



In Their Words: Consumers' Vision for a Person-Centered Primary Care System

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COMMUNITY CATALYST

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CENTER FOR CONSUMER ENGAGEMENT
in health innovation

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Executive Summary

The Center for Consumer Engagement in Health Innovation commissioned these focus groups to understand consumer experience with and attitudes about primary care, and the intersection between the primary care relationship and social determinants of health. This work focuses on marginalized consumers of health care, including people who are low-income, who have disabilities, who come from communities of color, whose primary language is not English, who are elderly, and/or who have complex health needs.

These focus groups, conducted in August and September 2019 among nine distinct consumer segments spread across four states, identified a population that generally does not feel well-served by the health care system they encounter today. These consumers are dealing with a variety of significant challenges that in their estimation are having a direct impact on their health, while also impacting their ability to access needed health care and social services. These challenges are often defined by severe financial stress, and include lack of reliable transportation, food insecurity and lack of access to healthy food, and housing insecurity. People also described substance use and difficult mental health and emotional challenges, including loneliness among elderly participants and stories of family separation and estrangement.

The consumers we interviewed see a health care system that is financially driven, leading to short and impersonal primary care visits. They are cynical about a system that they feel is designed to churn them through as quickly as possible and move on to the next patient.

Most focus group participants could identify a primary care provider, but very few felt they had a provider who knew and understood them. Fewer still had a provider who engaged them in a broader discussion about external factors that helped determine how healthy they were, though nearly all of these consumers would welcome that broader discussion.

Asked to imagine a health care system that would do a better job of helping them live their healthiest, best lives, these consumers rose to the occasion, offering a variety of suggestions that we have synthesized into five thematic aspirations:

1. Consumers want a long-term relationship with their primary care provider, someone who will listen patiently and get to know them.
2. Given the complexity of the health care and social service systems, as well as the complexity of their own need, consumers value the idea of a coordinator or navigator who can help them manage their care and is willing to advocate for them when needed.
3. Consumers welcome a broader conversation with their primary care provider, not just focused on their medical treatment, but exploring the needs of the whole person.
4. Consumers resonated with the concept of a “one-stop shop” where they could receive a wide variety of services under one roof, including medical services, mental health treatment and counseling, and social services.
5. They hope for a provider who is culturally sensitive, able to relate to the consumer’s own life experience and struggle, and who uses language consumers can understand.

This research answers many questions about consumer needs, anxieties and expectations. Fruitfully, this work also raises many questions that policymakers and experts must consider in developing a more accessible system that consumers desire.

Project Objectives and Methodology

The Center for Consumer Engagement in Health Innovation commissioned focus groups to understand consumer experience with and attitudes about primary care, and the intersection between the primary care relationship and social determinants of health. This work focuses on consumers who are often marginalized: people who are low-income, who have disabilities, who come from communities of color, whose primary language is not English, who are elderly, and/or who have complex health needs.

We sought to create a trusting environment in the focus groups where these consumers could tell their stories, expressing both their anxieties and frustrations, as well as their hopes and aspirations for the primary care relationship and the broader health care system. Ultimately, we wanted to understand what kind of a system they believed would serve them better, helping address not just their immediate medical situation, but the underlying social and economic factors that affect their health.

This was accomplished through a battery of nine consumer focus groups, conducted in four states across the country during August and September 2019. Each focus group was a roundtable discussion lasting two hours and facilitated by one of two professional moderators whose own background and life experience allowed participants to relate well to her and to each other. Between five and nine consumers participated in each group, a comfortable size for free-flowing discussion. The goal was to create a cohesive group so that when participants speak, others relate to their experience and a positive energy develops which allows participants to get beneath barriers and inhibitions, encourages them to feel safe offering their deepest perceptions, exposes their honest fears and anxieties, and allows them to imagine a health care system that would serve their needs.

The nine segments were:

- Urban low-income, African-American (Atlanta, Georgia)
- Latinx, Spanish-dominant (Atlanta, Georgia)
- Rural low-income, white (Dawsonville, Georgia)
- Working low-income and homeless, Multiple races/ethnicities (Denver, Colorado)
- Elderly and chronically ill (Denver, Colorado)
- Rural low-income, white (Washington, Pennsylvania)
- Elderly and chronically ill (Washington, Pennsylvania)
- Working low-income and homeless, Multiple races/ethnicities (Fresno, California)
- Latinx, Spanish-dominant (Fresno, California)

A total of 58 people participated across these nine groups, ranging in age from 22 to 91 years old. Ten participants identified as African-American, 32 as white and 16 as Latinx. Forty of the participants were women and 18 were men. Two of the focus groups were conducted in Spanish.

