engaged. But I believe once we're empowered in that area, then it becomes easier for us to speak up and hold our leaders accountable for what they promised to do. (Boston, MA)

Participants in one community also noted the great impact of structural racism on their neighborhoods and wanting improvements to focus on the inequities experienced by community members as a result.

First and foremost, what I would really like to see improve is the level of inequities that we have based on race and ethnicity and the lack of opportunities for people of color in the community. For example, in the community, the neighborhood I live, there's no community center. There are plans to build one in the next 3 to 5 years. They just built a park maybe 3, 3 years ago. So the built environment is lacking. Consequently, it's also a food desert. Consequently, people are

eating unhealthy because first and foremost, they don't have the money, nor do they have the place, to go to buy food. So I'd like to see that we would reduce food deserts. It would improve the built environment, would improve the overall quality of health. And we'd improve the inequities that are happening in the community. And with that improvement, I would like to see us building and creating more opportunities for people to become leaders. (Denver, CO)

How would you know efforts to improve your community's well-being were working?

An overarching sentiment expressed across most communities was that they would know their community had improved when their needs could be met within their neighborhoods. These indicators included being able to work and live comfortably within their neighborhoods with access to quality food, housing, stores, schools, recreation, and support services.

As participants talked about a range of tangible indicators of improvement in their communities, they mentioned the following measures or information sources to assess that change:

- **Education:** School rankings (e.g., Great Schools, *U.S. News & World Report*)

- **Economic development:** Number of jobs in the community, hourly wage, number of businesses within the community, number of Black or Latino-owned businesses, number of essential businesses such as grocery stores and pharmacies within a neighborhood

- **Health care:** Health outcomes and disease prevalence rates (e.g., African-American maternal mortality rate), wait times for accessing services, and number and type of health care facilities

Participants also discussed the need for documenting goals, assessing progress, and monitoring change. Although this documentation may not align with cultural norms in some communities, it is important to sustain the work within U.S.-based systems.

> *I wanted to add on something small. The other thing I would love to see improve is about documentation in the health world. Usually they say if you didn't write it down, then it wasn't done. I kind of see, there is a lot of work that we do in the community as Africans, but it doesn't get documented because it's not in our culture to document stuff. Like in a community kind of setting, you kind of like do things for the well-being of the other people. But the way things work here in the United States, you need to document stuff because that's where the money comes from, that where proposals are put together.* (Boston, MA)

How can community members tell that improvements were experienced by everyone?

When asking how participants would know that improvements in their community were benefiting everyone, some talked about how everyone would have equal access to systems and resources and that there would not be differences across neighborhoods; communities; or racial, ethnic, or cultural groups. These indicators included access to quality education and youth recreational services and increased Black and Latino representation in local government. Many participants also discussed the importance for all community members to be treated with respect, especially related to schools and policing. Within

the two immigrant communities, participants talked about the importance of having systems work for them and valuing their contributions without experiencing racism, prejudice, or stigma.

I was thinking about places like you, like the Café. It's a place for the community. One thing I like about the members of Café, which I think is important, is that they are people who treat us with respect and good manners. But sometimes, when we approach places like [another community organization], or other places, from the moment you look at the receptionist you feel terrified because their attitude is 'oh, you've come for something.' We almost always feel this way and arrive feeling terrified because we think: 'How are they going to treat us?' We arrive asking for things. It is important to have the organizations educate themselves to treat people with respect. We all need to have the confidence to go. I don't speak good English but I do my best. I learned how to say that my English isn't good, but I want to try. I'm scared, but I know it's the only way for my English to get better. These kinds of places seem to help when they feel like it, or when they already know you, or you know someone that knows you. But sometimes when you go to a new place, you're scared. (Wenatchee, WA)

I've received support from WIC, DHHS, food banks. . . . I always see many Whites, but the only difference is that they, since they were born here, have good social security, rights, and it's easy for them. They go to DHHS and suddenly people hear them. You go to DHHS and hear someone speaking loudly, and it's a White person. When you look at the other side, when it's Latinos or African Americans who go, those of us not born here, they make it harder for us because, I feel, they put up a barrier. My parents are Mexican. I'm Mexican but born here. I consider myself Azteca. I have rights and benefits and have been treated well. But suddenly people are putting up barriers. You have to have this trust/confidence to go on your own, remember that you have rights of your own. You have to remind yourself that 'I'm here. I have rights.' People can think what they want. Educate yourself. And know your right to get the benefits you need. (Wenatchee, WA)

When every child can have equal education. Whether you live in a rundown city that has, . . . The revenue isn't enough. We know how important it is that everyone obtain a great education. Not just to move them forward but to move our nation forward. When a child is no longer hungry. All children are hungry, and when they're fed, they can go to school and feel safe. That would be that the job has been done. (Jackson, MS)

However, participants in one community noted the limitations with finite resources and that all communities cannot have the same level of resources or access.

