

## **Putting Patients at the Center of Care in the Twin Cities Region**

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In order to inform community forums about improving health care in the Twin Cities region, Public Agenda conducted focus groups designed to learn what people in the region who use the health care system think should be done to make care more patient-centered. Public Agenda convened two online focus groups August 26 and 27, 2020 with low-income residents of the Twin Cities region who were covered by Medicare, Medicaid or were uninsured and who had either a chronic condition or a recent hospitalization. The methodology is described further at the end of this memo.

### **Findings in brief:**

1. Complicated administrative practices make it difficult for people to access the care they need, threatens the quality of care, and creates frustration.
2. Inequities by race, income and insurance type all affect whether care is patient-centered.
3. Patient-centeredness depends on the quality of interpersonal relationships with clinicians and staff.
4. Participants' ideas for making care more patient-centered include simplifying administrative practices, better coordination and communication within health care systems, easing the stress of appointments, using patient advocates, and creating affordable universal coverage.

### **Findings in detail:**

#### **1. Complicated administrative practices make it difficult for people to access the care they need, threatens the quality of care, and creates frustration.**

Focus group participants cited administrative complexity as a foundational problem that affects their entire health care experience and that makes care less patient-centered. The journey that participants described begins with the challenges of accessing the health care system. They discussed struggles with scheduling appointments, receiving inconsistent messages about which providers and services are covered, and otherwise getting inaccurate or confusing information from administrative staff or systems. And they described feeling like they had no recourse to hold these big, confusing systems accountable for how they have been treated.

“Having MNsure can sometimes really make it hard on who we can go to. All of a sudden it switches, and I can't go to that person anymore. It's just really hard when you've been seeing someone on a regular basis and then all of a sudden somebody switches, and you have to explain that whole thing to somebody else.”<sup>1</sup> —Person with Medicaid; in her 30s; white; with a chronic condition

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<sup>1</sup> Focus group quotes have been minimally edited for clarity.

“I attempted to reach the [insurer’s] corporate compliance officer and I actually had a person who worked there who said we don’t have corporate compliance officers. I mean how stupid do they think we really are? They’re a big monopoly and do just what they want and there’s really no way to hold a fire to them and hold them accountable for what they’re doing.” —Person with Medicare; in his 50s; white; with a chronic condition

### **Miscommunication and failures to share records threaten quality of care.**

Focus group participants explained that even once they get to appointments, administrative missteps threaten the quality of their care. They described miscommunication among health care professionals and lack of coordination which can result in important health information being missed or garbled. The lack of recording—sharing and miscommunication could lead to errors or at the very least make appointments a waste of time – participants often noted that they work hourly jobs or have family to take care of – and a waste of clinicians’ time.

“When it comes to looking at your record charts, sometimes it takes a week or two for the other doctors to even get anything from one doctor. They should at least be able to come up with a better system where the other doctors shouldn’t have to wait so long to get the records to be able to see what’s going on with you.” —Person with Medicaid; in his 50s; Black; with a chronic condition

“I show up for a full body scan and somebody’s got me scheduled for an abdominal scan. Somebody didn’t communicate. Nothing works. It’s being thorough and detailed. The more detailed you are and the more information you have, the smoother things work.” —Person with Medicare; in his 60s; Black; recently hospitalized

“Being transferred around from place to place and then having to explain the same thing to each person that you speak with really irritates me. You call the doctors’ office and try to tell them something. And then you call insurance and try to tell them. They should have some kind of communication between them. That gets very, very annoying.” —Person with Medicaid; in her 40s; Native American; recently hospitalized

### **Participants want to know which doctors are covered by their insurance and whether they can afford the care they need.**

Due to administrative opacity, inaccuracies and misinformation, participants described having difficulty affording their care, difficulty knowing which providers are covered, and difficulty knowing how much their care will cost them. Participants often described health care as a business designed to extract money from them.

