

## **Putting Patients at the Center of Care in the Jackson, Mississippi Region**

By David Schleifer and Erin McNally

May 2021

To inform community forums about improving health care in the Jackson, Mississippi 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 October 27 and 28, 2020 with low-income residents of the Jackson 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. Focus group participants insisted that coverage and care must be affordable in order to be patient-centered and explained how unaffordability undermines their access to care, health, and financial well-being.
2. In order to make care more patient-centered, focus group participants wanted staff and clinicians alike to be compassionate and to listen to, trust, and respect patients.
3. Focus group participants saw staff and clinicians as hemmed in by the system, burdened by high caseloads, and unable to communicate with each other—all of which get in the way of providing patient-centered care.
4. Participants described how long-standing and deep-rooted inequities by race, income, and insurance type negatively affect their care.
5. Participants saw politics and entrenched economic interests as impediments to making care more patient-centered in Mississippi.

### **Findings in detail:**

#### **1. Focus group participants insisted that coverage and care must be affordable in order to be patient-centered and explained how unaffordability undermines their access to care, health, and financial well-being.**

Unaffordable care and coverage fundamentally shaped focus participants' experiences with the health care system, especially those without insurance. Participants described exorbitant costs for routine care, surgeries, emergency room visits and ambulances, as well as confusing billing practices. Participants said high costs fuel a fear of using health care services at all and described forgoing care that they knew they needed because they were afraid of how much it would cost. Some described driving themselves to the hospital in severe distress because they feared the high costs of an ambulance ride.

“I do not have any type of health insurance and I won't go to the doctor unless I absolutely have to. That's why a lot of people are suffering. They don't know that they have certain illnesses or diseases because they don't have the health insurance to be able to go to the doctor. If you do have to go to the doctor and you can't pay for it, you just shouldn't be allowed to sue people for that. That scares people from going to the doctor.

A lot of people won't go unless they're pretty much on their deathbed and it shouldn't be that way."<sup>1</sup> —Person without insurance; in her 30's; Black; recently hospitalized

"After I got out of the hospital, I was on the phone at least two or three days a week trying to get the billing straight. It took me hours and hours on the phone, and I would keep getting billed. That's not easy to do when you've been in an accident and you're not thinking straight already." —Person with Medicaid; in her 60's; Black; with a chronic condition

"Me and my wife, we live paycheck to paycheck. I can't tell you the last time I went to the doctor. When my wife went to get insurance through her work, just adding me bumped her insurance to \$700 and something a month. And without me it's only \$36 for her. So, I don't have insurance but her and my kids they do." —Person without insurance; in his 40's; white; recently hospitalized

Participants described the health care system as acting punitively towards people who cannot pay bills. They noted that when a hospital bill goes unpaid, it negatively impacts their credit. Several participants had been sued by hospitals or had friends and family who had been sued. Participants found these lawsuits outrageous—asking if they cannot afford to pay their hospital bill, how can they handle the costs of a lawsuit? These experiences seriously damaged participants' trust in the entire health care system and engendered anger and fear.

"I rode an ambulance from Raymond Road to UMC. It only takes you eight minutes to get there and they charged me \$1500. If I didn't pay that \$1500, they would sue me. That needs to change." —Person with Medicaid; in his 50's; Black; recently hospitalized

"Most people know that if they call that ambulance or they have to be air lifted, it's going to ruin them financially." —Person with Medicaid; in her 70's; white; with a chronic health condition

"They transported me from a car wreck out here and it was around \$8,000. Even with insurance, a normal person cannot afford that." —Person without insurance; in his 40's; white; recently hospitalized

"My ex-boyfriend had an abscess on his forearm. They didn't even numb it because he asked them not to because he didn't have insurance already, so they just cleaned it and they charged him about \$3,000. They didn't send him home with any medicine, they didn't give him any medicine, they didn't do anything but charge him and then they sued him because he didn't pay that bill." —Person with Medicaid; in her 20's; white; with a chronic health condition

## **2. In order to make care more patient-centered, focus group participants wanted staff and clinicians alike to be compassionate and to listen to, trust, and respect patients.**

---

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

Focus group participants pointed out how their care experiences could be improved if both clinicians and staff change how they interact with patients and family caregivers. Participants saw a need for the people they encounter throughout their entire health care experience to be more caring, compassionate and empathetic. They said they wanted staff and clinicians alike to “act like they like their jobs” and to treat patients and family caregivers as they themselves would want to be treated.

