

Putting Patients at the Center of Care in the Albuquerque and Santa Fe Region

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To inform community forums about improving health care in the Albuquerque and Santa Fe region of New Mexico, 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 November 17 and 18, 2020 with low-income residents of New Mexico who were covered by Medicare, Medicaid or were uninsured and who either had a chronic condition or had recently been hospitalized. The methodology is described further at the end of this memo.

Findings in brief:

1. Participants described how the shortage of doctors in New Mexico and the complexity of benefits and scheduling makes it difficult for them to access care. They expressed anger, frustration, and bewilderment at how inaccessible care is.
2. Accessing care was particularly difficult for participants who must travel long distances to see providers.
3. Tensions over narcotics and other substances—including doctors under- or over-prescribing, doctors suspecting patients of drug-seeking, and the prevalence of substance use in families and neighborhoods—shaped participants' lives and their relationships with the health care system.
4. Participants outlined what they think would make care more patient-centered: transparency about what their insurance covers and who accepts it as well as care that is more coordinated, integrated, and compassionate.

Findings in detail:

1. Participants described how the shortage of doctors in New Mexico and the complexity of benefits and scheduling makes it difficult for them to access care. They expressed anger, frustration, and bewilderment at how inaccessible care is.

New Mexico faces a shortage of doctors and other medical professionals.¹ Focus group participants described how those shortages, particularly the shortage of doctors who accept their insurance, negatively affect their health.

“It’s hard to even get a PCP because it’s just so overloaded. It’s easier just waiting two hours in the ER because I haven’t found any PCPs that are actually taking my insurance as of right now.”² —Person with Medicaid; in his 30’s; Latino; recently hospitalized

¹ Zhang et al. “Physician Workforce in the United States of America: Forecasting Nationwide Shortages.” *Human Resources for Health* 18: 8 (2020). <https://doi.org/10.1186/s12960-020-0448-3>

² Focus group quotes have been minimally edited for clarity.

“My biggest problem was actually getting to see an actual doctor. I tried going into the emergency room a couple times when my flare up was really bad. And they said we can’t help you, here’s a couple Tylenol go home and call your regular doctor and make an appointment. And I’m like well I’ve tried that, and I can’t deal with this for the next three months waiting for that appointment.” —Person without insurance; in his 30’s; Latino; with a chronic condition

Focus group participants described how the health care system’s frustrating complexity inhibits their access to care. In these heart-rending stories, people expressed anger, frustration, and bewilderment at the difficulty of accessing care. Participants wanted more transparency about who accepts their insurance and what it covers, discussed further in the finding four of this memo.

“I was paying a pretty good amount of money out of my own pocket for insurance at the time and any time I’d call customer service, they were more than happy to give me a list of doctors that according to them were accepting new patients. But none of them were taking any new patients whatsoever. I was at one point trying to arrange a three-way call where I could have the insurance company talk to the doctor but neither one was willing to talk to the other on my behalf.” —Person without insurance; in his 30’s; Latino; with a chronic condition

“With insurance, why is this not being covered? If you can just tell me like why and what alternatives there are? How can it be covered so that way I can go back to my provider and say that this is what they need so that way it can be covered.” —Person without insurance; in her 30’s; Native American; with a chronic condition

“I am a chronic alcoholic and I asked for medication to help myself through the issues but my insurance, they refused it. My doctor knew that I needed it. And for my insurance to refuse something as important as that was to me? I’ve been in the hospital, and they’ve covered everything, but they couldn’t cover a stupid little medicine? I have two daughters. I have a family.” —Person with dual Medicare-Medicaid; in his 50’s; white; recently hospitalized and with a chronic condition

“It’s just a big puzzle, even trying to figure out your insurance, trying to figure out what you’re covered for, trying to figure out what doctor, what hospital. It’s just all so confusing to me. Easier access to information would be really big. It’s kind of ridiculous because I applied for Obamacare back in the day and somehow, it’s just automatically renewed every year without me ever doing anything at all. Am I just lucky or did I do something that someone else could do, and how do you find that out?” —Person with Medicaid; in his 30’s; Latino; recently hospitalized

One participant mentioned that because he could not access the care he needed, he turned to alcohol to allay his pain.