“I let the doctor know that those billing people can make you look really bad really fast because ultimately, it’s your reputation that’s going to get messed up. They don’t care, they still got their job. When the doctor starts losing patients because billing is not doing their thing, he’ll be out of a job.” —Person with Medicare; in his 50s; white; with a chronic condition

“We pay in this country three or four times as much per capita as the next countries on the list for the same type of medical outcomes, sometimes worse outcomes. Prescription drug prices are outrageous. It’s definitely about the dollar, it’s money. There’s a lot of people that make too much for Medicaid but not enough to pay for health insurance. If you don’t have health insurance, good luck getting to see a doctor. For these people, urgent care is their only alternative.” —Person with Medicare; in his 60s; white; with a chronic condition

“It’s ridiculous that right now I’m paying nothing. But if I go and get a job that pays \$14 an hour, which is not a living wage, I all of a sudden have to pay a ton more.” —Person with Medicaid; in her 30s; white; with a chronic condition

### **Administrative complexities create frustration.**

Participants described how frustrating and enraging administrative issues can be, and how these issues shape their entire health care experience. They did not draw sharp distinctions between administrative and interpersonal issues but saw the health care system in a holistic way, for better and for worse.

“It’s combination of people and system. If that’s working and streamlined, people are happy. You’ve got a good system; it shows in their work and then they’re happy with their patients and then the patients are happy.” —Person with Medicaid; in her 40s; Native American; recently hospitalized

“It’s the way you’re handled, from bedside manner, from the time you walk in the door until you go in the waiting room, until the time you leave. You’re rushed. You feel like you’re just herded like an assembly line. I’m old school and you want your doctor to feel like they know you. They know something about your case and your history.” —Person with Medicare; in his 60s; Black; with a chronic condition

“They just do things to frustrate you so you will just go away. Even when I’m asking for their supervisor, does nobody want to take any responsibility?” —Person with Medicaid; in her 50s; white; with a chronic condition

### **2. Inequities by race, income and insurance type all affect whether care is patient-centered.**

Focus group participants described how multiple forms of inequity shape whether their care is patient-centered. They discussed racial inequity, inequity by insurance type, income inequity, and the socio-economic status of their neighborhoods. Participants described feeling the effects of these various inequities for years.

They linked these inequities to underfunding and technological disadvantages of clinics and hospitals serving low-income neighborhoods. They described how having Medicaid or being uninsured can affect the quality and accessibility of their care. Some noted that people of color

are not included in decision-making in health systems and feeling the lack of clinicians of color, particularly in mental health.

“If you weren’t in a certain category for income or race, you weren’t going to get the best of the service when it comes to your health. A lot of things get put in place by Caucasians. They’re not getting input from another race. They’re just looking at it as a one-sided thing instead of trying to come together and work together and come up with a better system.” —Person with Medicaid; in his 50s; Black; with a chronic condition

“I had a total knee replacement done back in 2015. When I first went back to do a follow-up with my doctor, there was a guy that had a total knee replacement done a day after I did. He had private insurance and he was walking without crutches just seven days out the wards. Me, I’m still having a problem with my knee. And that was over five years ago. I feel that since he had the private insurance, he got better service than I did because I had insurance through the government.” —Person with Medicaid; in his 50s; Black; with a chronic condition

“In poor communities if you go to a community clinic, they don’t have the technology. The richer communities have better technology, they have better systems in place. That means they have obviously better doctors and probably better people working there.” —Person with Medicaid; in her 40s; Native American; recently hospitalized

“I had a white therapist. Not like her service was terrible, but I felt like there was a lot of things that she didn’t understand or that she didn’t take seriously. I looked online for black therapists. Because we share a similar background, they’re more likely to understand how social or economic or racial factors really play a role in my health.” —Person with Medicaid; in her late teens; Black; recently hospitalized

“Clinics can become less clinical and more about community. Represent the community better in terms of the racial makeup, the gender makeup of the staff. Reflect more about the community that they’re based in than just being a clinic.” —Person with Medicare; in his 40s; Latino; recently hospitalized

### **3. Participants want clinicians and staff to listen to them, trust them, explain without being condescending, get to know their medical history, be friendly and make them feel cared for.**

Participants described how interpersonal relationships with clinicians and other staff affect their experience of care. While they explained that administrative complexities make relationships with clinicians and other staff difficult to create and maintain, they also recalled examples of positive relationships and described what those relationships ideally should be like.

