Putting Patients at the Center of Care in Brooklyn and Queens

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To inform community forums about improving health care in Brooklyn and Queens, New York, Public Agenda conducted focus group research designed to learn what people in those parts of New York City who use the health care system think should be done to make care more patient-centered. Public Agenda convened two online focus groups February 23 and 24, 2021 with low-income residents of Brooklyn and Queens 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. Focus group participants want care that is accessible to them; enough doctors in their networks; and clinicians to stop overbooking appointments.
2. Participants described how intersecting inequalities based on race, gender, and insurance type affect the quality of their care.
3. Participants said that developing strong interpersonal relationships and cultivating constructive communication between clinicians and patients, as well as maintaining professionalism, are all essential to fostering patient-centered care.
4. Participants' recommendations for improving the health care system included updating the referral system, establishing a central database of personal medical information, and transparency about what their insurance covers. They also wanted access to healthier food and space to exercise in their neighborhoods.

Findings in detail:
1. Focus group participants want care that is accessible to them; enough doctors in their networks; and clinicians to stop overbooking appointments.
Focus group participants said they struggled to access clinicians and services and felt frustrated by the limited number of providers who accept their insurance. They complained about the burden of getting referrals for specialists, which causes delay in their care. Some participants pointed out that the combination of their complex medical needs and their narrow networks can make it difficult to find and to switch primary care doctors or specialists.

> "You can't go because he's not in the network. That's the way they have it now and to me, that makes everything more complicated and annoying. They make you wait for referrals or send you to places way out of your area because they'll say that doctor is in their network and that's the insurance that you have."[1] —Person with Medicare and Medicaid in her 50's; Black; recently hospitalized

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[1] Focus group quotes have been minimally edited for clarity.

"I wish there were more doctors in the network. When I switched from a PPO plan to Medicaid, maybe one out of like eight of my doctors actually took my new Medicaid insurance which makes it very challenging to find all new doctors when you already have existing conditions and you already know what's going on and you don't want to start all over with someone new."—Person with Medicaid in her 30's; Latina; with a chronic condition

When patients are able to find providers that are covered by Medicare or Medicaid, they said they find overbooked primary care doctors and specialists. Some hypothesized that doctors are overbooked because they are trying to make money by booking as many patients as they can. Participants complained that overloading appointment times leads to doctors rushing through appointments and to worse quality care, which several described as "malpractice." They wanted clinicians to take time and get to know their patients as people.

"Doctors who take a lot of Medicaid patients, they overbook. They're so greedy with the Medicaid compared to when I had my insurance with my old employer. And they don't respect your time. They think, oh, they have nowhere else to go, they're gonna just wait here two hours, you know?" —Person with Medicaid in his 40's; white; with a chronic condition

"I think they shouldn't book themselves up too much. The doctor that I just left, I think that he was doing too much. He couldn't attend to what people needed because there was so much going on. I felt like he just forgot a lot of things and it was like medical malpractice for me in a way."—Person with Medicare in his 50's; Black; with a chronic condition

"Overbooking is really the main issue because if you overbook then that leads to longer wait times. When you're waiting for the doctor, its shorter time to actually sit with the doctor so that he can address your issues and your problems. And then that leads to malpractice to a certain extent because then that can lead to like misdiagnosis, or they didn't really help any issue that you were specifically going to the doctor for." —Person with Medicaid in his 20's; Black; with a chronic condition

"Just like anything else, it is a business which is the bottom line. The airlines do that all the time. They want to make sure that they fill that plane up regardless of what the destination is and they overbook. And so doctors do the same thing; it's like any other business."—Person with Medicare in his 60's; Black; with a chronic condition

Some participants empathized with burnt out clinicians, blaming insurance companies and the health care industry as a whole for the pressure to fill appointment books. But they insisted that nonetheless, people need care that is easier to access and meets their needs.

"I know sometimes doctors are overwhelmed and they're overbooked and they're stressed out. But that shouldn't have to be my problem because I'm already stressed. You don't know what my ailment is. I'm sick so I'm coming to you. I expect to be

treated a certain way." —Person without insurance in her 50's; Black; with a chronic condition

2. Participants described how intersecting inequalities based on race, gender, and insurance type affect the quality of their care.