“I had got so fed up with like calling different doctors and the three to four month waiting period to see somebody that I just gave up on the whole situation. That’s where kind of where my whole drinking situation started, and I just started self-medicating.”
— Person without insurance; in his 30’s; Latino; with a chronic condition

When participants were able to make appointments, they were torn over the roles of nurses and other medical professionals besides physicians. Some welcomed these other professionals as good communicators who can alleviate overburdened physicians. Others felt that these other professionals provide lower quality care and that they should get to see a ‘real doctor’ after the difficult process of finding a provider who accepts their insurance, waiting weeks for an appointment and, in many cases, traveling long distances to get care.

“I live in such a rural area it’s going to take me an hour and a half, two hours. That’s just one way, you know? When I get there and they tell me, oh, the doctor can’t see you, but you can see his physician’s assistant. That just makes me so angry because I waited for months. My appointment says it’s with this doctor who is the specialist and now you’re going to palm me off on his assistant?” — Person with Medicare; in her 50’s; Latina; recently hospitalized and with a chronic condition

“More transparency, like what’s the reason I can’t schedule at this time with my provider? Why do I have to see a physician’s assistant? I’m sure a lot of the time it’s because they’re busy, super busy and if you communicate that to the patient, they might be more understanding and willing to see a physician’s assistant.” — Person without insurance; in her 30’s; Native American; with a chronic condition

“They have delegated all the communication to the family to nurse practitioners or physician assistants. At first, I thought well gee I kind of want to talk to the horse that’s doing the work. But the other person was a better communicator. They were able to call and give me test results, so I knew what was going on to make decisions.” — Person with Medicare; in her 60’s; white; with a chronic condition

Participants recognized that clinicians are burnt out and empathized with how overwhelmed medical professionals are. But they also felt that because of burnout, doctors have become desensitized towards their patients’ needs, which can make their care less patient-centered.

“The doctors are really, really brutally overwhelmed. I did talk to one doctor [and] he was talking so fast, he was in such a hurry, I don’t even think he knew what he was doing.” — Person with Medicare; in her 60’s; white; with a chronic condition

“I feel like there’s kind of like a desensitizing that goes on in those high level of stress environment. I can’t really blame the people and I could see the stress level on a lot of

their faces, so I could kind of see it from both sides of the spectrum.” —Person with Medicaid; in his 30’s; Latino; recently hospitalized

“I think that sometimes they get overwhelmed with people that maybe do have addiction or trauma issues and they don’t necessarily take the time to really understand the person as a human or as if this was their child or their parent.” —Person insured through employer; in her 40’s; white; with a chronic condition who is a caregiver for person with Medicaid with a chronic condition

Participants experienced the frustrations and complexities of the health care system not just as patients themselves but also as caregivers. They said that too often, clinicians, administrative staff and insurance personnel fail to communicate with family members who are coordinating care for dependents or parents. Participants said they wanted clinicians, administrators and insurers to work collaboratively with patients’ family members and other representatives. One participant saw a silver lining to the COVID-19 pandemic, which she said has actually made providers more responsive to phone calls.

“I’m a caregiver for several people, [including my brother]. A lot of times they don’t understand that I’m his sister and power of attorney. If you say somebody has dementia or limited capacity or memory issues, clinicians act like you’re making it up. I tell them so they’ll understand. Sometimes you really have to be assertive with clinicians and say, no I’m talking for him, he can’t remember.” —Person with Medicare; in her 60’s; white; with a chronic condition

“Normally it’s very difficult to get through or to get a return phone call back. But I think because of the COVID and because of the inability for family members to be present, they are more available. In the past if you’re [calling], maybe in their eyes you could be there if you were that concerned, versus now where you can’t be present. I just think that it’s given them a better understanding of communicating with the family and I think that they are more empathetic.” —Person insured through employer; in her 40’s; white; with a chronic condition who is a caregiver for person with Medicaid with a chronic condition

2. Accessing care was particularly difficult for participants who must travel long distances to see providers.

Participants described how inconsistent, inadequate public transportation and long travel distances make it difficult to get to doctors’ appointments and hospitals.