Participants were recruited from the general population in each of these communities in response to digital and print ads, posters and handbills, and word-of-mouth networking through community-based organizations. They were screened by telephone to ensure that they met the demographic and socio-economic parameters for each group, were not employed or volunteering in the health care field and had at least some experience with health care delivery as a patient or caregiver. Each person who participated in a focus group received a financial stipend in recognition of their time and the effort to attend.

This report summarizes the key findings of this consumer research. Our focus was on finding the solutions these consumers support, which are summarized below and contextualized in their experience and perceptions of the health care system as it exists for them today.

Detailed Observations

Context for This Research: Consumers' Life Experience

Across these nine distinct consumer segments, we encountered people who are often dealing with significant and sometimes overwhelming health and social challenges. In particular, we explored with participants how the social determinants of health—the conditions in which they live and work—affect their health risks and outcomes.

First among these for most of the people we interviewed was poverty and financial stress, which translated into a variety of other challenges for them:

- Lack of reliable transportation for some participants, including the dramatic case of a rural mom whose car had been repossessed and was walking great distances with her child to reach appointments and access services, due to the lack of a public transit system.
- Food insecurity and poor nutrition, epitomized by one participant who said he used to look down on fast food but now was simply grateful when he had two dollars to buy a fast food hamburger.
- Housing insecurity, including many participants who live in substandard housing, or have no housing at all, or who are sleeping on couches thanks to the generosity of relatives and friends.

“Most of us walk because you don’t have bus fare. So, you walk where you can, and in the position I’m in, it sucks. But you got to get to where you need to go, you got to get to your appointments, and you got to keep things going forward. But, at the same time it really sucks. And by nighttime, you can’t even stand up.” – Denver participant

“So I mean, you go to the grocery store and yeah, you’d like to buy the fresh fruits and vegetables and good quality cuts of meat and stuff. You just can’t do it. By the time you paid your bills and like I said, by the time I paid for my doctors and my medicine that, you know, I’m pretty much done. I’m done. And like I said, so it’s like, what does McDonald’s or Burger King have on sale this week? That’s what I’m living on. You know because you can’t afford to go to a grocery store. I can’t remember the last time I walked into the grocery store and bought a big cut of steak or even chicken breasts. I can’t remember the last time. You just do what you got to do to.” – Pennsylvania participant

These financial difficulties were palpable for many of our focus group participants and defined so many of their daily habits and decisions which they knew affect their health. Financial difficulties also limited participants’ access to health care services. Repeatedly in the focus groups, consumers told stories about deferring needed care because they knew they could not afford treatment or medications that would be prescribed. They described avoiding medical visits because they are afraid of what they will hear, not knowing how they would ever come up with the money needed to pay for their care.

*“Being able to go see my doctors like I need to without worrying about money.”
– Atlanta participant describing what is keeping her from living her “healthiest, best life”*

We also heard heartbreaking stories about surprise medical bills, which in the most extreme case amounted to tens of thousands of dollars, nearly bankrupting a Latino small business owner. Some low-income focus group participants, who would possibly qualify for Medicaid and other forms of public assistance, indicated they did not know what they qualified for or how to successfully apply, and were avoiding care that might be free or in fact very low cost for them.

“So then as a result of that, this took place a number of years ago. So all the bills began to pile up. So we were doing well, but then our life became really troublesome. All kinds of savings went away, so it was very critical situation.” – Atlanta participant

Throughout the focus groups, participants frequently expressed cynicism about the financial incentives within the healthcare system.