Focus group participants explained how inequities and discrimination based on their race, gender and type of insurance impacts the way clinicians treat them, like failing to listen to their concerns and needs. Participants felt that clinicians often mistrust them, which in turn leads them to mistrust clinicians – sometimes leaving them in pain while damaging their confidence in the health care system.[2] Participants also described mistreatment by non-clinical staff, such as administrators, which has negatively impacted their experiences with the health care system.

> "My daughter told me that her ears hurt. I took her to the emergency room, and they told me that she couldn't tell me that and about four hours later she had a full-blown ear infection. It made me think that because she was Black, it had to be a race issue. I never went back to that place because you didn't respect what my child said. She knows what's bothering her and she said her ears hurt. And they said she can't tell me that. They weren't listening and she's the patient."—Person with Medicare in her 70's; Black; with a chronic condition

> "I don't always like to bring gender and race, but I feel like it's important. I feel like as a woman, as a Black woman, I don't feel like I get the services that I need. I'm never really confident. And it's based on the communication because I think I'm articulate but then I feel like they just kind of rush me through." —Person without insurance in her 50's; Black; with a chronic condition

One participant also noted having a better experience with a woman doctor, who she felt listened to her concerns about fertility-related side effects of medications.

> "I was at one point seeing a GI doctor who I just felt was very stuck in his ways and wasn't willing to kind of like try to think outside the box for new treatments and wanted to put me on something that I had concerns with about how that would affect my future if I wanted to get pregnant. When I wound up switching to a female doctor, she totally understood where I was coming from, and it was a much different experience."—Person with Medicaid in her 30's; Latina; with a chronic condition

Focus group participants also raised concerns about inequities and discrimination by insurance type. Some said that clinicians' and staff members' demeanors changed when they found out that they are covered by Medicare or Medicaid, leading them to rush them through appointments or not listen.

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[2] 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/

"The staff's nicer when you have the regular insurance. I think it's like a domino effect because when you have Medicaid they know your insurance is not as good for prescriptions so they're not going to prescribe you the newest, most expensive drugs that you might get if you had a PPO or something from a regular employer."—Person with Medicaid in his 40's; white; with a chronic condition

"There is kind of like an unspoken change of demeanor of a doctor just knowing that they may not get [paid] as much as through a private insurance." —Person with Medicare in his 20's; Latino; with a chronic condition

But not all participants described experiencing worse quality of care due to their type of insurance.

"I never felt like doctors were giving me poor treatment because of my Medicaid. When I go in the clinic for treatment or to get a referral, they're rushed. I don't think it's because I'm on Medicaid. I just think that's the environment of the facility." —Person with Medicaid in her 40's; white; with a chronic condition

3. Participants said that developing strong interpersonal relationships and cultivating constructive communication between clinicians and patients, as well as maintaining professionalism, are all essential to fostering patient-centered care.
Participants emphasized the importance of constructive communication – both between clinicians and patients and among clinicians themselves. Across the board, focus group participants said communication is essential as they coordinate and navigate multiple specialists and types of care. Participants said that doctors and clinicians should get to know them, ask good questions, and remember their medical histories and their families' medical histories.

"Treat me like a human being. Communication is the key. If you ask the right questions, then I know that you at least read my chart. I know you have a lot of patients, but at least when you meet with me, I want to feel like technically I'm the only person in the room. So, pay attention to details and communicate with me. I'm a human being and treat me like you would treat your family and talk to me."—Person without insurance in her 50's; Black; with a chronic condition

"I've had a doctor who I went to like ten times and every time I went there, he was looking at me like he never saw me before. I'm like, what the hell? When I was in the hospital with COVID and he was like, 'You had COVID?' He was pretty much saying who the hell are you, you know? I like a doctor to know you on a personal level just so you can grow, have a relationship."—Person with Medicaid in his 40's; white; with a chronic condition

Participants said that in order for care to be patient-centered, clinicians need to develop human relationships with their patients, getting to know them and the resources and assets they have to take care of themselves. Focus group participants noted that this includes explaining their care and what they need to do for themselves at home.