“If they actually cared, it would make a difference. If you treat us like you want to be treated.” —Person with Medicaid; in her 30’s; Black; recently hospitalized

“We’re humans just like they are. Everybody’s got feelings, nobody wants to be a number on a file. I don’t like doctors who are afraid to touch their patients. I watched when 80-year-old patients need to be touched, even if you got on gloves. They need that human interaction.” —Person without insurance; in her 50’s; Black; with a chronic health condition

“My overall thought is compassion. With compassion these are things that will fall into place. You’ve got to care about each other. That includes the politicians, the doctors, the social workers.” —Person with Medicare; in her 70’s; Black; with a chronic health condition

“Be the support, make sure everything is all right with you before you leave. Ask questions about how you really feel and have concern. They should listen to the patient more and not let it just be a job to them. Show love, you know, compassion.” —Person with Medicaid; in his 50’s; Black; with a chronic condition

While health care researchers and advocates often focus on improving doctor-patient relationships, participants emphasized that all staff –not just clinicians –need to be empathetic, compassionate, and caring. They described how the behavior and demeanor of staff reflect on doctors and on hospitals and clinics as a whole. Staff at insurers and pharmacies can also have a tremendous impact on whether people’s care feels patient-centered.

“I’ve had quite a few experiences where the staff at the front desk, they’re just not happy and I feel like if you’re not happy with your job then maybe you should try something different. We’re concerned and afraid. We don’t need anybody to make this any worse.” —Person with Medicaid; in her 30’s; Black; recently hospitalized

“I was in excruciating pain. I was throwing up. The lady in the waiting room had the audacity to tell me, “Did you throw up in my can? Don’t you throw up in my can like that!” They just talk to you in such a condescending manner. I had to hold my wife back because she was livid. I got treated harshly by the person that was on security duty. They wanted me to walk from way back in the garage parking area because I didn’t arrive in an ambulance. Instead of the personnel trying to treat the people who were waiting to see a doctor, the security and the hospital personnel were talking and laughing like they’re making plans to go on a date or something. I think that’s really

pathetic, the way that I was treated, and I'll never forget that." —Person with Medicare; in his 60's; Black; with a chronic condition

Participants discussed the importance of doctors and other clinicians listening to them and believing their descriptions of symptoms and health concerns —especially regarding pain. Many spoke about feeling like doctors, clinicians and staff do not trust them and their accounts of their health and do not respect their need for care.<sup>2</sup> Participants spoke of feeling rushed by health care professionals, leaving them in intense pain or other forms of suffering. They also talked about being suspected of drug-seeking when they in fact needed appropriate pain medication. When participants were asked about positive experiences where they felt that they as patients were being centered, they often focused on clinicians who listened to them carefully and acted quickly to address their needs.

"The doctor that's assigned to me, he's not giving medicine because he thinks I don't need it. And I know I do need it. He's not inside my body to feel my pain. He asked me was I ready to [leave the hospital]. No, I'm still in pain. Why would you want to send a sick patient home and they in pain?" —Person with Medicaid; in her 30's; Black; recently hospitalized

"On my first visit to the doctor, he listened to what my problem was, and he instantly knew he had to go ahead and do something about my situation because of my age and family history. That was my first time ever going to a doctor and telling them what it is I was experiencing; what it is I was feeling and they immediately jump on the situation." —Person with Medicaid; in her 30's; Black; recently hospitalized

"My son has been dealing with some issues and we ended up switching doctors because he really wasn't listening to me and things that I would ask him about, he just ignored. We ended up switching providers for that." —Person with Medicaid; in her 30's; Black; recently hospitalized

Participants saw room for improvement in how doctors and other clinicians explain diagnoses, provide information and discuss treatment plans to. They noted that having doctors who sit down and explain things without being patronizing makes them more confident about the care they are getting and more confident about their health overall.