“The primary problem is that it (healthcare) is a business.” – Fresno participant

“So then they go overboard, so they then want to do checkups, exams because they want to extract as much as they can or suck as much as they can out of the government. So at the beginning of the year they do all kinds of physical examinations.” – Atlanta participant

“Sometimes when you calculate all these costs, you are better off not having coverage. So for the appendicitis I got the bill. I started checking it, you know, just itemized. \$42,000. \$8,500 for a 15-minute stay at the ER. So what did they do? They took my vitals, they put an IV on me and they prepped me, and then for those 15 minutes they charged \$8,500. The rest of it, whatever they did. In the operating room, supplies. They gave me medication for pain, \$1,800. I mean...this is a business. Health is a business, you know?” – Atlanta participant

A second common challenge among the people we interviewed were difficult family issues. People were struggling with separation and alienation from family members including children and grandchildren, ex-spouses and partners. These separations often caused significant distress that participants openly expressed, while saying that the system that exists for them today does not give them adequate access to the counseling and other family services that they feel they need.

“I would feel more comfortable finding a good church and having them help me rather than a doctor... There would be confidentiality.” – Dawsonville participant

Beyond the people who have already experienced that sort of separation and loss are many others who live in fear of losing their children due to housing insecurity and other forms of instability, substance use, or other challenges. Often, parents in this situation feel estranged from social service or medical providers who they fear may remove their children from them.

Third, we heard widespread concern about mental health. Participants sometimes discussed their own or loved ones’ challenges with difficult mental health diagnoses. Many others, particularly elderly and pre-elderly participants, talked of extreme loneliness, as well as anxiety about losing their capabilities.

“When you get older you get lonelier and everybody around you is dying...and that works on you, that stress (works) on you.” – Pennsylvania participant

Hope for a Better System

Though the challenges and barriers can be overwhelming, consumers we spoke with want to – and often do – engage with primary care providers. Most can imagine a system that serves them much better than it does today and they have ideas for what would make the system work better for them.

Almost across-the-board, the consumers we interviewed want to have a relationship with a primary care provider. They understand the value and are generally willing to invest time and effort to build that relationship. But they experience a medical system today that presents structural barriers. These consumers vividly described providers who are too rushed to listen to them, who talk down to them or are not culturally sensitive, or who do not speak their language.

“They’re so busy, they don’t have the time to actually check you out. Right? Let alone to talk to you about food and your house and everything else. They’re lucky if you can get down to what you’re in there for.”
– Pennsylvania participant

“They got to get you in and get you out and get that next one in there because it’s all about the money. I don’t think doctors are like they used to be back in the day. They really don’t care about their patients.”
– Dawsonville participant

“So we’re looking at a health system as more like a factory type of a thing. So as like a conveyor belt where they are milking the cows.”
– Atlanta participants discussing their experience with the health care system

These consumers understand the impact of social determinants on their health. It does not need to be explained. No one needs to tell them that they are less healthy because they are in poverty, or do not have transportation to get to medical appointments, or do not have ready or consistent access to healthy food, or live in housing that is unhealthy and/or unstable. This translates into a desire to have a more holistic system that addresses all of their needs via a primary care relationship that provides a gateway to the help and resources that enable them to live a better life.

“I think it can be a never-ending cycle for people sometimes where...if we don’t get to the root cause of what’s really going on, then things just keep happening and sometimes it keeps getting worse and worse.”
– Dawsonville participant

“And you can kind of tell through somebody’s life, what health effects they’re actually going to have or not because they’re at a greater risk for suicide, heart disease, diabetes, you know, hepatitis, all these different things. So I guess for myself, because I’m thinking constantly, you know, what’s the link between my everyday worry and my health?” – Denver participant

While these consumers are largely disappointed by the system that exists today, and even cynical about it ever effectively serving them, nonetheless we found that most of them were able to imagine a better system and wholeheartedly wanted to see that better system come into existence.

A distinct minority of focus group participants felt well-served by a primary care provider or advocate today and their testimony was extremely compelling to others in the group. These experiences attest to positive existing mechanisms that provide consumers who have complex health and social needs with the support they need and desire.

Following is a summary of the aspirations and solutions that consumers offered, organized thematically. We see these solutions breaking down into five major themes or aspirations.

Consumers' Aspirations and Solutions for a Better Health Care System



Aspiration #1: An Enduring and Mutually Respectful Relationship with the Primary Care Provider



Aspiration #2: Access to a Navigator



Aspiration #3: Welcoming the Broader Conversation



Aspiration #4: A Holistic, One-Stop Shop



Aspiration #5: Cultural Sensitivity and the Ability to Relate to One's Life Experience



Aspiration #1: An Enduring and Mutually Respectful Relationship with the Primary Care Provider

Consumers want a broader, deeper conversation with their primary care provider undertaken with patience and empathy. They want to get to know their provider personally, and to have the provider know and respect them as a whole person. They imagine this as an enduring, trusting and mutually respectful relationship.