“In a rural neighborhood, food and transportation services that Medicaid and Medicare provide are very inconsistent. 90% of the time they don’t show up or you spend two to three hours of your day waiting for them to pick you up. Transportation is a huge issue especially when elderly people are traveling and not everybody has family that can take them to and from places.” —Person insured through employer; in her 40’s; white; with a chronic condition who is a caregiver for person with Medicaid with a chronic condition

“Say you’re diabetic, you may have to drive 200 or 300 miles to get to an endocrinologist. It’s insane. It’s like third world. How come this is still an issue, you know? It shouldn’t be. It’s disgraceful. You go up to the little towns up north, they don’t have access and they had to drive to Santa Fe or Albuquerque, and you know you can’t always do that.” — Person with Medicare; in her 60’s; white; with a chronic condition

“The location of the hospitals, they are far and few between, like on the reservations, on the pueblos, it’s really hard for people to get to the hospitals.” — Person without insurance; in her 50’s; Native American; with a chronic condition

Besides accessing health care, lack of transportation also affected people’s ability to do what they need to do to maintain their health.

“I’ve had neighbors say that it’s hard for them to go to the doctor, go get groceries, leave their house and accomplish whatever they need to do for the day because they don’t have transportation. If they were to expand public transportation a little bit more, they’d get more of the local people would be able to receive the help that they need.” — Person with dual Medicare-Medicaid; in her 30’s; Latina; with a chronic condition

“Because of my age and everything, I’m in a wheelchair and I have to depend on my caregiver, or I have to depend on a public transportation for the wheelchair. I have to call so many days ahead of time and sometimes my doctors or I need to go to get food, or I need to get medication and it just doesn’t happen. You depend on these people. I can’t wheel down the street in my wheelchair. I can’t go that damn far, you know?”
— Person with dual Medicare-Medicaid; in his 50’s; white; recently hospitalized and with a chronic condition

3. Tensions over narcotics and other substances—including doctors under- or over-prescribing, doctors suspecting patients of drug-seeking, and the prevalence of substance use in families and neighborhoods—shaped participants’ lives and their relationships with the health care system.

Focus group participants cited tensions with clinicians related to both under- and over-prescribing of narcotics and other substances. In both cases, participants expressed anger and frustration when they felt clinicians did not trust them, did not believe that they were experiencing pain, or did not respect their preferences for avoiding prescriptions that they felt were unnecessary or addictive.³ Some said they felt taken advantage of and angry when doctors failed to listen to them or trust them.

³ 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/>

Several participants insisted that while doctors may see them as drug-seeking, they know their bodies and their medical needs. In fact, some felt that doctors are less inclined to believe them precisely because they know their bodies and needs so well.

“Because I’m knowledgeable about my condition and I try to speak to the doctor, they think I’m drug seeking. I’m not drug seeking. I just know what my body can handle and what it can’t. My primary care provider is just giving me pain medications to help me live every day, just to help me get out of bed. But [other doctors] start doing some kind of assessment to see if I’m a drug addict. And I try to explain to them I know the difference between addiction and dependence.” —Person with Medicare; in her 50’s; Latina; recently hospitalized and with a chronic condition

On the other hand, some participants described doctors who pushed unnecessary narcotics and other treatment on them – and felt that doctors profited by pushing those prescriptions, which made them mistrust other providers and the health care system more generally. Some participants became frustrated, to the point of refusing care, because they said that even after speaking with their doctors about their substance use disorders, clinicians continued to push treatment with narcotics.