Taking time and listening carefully were common themes when participants described what those relationships should be like. They wanted doctors to get to know them and staff to recognize them when they walk into the office. But they described instances in which they felt

that clinicians and staff mistrusted them, failed to listen, did not respect their expertise as patients, talked down to them, and otherwise did not make them feel cared for.<sup>2</sup>

**Participants want clinicians and staff to listen to them and trust them.**

“It took me a long time to find a doctor that actually believed me. I was walking around in pain for five years because nobody believed me. Why did I have to suffer for so long? Why did no doctor believe the pain that I was in?” —Person with Medicaid; in her 40s; Native American; recently hospitalized

“The neurologist I went to see today was very attentive. He listened to what I had to say, didn’t berate me because I do my own due diligence. I’ve had doctors say ‘Well, you don’t have a medical degree, how do you know what you’re talking about?’” —Person with Medicare; in his 50s; white; with a chronic condition

**Participants want clinicians and staff to explain things to them in clear and comprehensible ways but not talk down to them.**

“When they were working to get me off the ventilator, the respiratory therapist was really good. He was calm. He said, ‘You might feel a little panicked. That’s normal. You’ve got to get your lungs back to working on their own,’ those types of things.” —Person with Medicare; in his 40s; Latino; recently hospitalized

“They talked to me like I was a normal person. They didn’t talk to me like I had a problem, like I was disturbed. They made me feel like the problem that I was going through wasn’t that bad, and it just made me feel better about myself.” —Person with Medicaid; in his 50s; Black; with a chronic condition

**Participants want clinicians and staff to recognize them, get to know them and their medical history, and be friendly.**

“I think it’s important that doctors spend the time to pre—look at your record. They have like ten minutes to spend with you. They have to see too many clients. People are more willing to open up and talk to a doctor that they feel like they know.” —Person with Medicaid; in her 50s; white; with a chronic condition

“When I show up at the office, they know my name. They say, ‘How are you doing?’ And every year they make sure all the tests are run. I feel like part of the family because

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<sup>2</sup> Survey research from Public Agenda found that most primary care doctors and most people with Medicaid believe it is important for doctors to trust their patients in order to provide high-quality care: <https://www.publicagenda.org/reports/a-two-way-street-building-trust-between-people-with-medicaid-and-primary-care-doctors/>

they even have a case manager for the patients. I'm just amazed." —Person with Medicaid & Medicare; in her 60s; Latina; with a chronic condition

"The primary doctor was asking me questions about when I was like five years old. It helped her to work with how to treat me about certain things. Because the better you know a person, the better you can treat them." —Person with Medicaid; in his 50s; Black; with a chronic condition

### **Participants want to feel cared for by clinicians, healthcare professionals, and staff.**

"She sat down and talked to me about me, my family, things that I like to do. She talked to me as a person, and she didn't make me feel like I was just a paycheck to her. She did everything that she thought that was best for me. She was more concerned about my well-being than a paycheck." —Person with Medicaid; in his 50s; Black; with a chronic condition

"They really care about you. If you have an issue, they'll research it. Anything you have a problem with, they'll take care of it for you. It's the insurance company who's doing this which is very unusual because that's not usually what happens. The doctors are great too but the insurance company's part of the package." —Person with Medicaid & Medicare; in her 60s; Latina; with a chronic condition

### **4. Participants' ideas for making care more patient-centered include simplifying administrative practices, better coordination and communication within health care systems, easing the stress of appointments, using patient advocates, and creating affordable universal coverage.**

Participants discussed specific ways in which health care can become more patient-centered. Some of their ideas were very specific, like using social workers as patient advocates and giving doctors more time to read patients' charts before appointments. Some ideas were broader calls to action, like creating universal health care coverage.

#### **Simplify, coordinate, and communicate. Leaders should put themselves in patients' shoes.**

Participants called for health care systems to be administratively simpler and streamlined. They wanted better coordination of care and often mentioned the need to digitize and share patient records between clinicians. Overall, they emphasized the need to make health care systems work for patients, instead of patients having to try so hard to make the system work for them.

"Create a standard operating procedure and stick to the script and follow it to the letter so that way there's no what ifs about what's going on. That way the patients can navigate what's going on and it should make it easier for the doctors." —Person with Medicare; in his 50s; white; with a chronic condition



Underlying many of participants' comments was a sense that people who do not experience the system like they do—as low-income people, with Medicaid or without insurance, dealing with chronic conditions—can never really understand how difficult it is to get the care they need. One participant insisted that government officials and industry leaders should have to have Medicaid themselves. According to him, if those leaders knew how frustrating the system is firsthand, then we would “watch how quickly things will change.”