"I can't go having to re-find everything. I had a really amazing relationship with my gynecologist, but she's seven hours away now. So now I got to try to build that with somebody else who hasn't known me since I was 14 so it's a different situation for me now. Now, I don't even really want to go (to the gynecologist) just because I already did all that in North Carolina, I built the relationships, I found the people. ...I used to sit in her office. I didn't even sit in the, we didn't even do the doctor room thing with the paper bed. We sat in the office. So, it's just having to find all that again for me...I don't need the bother."
– Atlanta participant

"Those TV shows like Mayberry and whatever Doc. ...What makes them so endearing to their patients? It's personalism. ...They know you, you're not a number." – Fresno participant

“Being like how she was saying, more up front, straight forward, don’t bullshit. Take the time to listen to the patient, to know exactly what they’re going through. And, then not only that, but to make sure to explain to the patients, show the patient that you’re caring, and the information about what their problem is, and show them that you’re doing something about it. You know what I mean? Basically, I mean just showing the true interest and taking care of what the problem really is.” – Fresno participant

“More empathy from doctors and nurses. They need to take like some type of empathy class to say, okay, even though this is your job, these are patients, they need more than just you telling them what’s wrong with them and everything else. You need to actually act like you care. But it’s wild that retail, a place like Walmart might have that kind of training, but they’re not saving lives. But a doctor’s office wouldn’t have that same kind of training. That’s what makes it backwards to me. It’s not that people at Walmart don’t need it, but they might not even interact with the person, they’re stocking shelves and they’re sitting through an hour-long how to talk to people. But your doctor needs to be able to tell you with, you need to walk out with your dignity. You need to walk out the office with your dignity but you can’t in a lot of places. They’re the ones that need to be sitting in these trainings.” – Atlanta participant

If there was an overriding barrier to satisfactory care that was expressed in every focus group, it is the lack of time and attention that primary care providers give to consumers. These consumers’ experience is a health care system that is on the clock, churning patients through rapidly, conducting triage to address immediate medical needs. Focus group participants almost universally held the perception that the health care system is, at its root, financially driven. Patients represent revenue to health care providers, and quotas must be met. In the perception of these consumers, powerful economic forces prevent their providers from spending the time with them that consumers feel they need.

“(Doctors) are so busy and have so many patients. I’m not sure exactly if they’re going to take the time to ask you all those questions. And I see that more and more, as I get older. I mean, I see my appointments getting shorter, less questions, unless I had a real serious problem. They don’t take the time to do it.” – Denver participant

“I used to have a doctor that...asked me questions and he was looking at his computer the whole time. Never even looked at me straight in the eye. Asked me these questions, but they were all medical questions. Nothing about my welfare, or my life or how thing’s going. It was just medical questions and we changed doctors because of that. ... I mean, he was a good doctor to begin with, but as his practice grew, (he had) less time with the patients. And my husband’s a diabetic, so every time something went wrong, my goodness, not really thinking about things, he would just give him another medication. He was up to 12 medications a day.” – Denver participant

“The ideal plan between diagnosis and the treatment plan, is to explain to the patient that they have options. ...(But) two hours waiting for a doctor and the doctor spends three minutes with you. So they don’t take time to explain to you the diagnosis. This is just like a production deal, I mean.” – Atlanta participant

Furthermore, many of the low-income and marginalized consumers that we interviewed often see a different primary care provider each time they visit, preventing familiarity with them or their medical situation.

As a point of clarity, many focus group participants indicated they are not concerned about the specific medical credential of their primary care provider. They were not hung up on the idea that their PCP must be a physician, or a nurse practitioner for that matter. Of course, ultimately consumers said they want to be seen by highly skilled medical providers when that is needed, but at their point of entry into the process they are much more concerned to encounter someone who has the time to talk with them, who can listen.

"I want to go sit down and talk to you face to face. I'm going to feel better when I'm talking to you."
– Pennsylvania participant

What these consumers are imagining as an alternative represents a dramatic restructuring of health care delivery, at least at consumers' point of entry.