“When I was a child, the doctors deemed me ADHD and the only way to solve that was by giving me Ritalin. He just kept on raising the dose to the point where I was taking like nine pills every morning. And then they switched me to Adderall. They kept on upping me. I was getting severely underweight, and I would have the symptoms like I would pick my skin. I looked it up when I was 18 and I couldn’t believe what they had been giving me for the past 14 years and how much of it they had been giving me. And my mom had no clue either. I felt kind of taken advantage of because I know how much money they can make off of that. So, I definitely have had a hard time trusting doctors or what they want to give me. I won’t take oxies; even during my surgery I just didn’t take them. I just don’t trust it.” —Person with Medicaid; in his 30’s; Latino; recently hospitalized

“The doctor don’t care, the doctor gets paid to just feed you pills. I had a doctor that kept me on Hydrocodone and I wanted to get off of ‘em. And he kept prescribing them and prescribing them and pushing the dosage up and up and up and up. I finally had to take myself off of them because I know they’re addicting. I am an alcoholic, so I have an addictive personality. For a doctor to keep prescribing more and more and more and you have to get yourself off, because the doctor don’t give a sh*t?” —Person with dual Medicare-Medicaid; in his 50’s; white; recently hospitalized and with a chronic condition

In addition to participants feeling that clinicians pushed unnecessary drug treatment, some felt that their doctors jumped to medicating too quickly without considering alternative options or

getting to know their medical history well enough to provide insight into the root causes of their pain or other symptoms.

“I told the doctor I don’t want to take medication, what else do you have? Do we have alternative therapies? Instead of pulling out a prescription pad, let’s say go to the gym. They need to be considering alternative medication or physical therapy. Not everything will be healed from a pharmacy.” —Person with Medicaid; in his 50’s; Native American; recently hospitalized and with a chronic condition

“They’ll pay for the oxies or whatever else, but they won’t pay for counseling or therapy or a psychiatrist or a drug that needs to be taken for alcoholism to help with withdrawals. It’s very unfortunate.” —Person insured through employer; in her 40’s; white; with a chronic condition who is a caregiver for person with Medicaid with a chronic condition

“By the time I finally did get to see the pain specialist from my spine injury, his first answer was surgery and meds like Oxycodone. I’m an alcoholic and I turned down the oxies right off the bat. I asked him for some alternatives and he kind of threw it at me begrudgingly, but he was like, it wouldn’t hurt if you lost like 20 or 30 pounds and if you maybe stood up at your job instead of sitting down for eight hours a day. I never ended up going through with the surgery. I cut all the meds right off the bat and hit the gym and I was good to go six months later.” —Person without insurance; in his 30’s; Latino; with a chronic condition

Focus group participants described how addiction creates ripple effects that hurt family and friends. Many told emotional stories of broken relationships and deaths. But they also described positive experiences with social workers who have helped their families manage these challenges.

“My wife and I were raising our grandson and our daughter was having another child and the child had been exposed to opiates. For the next two years we were fighting it out in court with the other side, all of whom have died from drug overdoses to be plain. It drained us horribly. There was no money for anything. It was really hard.” —Person with Medicare; in his 60’s; white; with a chronic condition

“My sister’s on the street, she’s addicted to methamphetamine and a year ago she had my niece. Since my niece has been exposed in the womb to methamphetamines, we’ve been working with social workers through Presbyterian Hospital and they’re great. I have had nothing but great experiences with getting help, finding early intervention programs stuff like that.” —Person with dual Medicare-Medicaid; in her 30’s; Latina; with a chronic condition

Participants also explained how substance use affects their neighborhoods and communities. They described parks and sidewalks as littered with used needles and described one

neighborhood in Albuquerque as the “War Zone,” which they said has many substance users and is plagued by violence – while noting that many other neighborhoods face similar problems.