"I often have bloodwork. And they sit down and explain the blood that was drawn and the results. My endocrinologist keeps up with my A1-C and lets me know where that stands. That's why I feel I'm really in a good situation health-wise." —Person with Medicare; in her 70's; Black; with a chronic health condition

"What makes great health care to me is when they have great bedside manners. They're patient, they're understanding, and they don't make you feel like you're just an idiot

---

<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/>

talking and trying to explain things.” —Person with Medicaid; in her 30’s; Black; recently hospitalized

**3. Focus group participants saw staff and clinicians as hemmed in by the system, burdened by high caseloads, and unable to communicate with each other—all of which get in the way of providing patient-centered care.**

Participants described clinicians as hemmed in by health care systems –and specifically by insurers. They felt that insurers force doctors and nurses to see too many patients, which makes appointments rushed and make it difficult for clinicians to remember who patients are and what they need. Some complained that insurers limit the types of care clinicians can provide.

“They get in a hurry, and it really makes you feel like you’re a bother. A patient doesn’t need to come in and feel like they’re being in the way. You’re already upset because you’ve got to go to the doctor. You certainly don’t want to be there and be treated as though you’re taking up time.” —Person with Medicare; in her 60’s; Black; with a chronic health condition

“The system holds some of the stuff back where the doctors and nurses can’t do some of the things they may need to do, like where the doctors may be able to use their better judgement in some cases that way. They get worried and scared because if they try and buck the system a little bit, they will lose their job or be reprimanded.” —Person without insurance; in his 40’s; white; recently hospitalized

“I understand that sometimes doctors have to see a certain amount of patients a day. They have to meet this quota because some insurances work that way. I think they could do a little bit better with their scheduling. I had to take my daughter to the doctor Monday. I understand I’m not going to see the doctor as soon I walk through the door. But it was an hour and a half. And then once we got in the room, the doctor came in, he asked what was going on, and he said hold on one second. And then he ran to the next room. When he came back in there with us, he forgot all about what her situation was, and we had to start all over again. You get to the point where you’re almost ready to say, you know what, forget it. I don’t even want to see the doctor no more. I’m going to go home.” —Person with Medicaid; in her 30’s; Black; recently hospitalized

In these rushed and overworked settings, participants argued that poor communication between health care professions makes care less patient-centered. They complained that when doctors and other clinicians fail to communicate with one another, patients have to wait for days in order to see specialists, get test results or get prescriptions.

“They need to interact more with one another. I’ve had doctors or nurses come in and they’re looking at my chart and they’re like, I didn’t know this before I come in here. Well, if you were getting together with the other doctors and getting to know the patients –if you don’t interact with the other people working with you, you may not know something that’s important that’s going on.” —Person without insurance; in his 40’s; white; recently hospitalized

“I know that there are services available, but the office staff must fill out the necessary paperwork accurately for those services to be rendered and sometimes they don’t. And that does cause problems for the patients in getting assistance. They need to really take the time to be accurate in the information that they submit so that the patient does not have to jump through hoops to get services that are actually available for them.” — Person with Medicare; in her 70’s; Black; with a chronic health condition

Furthermore, participants also described clinicians failing to communicate with family caregivers. This was especially problematic for those who were taking care of older family members in long-term care facilities or hospitals.

“Doctors need to communicate more with the person who the patient has appointed to be their spokesperson or power of attorney. There have been times when my grandmother was taking something where the prescription dosage may have been too high for her, or it was interacting with her other prescriptions and she wasn’t able to relay that message to the doctor herself. She couldn’t remember what medicine was that she was taking.” — Person with Medicaid; in her 70’s; Black; recently hospitalized

“In my mother’s case, they didn’t give us any information. She comes out of the hospital with medicine we don’t know anything about. She can’t tell me what the doctors did. She can’t tell me what’s been going on. I’m talking to her all day long and she still can’t tell me anything. They need to talk to me because I’m the person who ultimately has to make her decisions. But they don’t.” — Person without insurance; in her 50’s; Black; with a chronic health condition

Although participants noted that social workers can help overcome some of these problems with communication and coordination, they also noted that there are good and bad social workers. Good social workers, they said, can do great things to coordinate care, communicate between clinicians and get people access to the care they need. But bad social workers –which participants said were all too common –are simply no help at all.