Aspiration #2: Access to a Navigator

In focus group discussions, consumers were often overwhelmed by their challenges. They expressed confusion about the complexity of the health care system and their inability to navigate it without some help. Often, they exhibited a lack of knowledge about the services that are available to them today, which was made clear when peers within the focus group informed them in the moment about programs and services for which they might qualify.

"I don't feel supported. I feel like it's me. I feel like I have some people who are rooting for me, but not supporting me. Yeah. I feel like it's only me (who) is going to make it or break it." – Denver participant

"Nobody really cares. Who do you turn to for help? Who do you go to?" – Pennsylvania participant

Occasionally in focus groups an idea emerges that participants had not considered before, and once discussed has a transformative impact on them. A compelling example from this project is the idea of a navigator or a coordinator who can get to know the consumer and connect them with the services they need – whether medical or social – and who will advocate for them throughout the process so they are sure to get the help they need. On two specific occasions in these focus groups, individual participants spoke passionately about a relationship they had with someone who played this role for them. A Denver participant was so emphatic about the positive impact of this navigator on her situation that she said she carries cards for the non-profit wherever she goes, and she passed them out to other participants and buttonholed several on the way out the door after the group.

"I'll get mail from Colorado First or whatever Medicaid is. I'll get mail. I don't even open it. Because if I do and I try and read it, all I'm going to see is mumbo jumbo mumbo jumbo mumbo jumbo. (If I) ...take it to my health care navigator, she'll glance at it and say, 'Oh, this is what it is. You need to do this.'"
– Denver participant

"It would embrace me. I would feel...a comfort factor knowing that somebody cares about me... Yeah, I would feel absolutely embraced." – Denver participant

The reaction of others when they heard about this was striking. All at once, this single solution addresses many of their concerns: lack of knowledge about what is available to them, lack of understanding by a primary care provider of their true needs, inability to gain access to specialized providers or failure to qualify for critical social services, etc. As much as any other idea discussed in these focus groups, the prospect of a knowledgeable, assertive, empathetic navigator was exciting to participants.



Aspiration #3: Welcoming the Broader Conversation

Consumers had many interesting and compelling ideas to improve the way the health care system meets their needs and addresses the social determinants of their health. But in the end, would consumers welcome a conversation with their primary medical care provider about topics other than strictly their health?

Yes, is the answer. A primary care provider should ask questions about their life and their challenges, nearly all of these consumers said. As long as the provider's motivations are clear, and she or he communicates patiently and exhibits understanding of consumer's life experience, consumers want to be part of such a relationship. That relationship is a key, they felt, to a system that better meets their needs and helps them live a healthier, better life.

"I'd be shocked."

"I'd be dumbfounded."

"I would like it."

– Pennsylvania participants reacting to the idea that their primary care provider might ask them non-medical questions about the other challenges they are facing

One participant described a positive experience after a surgery, in which the team caring for her did address her social needs.

"Part of the program is (you) come home, somebody is there within a day or two to assess how well I can handle how I'm living. Do I have adequate food, this thing, that? Am I able to make it around my apartment with this surgery? So I, for my particular situation, they were directly involved in making sure that I was covered...In essence, I felt embraced." – Denver participant

While welcoming this broader conversation with the primary care provider, some consumers said that providers sometimes ask questions that make them uncomfortable, causing them to question the provider's motivations and suspect a hidden agenda. The issue of trust was an important one for many participants, and establishing trust is critical to enabling this broader conversation.

"I was locked up for 11 years. So I've learned not to trust people. I don't trust people. Why are you asking me this question? I mean, do they matter to you, or you just trying to gather information. If you just try to gather information, tell me, you need to gather information, and I'll tell you what you need to know. But if you generally care, then I would open up to you.

"If you genuinely care about me as a person, then yeah, I don't mind telling you things. But if I just met you, or if I just come to you once a month or once every couple of months, then what do I need to tell you all this for. I'd say what goes on, what symptoms I have what, you know, what goes on in my head, but don't ask me questions, if you don't even care. I mean, that's how I feel." – Denver participant

"I got a new (doctor)...my other doctor had to retire because of health reasons. And I don't know, it's hard to explain. I was just there last week and he's asking me if I saw any good movies, and I just feel he's not really interested in my health care." – Pennsylvania participant

"Find me somebody that I could trust."