“The needles in Albuquerque is just crazy. I don’t know about anywhere else but I’ve seen them in all locations of Albuquerque not just in like the War Zone area. I live on the west side towards Ventana Ranch, that’s an upper class neighborhood and you can go down the street and you’ll find needles. You can literally see people on the street putting needles in their arms as they’re walking down the street. I think it’s a government issue. I think it’s a police issue. The community is afraid to go and say anything, to speak up and that’s where we lie at fault.” – Person with dual Medicare-Medicaid; in her 30’s; Latina; with a chronic condition

To help patients get the care they need – and avoid getting unnecessary medication – participants wanted clinicians to trust patients more readily and to be less judgmental about addiction.

“Not only the doctor’s judgement but the staff. Like front desk people or the medical assistants. If you feel like they’re passing judgement on you, you might just leave your appointment or whatever and go to another clinic or maybe not even receive the care because you feel judged or you don’t feel comfortable in that space.” – Person without insurance; in her 30’s; Native American; with a chronic condition

“I think it’s important that they’re nonjudgmental. I think that some of my experience with doctors and their staff is if somebody goes in there with an addiction problem, they tend to pass judgement. And so, they say well this person has an addiction problem. Well, no crap, but they’re here for a broken leg or whatever is the case. They get overwhelmed with people that maybe do have addiction or trauma issues and they don’t necessarily take the time to really understand the person as a human or as if this was their child or their parent.” – Person insured through employer; in her 40’s; white; with a chronic condition who is a caregiver for person with Medicaid with a chronic condition

“That brings us back to doctors knowing the environment we live in. Sometimes a person, a patient could be seen as, because they live in like a third world-type neighborhood, they only deserve third world-type care.” – Person without insurance; in her 50’s; Native American; with a chronic condition

4. Participants outlined what they think would make care more patient-centered: transparency about what their insurance covers and who accepts it as well as care that is more coordinated, integrated, and compassionate.

In their frustration with the health care system as it currently functions, participants described what they think needs to change in order to make care more patient-centered. For starters, they wanted more doctors to accept their insurance, clarity about what is and is not covered, and more reasonable premiums and other out of pocket costs.

“My husband and I are small business owners and before we both went on Medicare our insurance was ridiculous. But if you have a person with a serious heart issue, you can’t dare roll the dice on that one. So, we paid the insurance company. It was like \$1500 a month for each one of us for an HMO and we did that for six years. And it was hard to do. Who can afford that? You get where the premiums are so ridiculous, nobody can afford it. But yet in our case I thought, sure as shootin’ if we let that insurance go, he’d have a heart issue and [we’d lose our] house.” —Person with Medicare; in her 60’s; white; with a chronic condition

“My aunt had breast cancer and she has affordable health care. She went to UNM because the doctors there are great. But it’s sad for somebody who didn’t have a \$10,000 to \$20,000 credit card limit to put these expenses on. It’s honestly not fair. Your life is on the line and it’s basically an arm and a leg. I think it’s political.” —Person insured through employer; in her 40’s; white; with a chronic condition who is a caregiver for person with Medicaid with a chronic condition

Participants wanted care to be better coordinated – including providers sharing records and talking with each other. This was especially important for people who are acting as caregivers for family members with complex medical needs. One participant described her positive experiences at a clinic that coordinates every aspect of her care and her coverage.

“Every three, four, five months I’m sitting in front of a nurse or a doctor somewhere and they’re going through my medications and we’re right back to square one. Like nothing was ever done because the records are just all over the place. Why do I have to sign permissions 17 times in a half an hour for them to get this record, that record, and the other record and they still don’t get half of them because there’s no one on the other end taking the time to deliver? Why can’t it all be in one spot, you know? And once our records are updated why can’t they stay updated?” —Person with Medicare; in his 60’s; white; with a chronic condition

“Making sure that the services are available to people, and they don’t have to navigate through. If everybody accepts your insurance, one centralized place and all of these providers are talking to each other and able to have a team of experts. If you have a care team of doctors, dentists, psychiatrists whatever may be and those team of doctors work together to manage your care.” —Person insured through employer; in her 40’s; white; with a chronic condition who is a caregiver for person with Medicaid with a chronic condition