> "What's lacking now is the educational component. It's not just being focused on writing a prescription or just medicate someone but really explain in simplified ways what the person is currently going through, what they can expect." —Person with Medicare in his 30's; Latino; with a chronic condition

> "I felt like I was on lupus for dummies when I first was diagnosed. They gave me a pamphlet like, you know, read this and this. The pharmacy's going to have all your medications. But I have all of these questions like, what am I supposed to do to help prevent certain things? I do think advocacy, patients' post-care, should definitely be emphasized more than it is now." —Person with Medicare and Medicaid in her 50's; Black; recently hospitalized

> "If they're a doctor, they should take a personal interest in every patient. Get to know you personally, and your personality so if that's your doctor, they can see changes, from one time to the other time. They can just understand you more and even just look at your face and mannerisms to see if there's any changes to your physical wellbeing, even mental wellbeing." —Person with Medicaid in his 40's; white; with a chronic condition

Because focus group participants felt that doctors are so often overbooked and have to rush through appointments, they wanted better systems for doctors and patients to keep each other informed. These participants often had multiple chronic conditions and were especially focused on doctors staying informed about the care they receive from other providers. The complex referral process made this lack of communication between providers especially frustrating for patients.

> "You call up that referral and they don't take Medicaid. Then you've got to call up the doctor or send an email in the app and there's no communication for a while. And then they send another referral for another doctor, and they don't take Medicaid. It's horrible communication. Sometimes you're sick, you've got to see a doctor right away for something, you don't plan for all that bullshit, you know?" —Person with Medicaid in his 40's; white; with a chronic condition

Participants emphasized mutual trust between clinicians and patients. They urged doctors to listen to them and trust what they say. One participant with lupus shared an experience in which doctors told her that her pain and bruises were not symptoms of her chronic illness and was asked if she had caused the injury herself.

> "I had woken up with a bruise on my leg a couple of times and I was afraid that I was having like a clot or something like that. I hurried up and had my appointment and he was like, oh, well, are you sure you didn't hit yourself? And I'm like okay, if I hit myself

I would know. He kind of like joked it off and I got a little upset. He saw so he changed his tone and [ordered the test]. I had to really become upset in order for him to acknowledge what I was saying. I think the rush causes a lot of harm when they're not really listening to what your issue is." —Person with Medicare and Medicaid in her 50's; Black; recently hospitalized

Participants described the important roles that nurses and non-clinical staff play in their care experiences. They suggested simple improvements like paying full attention to patients and communicating about delays as ways to make care more patient-centered.

"The first people that you come into contact with make or break the experience. It's really up to the support system to ensure things go smoothly, that information is being conveyed accurately. It's the staff where you'll find someone who speaks Spanish for example or that speaks Polish and those are really the people that are helping to streamline the communication and oftentimes, they'll spend that extra few minutes with the patient." —Person with Medicare in his 30's; Latino; with a chronic condition

"What I think needs help is people at the front desk, the people that check you in. Sometimes you're standing there waiting to check in and they're looking at their cellphone or they're chatting, and they see you're there, but they ignore you. They should keep that out of the sight of the patient that they're dealing with. It's just rude. They represent the doctor, so they need to be on decent behavior. Professionalism would be nice."—Person with Medicaid in her 50's; Latina and Asian; with a chronic condition

"I'd like to see nurses be a little bit more professional. I know that they have a hard job. And even the staff, the receptionists. I feel like it has something to do with leadership because I feel like if the doctor is not paying attention, I don't think his staff might." —Person without insurance in her 50's; Black; with a chronic condition

"Professionalism is definitely a big key. Once, people were waiting at the doctor's office for a while and some got upset. They went to the receptionist and asked what is the hold up? The receptionist kind of put their finger up and was like, this is just how it is. You need to have to wait and deal with it. Not 'I'm sorry for the wait, is there something I can do to help you along till you see the doctor? Or let me go back there and check to see if the doctor can see some patients a little bit quicker.' Just those little key things that could improve the relationship between nurses, receptionists, and the patients." —Person with Medicaid in his 20's; Black; recently hospitalized

"It's like sitting on the tarmac when you're waiting on a flight and it's like no one's saying anything. At least come and talk to us. We're human and it goes back to us being human, right?"—Person without insurance in her 50's; Black; with a chronic condition

4. Participants' recommendations for improving the health care system included updating the referral system, establishing a central database of personal medical information, and

transparency about what their insurance covers. They also wanted access to healthier food and space to exercise in their neighborhoods.

Participants wanted an improved and updated referral system, or even to get rid of the referral system altogether, in order to ease access and coordination between primary care doctors and specialists. They explained that referrals were especially complicated for them because they have chronic conditions and, often, narrow networks of clinicians who accept their coverage.