"How do they gain your trust?"

"Not being judgmental."

– Fresno participants

“That’s why I don’t trust. I’m starting new with a new psychiatrist, a new primary care, and this orthopedic surgeon, they’re all brand new to me. So we’re learning to trust. And we’re in the learning process of whether I can trust them or not.”

“For some reason I connected with the orthopedic surgeon. And I trust him because he sat with me for almost two hours when I met him and talked to me about everything. And we went through everything so nothing would go wrong. ...And he was the one that I’ve never had one ask me, what about my housing, ...what about this or what about that. He sat with me and talked to me and I do trust him.”

– Denver participant

One specific example, mentioned in multiple groups, is the question, “Are there any guns in your house?,” which some consumers felt strongly conveyed an unwelcome political agenda. Consumers want their primary care providers to explain their reasons for asking questions like these.

“One time I was asked by a doctor if I had guns in the house, and now don’t ask me what the relevance of that was.” – Denver participant



Aspiration #4: A Holistic, One-Stop Shop

Consumers in nearly every focus groups gravitated towards one practical and overarching solution to many of their concerns. The concept is a medical facility that is co-located with the social services they need and organized with a single point of intake to help direct people where they need to go.

Often, regardless of their political orientation or cultural background, consumers in these focus groups expressed a reluctance to accept social services. If they did accept help, many of them expressed a desire to move quickly beyond what some of them saw as a handout. But this concept of a “one-stop shop,” as some called it, where their needs could be addressed holistically, alleviated those concerns. In the rural Georgia group, which was probably the most politically conservative and self-sufficiency-oriented of the nine, participants dubbed this concept the “Resource Center.” They embraced the idea of unifying medical and social services under one roof, with the goal of ensuring that people get all the help they need and no one falls through the cracks.

“I think there’s one place that they should have multiple counselors. And you’d be assigned to a particular counselor. Because if there’s different issues, you can say you have different departments. Mental, financial, whatever, they’re not going to hit you one time, you’re going in there for one thing specific. But if you go to a particular counselor, that every time you have something they may be able to help you with, you can talk to that one person and create that bond...” – Dawsonville participant

“It would be heaven. It would be because it’d be a one-stop shop. You go to your primary care (provider), you tell him what you need and he sees what you need by asking you the correct questions...And, it helps you, it makes you more at peace with yourself, more sound of mind because you don’t have to worry about it now and...you’re going to be healthier. ... a lot of what is making you ill or keeping you ill or making you worse is lifted off your shoulders.” – Denver Participant

In particular, many participants mentioned the importance of mental health care, family counseling and related services as a component of holistic medical care. They said that a mental health assessment needs to be part of every basic medical health checkup. These consumers urged that mental health services should be an essential part of this holistic, one-stop shop.

“When you’re talking about a PCP, they should let you have one for health and one for mental health...and then you could go see that (mental health) doctor and instead of maybe seeing them once every eight weeks, be able to see that doctor maybe a little more frequently to keep you a little better on track.”
– Pennsylvania participant

“This just came to (my) thoughts. When you go see your primary care or doctor for the first time, maybe the visit could include some type of mental health visit from a doctor, whether the doctor sits in with the primary care on a visit or if he talks to you maybe 10 minutes before your visit because...there’s a lot of mental illness. ...I have a family member that’s suffered bipolar and schizophrenia for a long time. And basically one out of four people have some form of mental illness, well that’s what the stats say. So I think if you could, do some type of mental health screening because a lot of times they intertwined with one another the mental and the physical. Just knock them out at the same time.” – Atlanta participant

“My psychiatrist does (ask me questions), but my primary care doctor doesn’t. He just spends like 15 minutes with me just like my psychiatrist, but she does ask me about what’s going on my life during that time. Not just medicine, but within the 15 minutes, she just ask me, “Is life good? How’s your relationship with your roommate? What’s going on there?” ... But my primary care doctor, he spends about 15 minutes with me too, but he doesn’t ask about anything other than my illnesses.” – Dawsonville participant

Beyond a sweeping idea of value, this one-stop shop concept also addressed a very practical concern for some participants: transportation. For a population that is accustomed to being shuffled to appointments across a large city or in a different small town, the prospect of meeting multiple needs in one facility was a welcome idea.