“When I first got sick seven years ago, the social worker worked for me. They did what they were supposed to do. These ones I got now, man, we went through three. In a lot of instances social workers don’t do nothing for you.” — Person with Medicaid; in her 30’s; Black; recently hospitalized

“Social workers don’t do nothing. They are supposed to do things for you to help you out with your medicines and stuff like this, but I can tell them that I need something and I end up doing it my own self.” — Person with Medicaid; in her 50’s; Black; recently hospitalized

#### **4. Participants described how long-standing and deep-rooted inequities by race, income, and insurance type negatively affect their care.**

Focus group participants described how racial inequity, inequity by insurance type, and inequity by income affect their access to care, the quality of care, and how they are treated

interpersonally by clinicians and staff. Participants noted how racism affects the way they are treated throughout the entire health care system.

“Especially here in the South, racism happens every day. I’ve seen other patients being treated more aggressively. We see it every day even in the emergency room or even to just regular office visits. You’re able to spot it every time.” —Person with Medicare; in her 60’s; Black; with a chronic condition

“Trying to dice us into these little groups, that’s what I don’t like. Treat them all the same regardless of race, religion, whatever. They automatically see one person or a certain group of people they assume, oh this person has diabetes, high blood pressure.” —Person without insurance; in her 30’s; Black; recently hospitalized

Focus group participants described how having a low income –and being perceived as having a low income due to their neighborhood or clothing –affects the care that they receive.

“University Medical Center here in Jackson has that reputation of not being very nice to patients because of their economic situation. If you’re the patient with insurance, you would probably get treated better and if you were the patient without insurance, the nurses give you the evil eye and you don’t get the treatment in a timely manner. You could wait for days over there and not be treated. It makes people not want to go there.” —Person with Medicare; in her 60’s; Black; with a chronic health condition

“Just treat you like you’re a person. Not just assume that you’re one way because you come in and you’re dressed one way, or you may not have any clean clothes that day and they think you’re a piece of trash. I’m sick, I’m here in the hospital, that’s one of the reasons why I look the way I do.” —Person without insurance; in his 40’s; white; recently hospitalized

“There are so many people here below the poverty level. Low pay will not get you the same type of care as the person that makes \$100,000 a year if they see you make \$20,000. People tend to put you in a box.” —Person with Medicare; in her 60’s; Black; recently hospitalized

Participants discussed social determinants of health, particularly lack of access to healthy, affordable groceries or restaurants. They noted that a lack of public transportation, the bad state of the roads, and the lack of hospitals in rural communities all impact their ability to access care. They also cited industrial pollution of the local water supply, which impacts health.

“We live in a small town. We have to travel 45 minutes just to have a decent grocery store. Or it’s 45 minutes for the better hospitals because the hospital we have here they are horrible. We have to travel so far in order to get quality services. And it goes back to the area that we’re in.” —Person with Medicaid; in her 30’s; Black; recently hospitalized

“In the South, public transportation is not very good, so you have to look at how you’re going to get to the hospital. Those are the things that deprive people of the care that they need because you will have some people that can readily get to a hospital and others

that can't, so they may put off their health care." — Person with Medicare; in her 60's; Black; with a chronic health condition

"You cannot eat healthy. The price of fresh fish, vegetables and fruit are too expensive, especially for the elderly that live on Social Security." — Person with Medicare; in her 70's; white; recently hospitalized

"We don't want a new McDonald's across the street from Burger King. Give us something different. Give us a gym, give us something that's going to motivate us to get up and do something." — Person with Medicaid; in her 30's; Black; recently hospitalized

## **5. Participants saw politics and entrenched economic interests as impediments to making care more patient-centered in Mississippi.**

Focus group participants talked about both wanting to keep politics out of health care and about a need for better politics and better politicians. At least one participant in each group used the phrase "Good Ol' Boy system" to describe a mentality in Mississippi that they said makes the status quo hard to change and that infiltrates politics and institutions like hospitals and insurers.