I was going to say the resources are limited, so certain things can't work for everybody. Because certain things, you only have a limited slot to take advantage of certain opportunities . . . very limited. Yeah, because there's only so much funding because there's only so much that can go around to everyone that may need it at that time. (Jackson, MS)

How would you like to be engaged in efforts to improve your community?

Participants identified several ways that systems could engage communities in efforts to improve community well-being. These included the following:

- Establishing community advisory boards

- Formal and informal discussions with elected officials and community leaders

- Paying community members for their input and contributions to initiatives

> *Well, I feel like, there should be a representative from each of these groups, these community groups to take the lead and be able to give us some feedback as a whole, as community, as a whole, to what it is, how they're benefiting from these systems. Are the systems doing what they said they do? Have the systems put in the time and the effort and the commitment that they said they were going to put in? I feel like each of these groups should have a representative to attack that, to be in charge of that.* (Asheville, NC)

Participants also commented on the barriers they face that prevent them from being more engaged in community matters. They spoke about lack of education and understanding around data, long work shifts, working multiple jobs, limited resources, and prioritizing efforts to meet their daily needs as inhibiting their ability to participate in improvement initiatives or using their voices to lift up community concerns. As a result, community initiatives tend to attract the same community members with availability to participate, preventing the sharing of diverse perspectives and inhibiting the ability to identify and address some community needs and preferences. As such, it is important for those who can participate in these discussions and initiatives to bring that information back to the community and serve as a liaison or bridge of sorts.

> *But what happens is that without pay, most people who are making low wages cannot spend that kind of time. Because I've been in a lot of advisory committees over these years, and if they don't pay you and you have to travel somewhere, well now we don't travel, we do Zoom but . . . I had to travel to a lot of these places and spend my time after work or even during the work day, and I wasn't getting paid for it. So it was tough, it was very tough, but I did it, but some people can't do it because they have a family to raise or just don't make enough money on their job to do that.* (Asheville, NC)

> *I think there are many resources and many organizations . . . . But every organization has different active projects. So often organizations don't know what the others are doing, so sometimes, organizations plan events on the same date, or only invite members of one organization and not others. I think it would be good if organizations could communicate with each other. Making connections between all the organizations would be good and improve participation. Also, activities via Zoom are fine but effective participation has to be in person. Also, not everyone has Wi-Fi, and that's necessary for this kind of stuff. Many people don't know how to use the software and figuring it out takes time, taking time away from people's work, from taking care of the home. . . . I love it, but many people that are busy from dusk to dawn don't want to participate. We have to make changes in a way that the community can participate and want those changes.* (Wenatchee, WA)

> *But educating the community about how to understand the stats and where do they come from. What that means. And what that means to you. What is the social determinants of health? We're not educated about all these things. And then they don't want to always read them and not*

saying that we don't want to read, but it's really like comprehension. You have to show people how to understand the information . . . a more comprehensive way. Not saying dumb anything down. It's really to kind of show respect and teach people that this is what this means to us. Make it relevant. Exactly. That's the key. (Denver, CO)

How would you know if you had an equal role in improving your communities?

When asked how community members can engage in the process of improving their communities, participants talked about having opportunities to speak up to leaders, being heard and seeing efforts to address their concerns, having a seat at the table, and setting the agenda or priorities for improvement efforts and discussions. Many participants discussed the desire to receive more information on resources and progress on community improvement initiatives from those in leadership positions outside of election cycles.

When I feel like that they are working with us than talking at us. I feel like there's a difference. I'm just going to say, I know the difference. I share the same police district with [a more affluent neighborhood], which is a . . . very affluent community in Chicago. There is a lot of police officers there. Their meeting . . . is run completely different than our meeting. Actually my state representative, she's over [the more affluent neighborhood], we just sit on the cuffs of the border, so when I attend her meetings, they are completely different than when I go to our town hall meetings. We're basically being talked at, instead of being made to feel a part of the decision making. In [the more affluent neighborhood], they tell them what the agenda is. When their alderman and when their state reps . . . [are] fighting for things, [it] is because their constituents have told them what the priorities are. In my community, my alderman, he does what he wants to do and not what we want him to do. That's how I know I'm a part of something, when I feel like the needs of my community . . . [are] being heard and those changes are being implemented on the city and state level versus them doing what they want to do. (Chicago, IL)

I just wish the leaders would just give us more information on what's going on because there's some things that we don't know. And by improving our community, we just need to know. We just need to know what we need to do from our leaders. Not on what we have needed to do or what she say we need to do, we need to know what our leaders know to help us. (Jackson, MS)

I think that the system is designed to not be equal, and in order for us to have equality in that process, we need to be part of the solution. Many times things are happening that people don't even know are happening, so the process has already been started. So I think in order for us to have an equal role in the process, we have to have a place at the table and not be on the menu. So I think part of that is struggling to be there and to make sure that we are activists and make sure that our voice is being heard. But in my opinion, the system is designed to keep us out of it. We have to force our way in to make sure that we have a role in the process. (Denver, CO)

How would you hold leaders accountable for making progress?

