# A TWO-WAY STREET:

By Rebecca Silliman and David Schleifer

Building Trust Between People with Medicaid and Primary Care Doctors





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By Rebecca Silliman and David Schleifer Public Agenda 2020

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# **EXECUTIVE SUMMARY**

This report compares the views of people with Medicaid and of primary care doctors on how to build mutual trust. Based on representative surveys of both populations, main findings include:

Finding 1: Primary care doctors and people with Medicaid agree that trust should be mutual. Both feel equally responsible for building it and both feel that it takes time to develop. Doctors overwhelmingly trust patients with Medicaid unless that trust is broken. But more people with Medicaid express wariness, with nearly 4 in 10 saying doctors need to earn their trust.

Finding 2: Primary care doctors and people with Medicaid agree that in order for doctors to gain patients' trust, good listening and communication are top priorities. But the two groups have different priorities regarding other ways doctors can gain patients' trust. People with Medicaid prioritize doctors following basic safety protocols, while doctors think it is more important to consider their patients' finances and lifestyles. Few people with Medicaid say that a doctor's race or gender affects their trust.

Finding 3: Nearly 4 in 10 people with Medicaid say they have been treated by a primary care doctor whom they did not trust. Most people who have had those negative experiences say that as a result, they have behaved in ways that could negatively affect their health, such as stopping medications or delaying care. More of those who have been treated by a doctor they did not trust also say they have behaved in ways that could damage doctors' trust in them.

Finding 4: Primary care doctors largely feel that patients with Medicaid are just as trustworthy as patients with other types of insurance. But when patients with Medicaid are actively engaged in their care, such as by participating in decisions or voicing their health goals, primary care doctors trust them more. These doctors are less trusting, however, when patients with Medicaid leave out information, exaggerate symptoms or insist on specific treatments.

#### **Recommendations for Building Mutual Trust in Primary Care**

- 1. By demonstrating that they take safety seriously, doctors can help build trust with patients.
- 2. Increasing patient activation and engagement may increase doctors' trust in patients.
- 3. Creating time and space in primary care practices for mutual communication can build reciprocal trust.
- 4. Doctors can build trust by finding ways to discuss social determinants of health without alienating patients.
- Developing the evidence base for how and why doctors should build trust in patients can help move health care away from paternalism and toward centering patients.

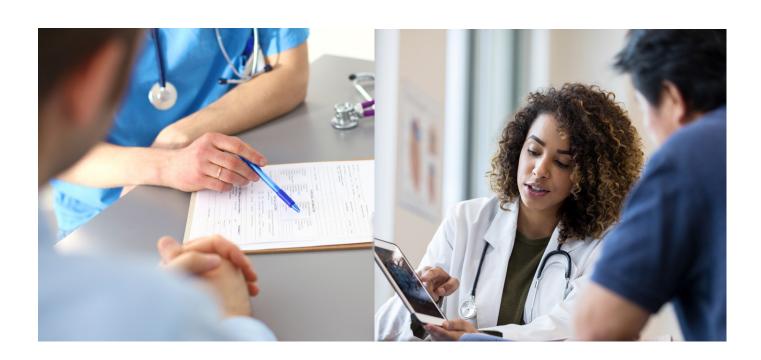
# INTRODUCTION

Trust is central to relationships between patients and health care providers. Trust is a complex concept that broadly speaking involves the optimistic acceptance of vulnerability.<sup>1</sup> Patients who are more trusting of their providers tend to be more satisfied with their treatment, behave in ways that are more beneficial to their health, report fewer symptoms and have a higher quality of life.<sup>2</sup> Yet over the last 50 years, trust in medical professionals has declined in the United States and not in other countries.<sup>3</sup>

The long-term problems of racism in health care and racial disparities in health outcomes are receiving renewed attention owing to both the Black Lives Matter movement and the coronavirus pandemic.<sup>4</sup> Even before the pandemic, Black Americans tended to be less trusting of physicians and hospitals than white or Latino/a Americans.<sup>5</sup> Lower-income people also tend to be less trusting of physicians than those with higher incomes.<sup>6</sup> COVID-19 infections and deaths have so far disproportionately affected low-income Americans and people of color.<sup>7</sup> This research was conducted before both the pandemic and the nationwide reckoning with racial injustice, which have further highlighted the need to build trust between health care providers and historically marginalized communities.

Research and interventions related to trust are almost universally unidirectional, overwhelmingly focused on patients' trust in physicians.<sup>8</sup> For example, there is only one validated scale that measures physicians' trust in patients, but many scales measure patients' trust in physicians and other providers.<sup>9</sup> But trust should be reciprocal in order to facilitate sustained physician-patient partnerships.<sup>10</sup> Physicians need to trust their patients for a variety of reasons, including to provide reliable information, participate in complex and potentially high-stakes decisions and follow treatment plans.<sup>11</sup>

It is therefore not only important to explore what patients believe can build or damage their trust in physicians—it is also important to understand what physicians believe affects their trust in patients. Comparing how well physicians understand what patients think affects trust and vice versa can help to identify where patients and physicians see eye to eye and where they misunderstand each other, creating a foundation for interventions that can build mutual trust.