"Everyone else is making money and you are getting sued, your credit is ruined, you can't get this, you can't get that. But in Mississippi that's the norm. They want the poor to stay poor and the rich to get richer." — Person with Medicare; in her 60's; Black; with a chronic condition

"That's the South, that's Mississippi. We have the worst time with insurance. Nobody to advocate for the people. The insurance companies run us over and we're just stuck. To me everything goes back to how politics goes." — Person without insurance; in her 50's; Black; with a chronic health condition

"We live in a Good Ol' Boy state. The little people, we can't do anything, we're just stuck where we are. And we keep on putting people back in office that are supposed to represent us, but they don't. We need a real good insurance commission. That would help us." — Person without insurance; in her 50's; Black; with a chronic health condition

"The Good Ol' Boy system is a well-oiled machine and that's why it's still being used by politicians and everyone else that has the power to keep you poor and them making money." — Person with Medicare; in her 60's; Black; recently hospitalized

"I think that we should just take politics out of the health care system, period. I think that would help a whole lot." — Person with Medicaid; in her 30's; Black; recently hospitalized

They specifically blamed decision-makers in government for cutting funding for vital services — naming low-cost community clinics, mental health, and Sickle Cell care. They said that state funding cuts had caused many of those services to close down, cutting off access to care and leading to pain, death and family members moving out of state.



“Down in the South, we have lost a lot of programs that would help us. Like the Sickle Cell Clinic for instance. I lost a lot of Sickle Cell brothers and sisters due to that.” —Person with Medicaid; in his 30’s; Black; recently hospitalized

“I have a brother who is schizophrenic and all the services and programs that he used to have, they cut all that out when they were here in Mississippi. Now he’s in Alabama and he gets all of that again. I think politics has a lot to do with it. I think a lot of these politicians do get in office and they cut programs for people who really need it.” —Person with Medicaid; in her 30’s; Black; recently hospitalized

On the other hand, participants also saw politics as vehicle to create change –if the right politicians get elected and follows through on campaign promises. Participants saw their voice, and their vote, as a potential tool to advocate for health care reform on a legislative level if they are heard. But they cautioned that they are up against a long-standing system that can make it discouraging to seek change.

“That plant was giving off chemicals that was getting in the water that was making people sick around here. If a small group of people try to voice the situation, it’s kind of like brushed off and sometimes in a smaller community we feel like our voices aren’t heard.” —Person with Medicaid; in her 30’s; Black; recently hospitalized

“It all boils down to politics. We’ve got to put people in place, we’ve been trying to put people in place but once they get elected, they don’t do what they say they’re going to do.” —Person with Medicare; in her 70’s; Black; with a chronic condition

“Is it true that just across the border in Canada everyone has health insurance, and they’re supposed to be one of the richest countries in the world? Then why should we as citizens of this country have to be so compelled to be chained to the bill that is placed upon our backs just because we seek something that merely a necessity as health insurance?” —Person with Medicare; in his 60’s; Black; with a chronic health condition

“We need to get out and vote. That’s where it starts. That’s where we’re going to make the major change. Without our votes we’re not going to get anything.” —Person without insurance; in her 50’s; Black; recently hospitalized

### **Methodology:**

Public Agenda convened two online focus groups October 27 and 28, 2020 with residents of the Jackson, Mississippi 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 Jackson-metro region.



A total of 15 people participated in the focus groups. The focus groups were all conducted in English. 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.

Community Research for Health Equity is a program supported by the Robert Wood Johnson Foundation, and administered by AcademyHealth. The views expressed here do not necessarily reflect the views of the Foundation or AcademyHealth. For further detail about these focus groups, please visit [our website](#) or contact [research@publicagenda.org](mailto:research@publicagenda.org).



Public Agenda is a research-to-action nonprofit organization dedicated to strengthening democracy and expanding opportunity for all Americans. Through research, engagement and communications, Public Agenda focuses on building trust and opportunity, raising up the voices of the public, and bridging divides to facilitate progress. Areas of focus include K-12 education, higher education, health care, economic opportunity, and democracy. Find Public Agenda online at [PublicAgenda.org](http://PublicAgenda.org), on Facebook [here](#), and on Twitter [here](#).