“The clinic that I go to it’s really beneficial for me because I can get all these services in one location, and they can refer me within the unit there. They have mental health, they have a dental program, it’s all in one area. They also have people who enroll you for insurance for Medicaid and then they also have like the spiritual part because they have a traditional wellness program there. More places need to do that where it’s like, more like a medical home and you’re not being sourced out to these different people.” — Person without insurance; in her 30’s; Native American; with a chronic condition

“A really good team like that working well together, you know, picking up on each other’s drops, that’s a good thing.” — Person with Medicare; in her 60’s; white; with a chronic condition

Multiple participants discussed the importance of clinicians tailoring care to patients’ needs and goals, such as incorporating diet and exercise into treatments instead of only prescribing medication, which made them feel like they were at the center of their care.

“I told him I personally don’t like taking medicine and didn’t want to take medicine. And he offered me some other options. They said, you could try and bring this down by diet and exercise and he referred me to the public health nurse at the clinic who is the diabetic educator there. The referral that he sent was able to get me into a gym program as well so that helped. I like that he gave me the option when I told him I didn’t want to take medicine and giving other options that were out there.” — Person without insurance; in her 30’s; Native American; with a chronic condition

“He told me that they had a federal grant to provide fitness memberships to people that were borderline diabetes or that had diabetes and wanted to do something about it and as an alternative to taking prescription medication. I went through that program, and it helped me immensely. I lost weight and I got everything back to the maintenance level. I’d rather do that than sit around and pop pills all day.” — Person with Medicaid; in his 50’s; Native American; with a chronic condition

For these focus group participants, patient-centered care was characterized by empathy – including on the part of non-clinical staff – and providers listening to and believing their patients. Participants also felt that non-clinical staff too often lack customer service skills, which can not only sour their experiences as patients but can also cost them money.

“Better customer service skills in my opinion. I had a dispute because the receptionist didn’t write down my appointment cancellation correctly and we ended up arguing over like a \$300 cancellation fee for six months or something. It might sound dumb because I’ve got bigger problems than people being rude or being polite, but I feel like that is a big thing. You’re there, you’re in pain, you’re paying them money to get help in one way or another. If it’s not coming out of your pocket, it’s coming from insurance or whatever. But if they’re getting paid to take care of you, they should act like it, you know?” — Person without insurance; in his 30’s; Latino; with a chronic condition

“They have that empathy, you know? If you don’t have empathy and compassion and you are unable to relate to your patient on some level, then I don’t know if being a doctor or whatever is really your field.” —Person with dual Medicare-Medicaid; in her 30’s; Latina; with a chronic condition

“They need to believe us. When we go to a doctor we’re not going there because we want to waste our time, their time or anybody’s time. We’re going there because we have an issue. What I found with my primary care physician is for three years I went to her with the same problem and she basically told me she didn’t believe me. I had to put it into a perspective as to what if it was her or what if it was her daughter that was in pain every single day. What would she do then? And then finally she sent me to the rheumatologist. They need to believe us.” —Person with dual Medicare-Medicaid; in her 30’s; Latina; with a chronic condition

“I want to share something about my doctor. I’ve been with him for probably 25 years and what I like about him is that he understands me, and he knows me and I think that’s important for a doctor to build a relationship with the patient to where I can trust him.” —Person with Medicare; in her 60’s; Latina; with a chronic condition

Methodology:

Public Agenda convened two online focus groups November 17 and 18, 2020 with residents of the Albuquerque and Santa Fe regions of New Mexico. 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. Participants were recruited who either had a chronic health condition or had been hospitalized for longer than 24 hours in the past five years. Public Agenda 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. Participants were recruited to include a mix of men and women and to include racial/ethnic diversity based on census benchmarks specific to New Mexico.

A total of 16 people participated in the focus groups. The focus groups were conducted in English and lasted two hours. Participants were paid for their time. Public Agenda staff moderated the 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 developed a coding system and coded the transcripts thematically.

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