Participants discussed several ways they would like to hold city, system, and community leaders accountable in their effort to improve community well-being. Several participants discussed the need to

hold government and politicians accountable by requiring them to have well-defined goals and having opportunities to ask leaders questions about priorities and progress.

> *But I also [want] to add, the starting point for accountability, I think also should be setting specific well-defined goals. Because if we don't have well-defined goals for the leaders, when they are taking specific roles, specific offices, it will be difficult for us to be able to hold them accountable. Because coming from Nigeria, we've dealt with all kinds of leaders of course, across Africa. [If] we don't have well-defined goals, how we want to handle a case like this, then it's easy for any leader to come at any point and make whatever decisions based on personal interests, political positions, or whatever. So I think within our communities, we need to have clearly defined goals for our leaders. So that from period to period, we can hold them accountable, using those defined goals to be able to question them. And I think that's, the starting point that we need to look at.* (Boston, MA)

Participants also wanted to see progress reports from community leaders and systems to document issues in the community, priorities for improvement, and their progress toward goals. In addition, participants discussed communities' power to hold systems accountable because they are funded with tax dolla*rs intended to serve them.*

> *I think that having some of the community-based organizations who are looking at these things, these social determinants of health. Kind of providing them with a report. Stats. Just how effective. I never been good on stats, but I do think it's helpful because that's really what informs funding and all that. . . . I received a report out the other day from this health department's priority task force for their priority engagement. I don't know if you guys got that, but it was so many stats. But then I was frustrated and they were showing you where all the pieces and everything and the different areas, like high rates of gonorrhea, chlamydia, and all that. But they didn't show you where they were really sending support in those areas. So I think those kinds of reports are important, but it's frustrating to look at with these priority documents when they gather all the data and then they just don't show you how they're really . . . not doing anything about it. Like you have high rates of STIs, gonorrhea, and chlamydia in the certain area, but then your reports not showing us what you're doing about it.* (Denver, CO)

> *And no matter where you are, you're going to have to search hard to find specific things that are going to be right for you, for your parent, for your child, for your community. The systems that we pay for, right? So none of this is something that they're doing out of the goodness of their heart. We pay for public health. We pay for public services. We pay for the health care systems that are in our area, and we need to be able to tell them, 'This is what we need,' and demand it because if you don't give it to us, we have a way to shut you down. We have a way to walk away from you. We have a way to organize and make you give it to us. If you want to keep your nonprofit status, if you want to keep your office, if you want to keep . . . I could go on and on.* (Chicago, IL)

What are the takeaways for using measurement that aligns systems toward equitable outcomes?

These initial takeaways highlight the need to center community voices in ways that give community members power in the process, engage them in a non-burdensome manner, and provide opportunities for them to monitor progress and hold leaders accountable.

- **Initiatives start with communities.** Determining priorities, goals, and measures of success for cross-system alignment initiatives must start with community members' own vision for improvements and how systems can work together to best meet their needs and priorities. Community members can be engaged in the process of creating and selecting measures—particularly outcome measures—that are tangible and resonate with people's lived experiences in their community. Community members need to be involved at the onset of planning (or as early as possible for existing initiatives) in the measure selection or development phases to identify metrics that really showcase meaningful change for them.

- **Engage communities where they are.** Community members vary greatly in what they would like to see improved and the barriers they face in being able to engage in improvement efforts. Creating opportunities for community members to engage in improvement initiatives in ways that do not add burden requires careful planning, especially for members struggling to meet their daily needs. Cross-system initiatives should explore what type of infrastructure and capacity-building efforts would be needed to bridge the gap in power dynamics between community members and the systems within their communities today, as well as a vision for re-centering those systems around community members' needs and priorities.

- **Scale is important.** Community members have different views on how they define their communities regarding geographic area and social connections. Communities may also span the spectrum of meeting basic needs, which can impact their ability to think about system changes needed for long-term, sustainable change. Considerations must be made to the scale of measurement and should match the level at which change matters most to community residents in both the short and long term. Incorporating immediate and short-term improvements may help facilitate long-term community engagement, positive relationships with community members, and sustainable change.

- **Include diverse community perspectives.** Communities are not monolithic, and participants showed that there is a huge range in perspectives within communities. Although leaders may come from the community, they do not represent all of a community's views. Initiatives using shared measurement should seek to engage multiple community perspectives to better incorporate the diverse needs, views, and experiences of people within a community

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Suggested Citation

Cowans, T., Firminger, K., & DePatie, H. (2021). *Knowing It When I See It: Listening to Community Members About What It Means for Systems to Align for Their Health and Well-Being.* (Prepared for the Robert Wood Johnson Foundation). Crystal City, VA: American Institutes for Research. Available at: www.air.org/sharedmeasurement

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