> "Maybe take away the referral system. Not totally but if they know that it's a chronic illness that you're going to have for the rest of your life you don't have to go to see your primary doctor so often just so you can get a referral. There should be another system in place besides that."—Person with Medicare in his 30's; Latino; with a chronic condition

> "Having lupus, not having to constantly be in touch with my primary doctor to give me referrals if there's an issue. I like to just be able to go to that doctor and have them accept my insurance or whatever."—Person with Medicare and Medicaid in her 50's; Black; recently hospitalized

> "My primary care doctor is at Northwell Health, so I always try to get referrals to Northwell Health because they have all my records and I have an app on my phone that shows me all my appointments, all my health information, all my medications pretty much my whole medical history. I always try to get a referral from that health care group. It's so much easier." —Person with Medicaid in his 40's; white; with a chronic condition

Some participants said that they felt that hospitals, clinics and doctor's offices actively do not share information with each other, and that patients must go out of their way to be their own advocates or get help from family or friends. Participants said they felt frustrated by outdated record-keeping and information-sharing systems. They said that with records and medical information scattered, they had to re-inform each new clinician and specialist about their medical conditions and histories. They wanted a streamlined, central location to keep all of their scattered records and medical information.

> "There are too many different touchpoints that delay things a lot of the time. If there was like one central place or one point of contact. Because you have to turn to like five different sources and you have to coordinate it yourself to make things happen where it should be a lot simpler. It almost feels like archaic and should already be more automated and not have to involve the patients."—Person with Medicare in his 30's; Latino; with a chronic condition

> "When I was going through my cancer diagnosis, I had to be my own advocate. I had to look pretty much look up and read up on everything because nobody really told me. There was no guidance. I've had a lot of friends who have friends that were diagnosed, and they would call me and ask me what I did. It's hard to navigate all of that and to figure out, it is really confusing."—Person with Medicaid in her 50's; Latina and Asian; with a chronic condition

"I was taking one of my neighbors back and forth to the specialist's office as his sight began to continue to deteriorate. He was dealing with Medicaid. I challenged the hospital: You get private funds, why aren't you using them for the Medicaid patients? When I challenged them all of a sudden, I don't have to try to take this half blind man on the train from Brooklyn to Manhattan. Now they have car services and everything."
—Person with Medicare and Medicaid in her 50's; Black; recently hospitalized

One participant wanted a centralized database of information about quality of providers' care in order to hold doctors and hospitals accountable.

"There should be a national database so that everyone in the medical field is a little bit more accountable for everything that they do. It would boost everything up on both sides. I think it would also help doctor/patient care. And then it would also help the patients pick the correct doctors for them." —Person with Medicaid in his 20's; Black; recently hospitalized

Participants said that their neighborhoods need better access to healthier food and spaces for exercise and activity. More equitable access to healthier foods could not only help people stay healthy but could also help people build stronger communities. They connected the lack of healthy food and environmental damage in their neighborhoods to politics, racism and classism.

"We live in a food desert. I live in East New York, near a water treatment plant. Just like lot of low income neighborhoods are always next to environmental hazards and things that I can't control when they affect my health. I do like to go to buy vegetables and fresh fruit but it's always a hassle to buy that when there's McDonald's and a Wendy's and a Burger King and everything else is within two blocks from me." —Person with Medicaid in her 50's; Black; recently hospitalized

"There's a lack of funding in our communities. We see what happened even with the census. And we saw with happened with COVID, right? Like we didn't have the proper care. There's a lot of politics behind that. I would add also racism. I mean unfortunately you tend to be a product of your environment so depending on where you live and where you come from, you know, we're targeted and when I say "we" I'm talking about minorities are targeted." —Person without insurance in her 50's; Black; with a chronic condition

"I actually have seen a few in Brooklyn where they have like a refrigerator for people who are homeless or who don't have access to good foods. It also builds like a sense of like community. Those are good things that could help your neighborhood out and people who might be suffering."—Person with Medicaid in his 20's; Black; recently hospitalized

Methodology:

Public Agenda convened two online focus groups February 23 and 24, 2021 with residents of Brooklyn and Queens in New York City. 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 Brooklyn and Queens.

A total of 14 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.

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