Aspiration #5: Cultural Sensitivity and the Ability to Relate to One’s Life Experience

In a variety of ways, consumers expressed a desire to relate to a primary care provider who understood their life experience and outlook, and could communicate with them effectively. This had several specific manifestations:

- Female focus group participants often said they were more comfortable relating to a female provider. This was sometimes related to discussion of sensitive health and reproductive matters that affect only women, but there was also a theme of communication style. Many women in these focus groups expressed the idea that they sometimes feel talked down to by male practitioners. They also expressed concern about what they see as male practitioners’ impatience with having to explain things, their arrogance, or poor listening skills that some female consumers relate to the practitioner’s gender. They simply feel that dialogue would be more fruitful and comfortable if they are talking with a woman.

“...But (now), I have a very good primary care physician who is a female, who I feel and my husband feel we can relate to a lot better because she asks a lot of questions and she takes the time with us. We don’t feel rushed.” – Denver participant

- Naturally, language and cultural affinity was a concern for some in the Latinx population interviewed. Spanish-dominant participants with more limited English proficiency expressed an almost self-evident concern that a language barrier was often hampering their communication with a primary care provider. But even among more strongly bilingual consumers, there was interest in seeing providers who understood and appreciated their cultural background.

“So to be given information hopefully, of course, in your own language, in Spanish. We speak English, you know, some, but sometimes medical terms are difficult... So because of that, one tends to look at the Hispanic doctors so that you have that conversation in Spanish, but it’s difficult. ...It’s just that they might be a lot further away from us. Or maybe we take an interpreter with us.” – Atlanta participant

- The lowest-income focus group participants, particularly those who suffered from homelessness or substance use disorder, earnestly wanted providers who understood their life experience. They felt their situation requires someone who has walked in their shoes and felt their struggle – if not literally, at least exhibiting a deep understanding and empathy for the challenges of their situation.

Moderator: *“What else do you want?”*

“Somebody that knows about financial, and that has been through financial problems in their life.”
– Dawsonville participant

Regardless of their background and orientation, consumers were saying one thing in common: that they want a primary care provider they feel they can relate to. They want clear communication, empathy for their situation and a clear understanding of the provider’s motivations.

In some cases, the solution they are seeking simply involves better communication. In other cases, what they are asking for is a better match with their provider – a priority which is clearly understandable given that consumers want this primary care relationship to be long-lasting, and a gateway to the care and resources they need.

Limitations of This Research and Recommended Next Steps

The qualitative method, as demonstrated by this work, relies on a small sample size. In this case, 58 consumers gathered in nine focus groups spread across four states have made a range of observations that are described in this report. This methodology excels at exploring ideas deeply within cohesive segments of the overall consumer population. It explores perceptions and reveals emotional responses, lifting up both the anxieties and the hopes that motivate consumers. What are discussed in this memorandum are consumer observations that were strongly felt and that were consistent across consumer segments, giving them validity. This method does not allow us to fully explore differences between consumer segments, and it would be important for future research to understand differences in the experiences of the different demographic groups represented, in rural versus urban areas, and in areas that have very different healthcare policies and markets.

Future research could test the ideas embodied in this report quantitatively, through a representative consumer survey, to understand how widespread and intensely felt these observations are in the broader public.

This work also raises the question of how we get from where we are today to the more integrated system that consumers want and need. Additional qualitative conversation with consumers, in the form of focus groups or in-depth small-group interviews, will be needed along the way to test what specific innovations might be needed as we move along the path towards these consumer aspirations.

The ideas expressed in this report are sweeping and transformative. The consumers we interviewed imagined a new health care system, characterized by an accessible, familiar relationship with a primary care provider who is concerned about the whole person and is mindful of the social determinants of health. They want ready access to mental health care and counseling, connections to social supports in the same conversation that addresses consumers' medical needs and a health care system that is overall less rushed and less financially motivated.

Marginalized consumers, facing many barriers and often complex needs, are not being well-served by the present system. Despite significant cynicism and frustrations with the system they see today, consumers have hope. This research indicates they are eager to help us think about how to get from where we are today to the new system they imagine.

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