**Clinicians and staff need to get to know patients' preferred styles of care and understand how health care fits into their lives.**

Participants emphasized the need for clinicians and staff to get to know the style of care that patients prefer. Participants emphasized that clinicians and staff need to understand their preference so they can tailor care to them. Some wanted efficiency while others wanted a more personalized touch. Some wanted to include family members, while others want to keep their health care to themselves. Some want a holistic approach and alternative medicine, while others want all the latest technological advances.

Participants also explained that they have busy lives including working long hours and taking care of family. Clinicians and staff need to understand and adapt to those constraints in order to make their care more accessible.

“If they had like a little bit of background on your home life, because I've had doctors who wanted me to do this and that three times a week or whatever, and when I'm a single mom I can't take off that many hours from work.” —Person with Medicaid; in her 40s; Native American; with a chronic condition

“I think it's really important that doctors understand and appreciate our time. I work contract jobs and so it can be hard to get into the doctor. I'm taking that time away from my job so I'm not getting paid. So, take the time to make sure that my questions are answered in the time that I'm there.” —Person with Medicaid; in her 30s; white; with a chronic condition

**Ease the stress of attending appointments with transportation and more home care.**

Participants urged industry leaders to do what they can to make health care more easily accessible. Their ideas included making it easier to cover as many needs as possible in a single appointment or day and decreasing the need to make multiple appointments on multiple days. They suggested making transportation available to those who cannot drive themselves. Some argued for using more in-home care for easier appointments and follow-ups.

**People need advocates, like case managers or social workers.**

Participants identified social workers and other case managers as a solution to cut through administrative complexity and coordinate care among various doctors, specialists, and other health care professionals. They noted that these advocates could make sure patients get the appointments they need, facilitate sharing of information, and help people access more

affordable care or programs to defray costs. However, participants also noted that there are good social workers and bad social workers, and that the bad ones are no help at all.

“I had an experience with my father at the hospital. He was on the third floor, then he was on the fifth floor, then he was in ICU. Three different social workers? Come on! One social worker follow the patient, figure out where he needs to go and deal with it. Don’t make me as the daughter come in and talk to every social worker on every floor in the hospital to get something done. I think that’s a system issue.” —Person with Medicaid; in her 50s; white; with a chronic condition

“I have a disabled son and so I’ve worked with social workers, and I find it to be very helpful. They’re kind of like backdoor to things. But it is all about who you get. Because if you get someone that’s not doing their job fully then it’s not really beneficial.” — Person with Medicaid; in her 40s; white; with a chronic condition

“They are a very good asset when you have a good one. They can get into nooks and crannies and get you into places and iron some of that stuff out for you.” —Person with Medicare; in his 60s; Black; hospitalized with a chronic health condition

#### **Create affordable, universal coverage.**

Some of the participants suggested a complete overhaul of the health care system, advocating for universal affordable health care coverage. Participants tended to grudgingly admit that something big needs to change, rather than passionately advocate for Medicare for All.

“Hanging over every health care worker’s head is bureaucracy. The simplest way to fix that is single payer health care. There is so much administrative cost dealing with all these different insurance companies, different plans, different criteria. It’s hard for them so it makes it harder for them to devote time to their patients. Whether it’s Medicare For All or something else, I think one single payer plan is the way to go. They criticize and say the government’s controlling the health care decisions. Well, right now, the insurance companies have control over our decisions.” —Person with Medicare; in his 60s; white; with a chronic condition



**Methodology:**

Public Agenda convened two online focus groups August 26 and 27, 2020 with residents of the Twin Cities metro region. A professional focus group facility recruited participants with household incomes under \$50,000 who were either covered by Medicare, Medicaid or were without health insurance. We recruited people who either had a chronic health condition or had been hospitalized for longer than 24 hours in the past five years. We defined a chronic health condition as any condition lasting for one year or more that requires ongoing medical attention or limits people's daily living activities or both. We recruited for a mix of men and women and for racial/ethnic diversity based on census benchmarks specific to the Twin Cities region.

A total of twelve people participated in the focus groups. Focus groups lasted two hours and participants were paid for their time. Public Agenda staff moderated the focus groups. The moderator informed participants that their experiences and ideas would be shared with health care decision-makers and stakeholders. The groups were video recorded and professionally transcribed. Public Agenda staff developed a coding system and coded the transcripts thematically.

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