#### **About This Research**

This research compares the views of two populations: people insured by Medicaid and primary care doctors who treat people with Medicaid. The research involved representative surveys of each population as well as separate focus groups with each population, described further below.

The research focuses on primary care because it is critical to individual health and to reducing disparities.<sup>12</sup> While only primary care doctors who treat people with Medicaid participated in this research, for brevity, this report uses the terms "primary care doctor" and "PCP." Because people with Medicaid who participated in the focus groups often used the term "primary care doctor," that term is written into many of this study's survey questions.

The research focuses on people covered by Medicaid because they tend to be low-income, with higher rates of disease and disability than the privately insured. Black and Latino/a nonelderly adults are disproportionately covered by Medicaid compared with whites.<sup>13</sup> People with Medicaid also tend to be less trusting of physicians than the privately insured.<sup>14</sup>

By focusing on people with Medicaid, this research does not capture the views of people who are uninsured. Nor does it include the views of people covered by private insurance or Medicare. However, people with Medicaid constitute about 20 percent of American adults. <sup>15</sup> So this research provides a representative picture of a large population that is easily identifiable for communications, programming and other interventions.

#### Methodology in Brief

This report summarizes findings from two representative surveys: one of 1,008 adults 18 years and older who are covered by Medicaid and one of 402 primary care doctors who treat people with Medicaid. This research was supported by a grant from the Robert Wood Johnson Foundation.

The survey of people with Medicaid was fielded from August 9 to September 13, 2019, online for Public Agenda by Ipsos using the probability-based web-enabled KnowledgePanel. Respondents completed the Medicaid beneficiary survey in English or Spanish. The data are weighted to the characteristics of lower-income Americans based on the March 2018 Current Population Survey.

The survey of primary care doctors who treat people with Medicaid was fielded from August 9 to September 13, 2019. Only doctors who treat people with Medicaid were surveyed. That survey was fielded online for Public Agenda by Ipsos using a sample drawn from the Physicians Consulting Network panel, a double opt-in panel of physicians and other medical professionals recruited through a license with the American Medical Association. Respondents completed the physician survey in English. The data are weighted to balance the sample to known characteristics of primary care doctors.

Before developing the surveys, Public Agenda conducted four focus groups in December 2018: two with people with Medicaid in New York City and Philadelphia and two with primary care doctors who treat people with Medicaid, also in New York City and Philadelphia. Public Agenda staff designed screener questionnaires to recruit participants to our specifications. We worked with professional focus group facilities to recruit participants based on our screener. Public Agenda staff designed the focus group moderator guides and moderated all the groups. Focus group conversations lasted two hours and participants were compensated for their time. The groups were recorded and the recordings were professionally transcribed.

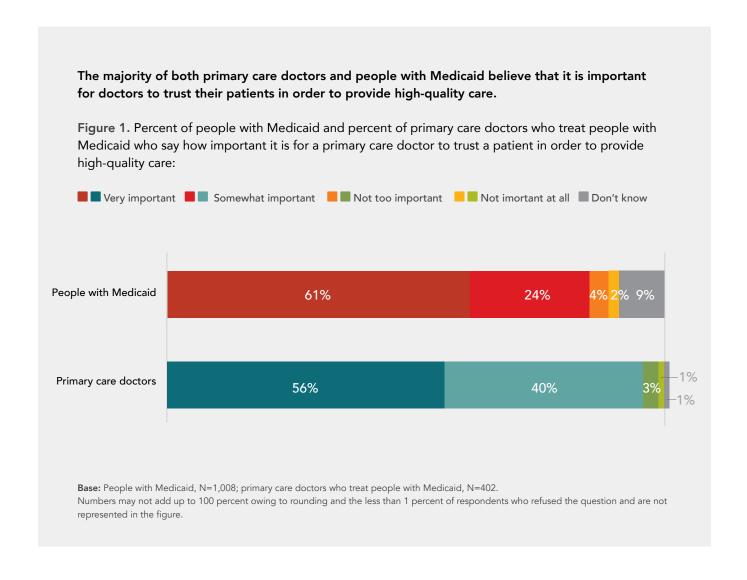
For a complete methodology providing more detail about the focus groups and surveys, sample characteristics and the surveys' toplines with full question wording, please go to <a href="https://www.publicagenda.org/reports/a-two-way-street-building-trust-between-people-with-medicaid-and-primary-care-doctors/">https://www.publicagenda.org/reports/a-two-way-street-building-trust-between-people-with-medicaid-and-primary-care-doctors/</a> or email <a href="mailto:research@publicagenda.org">research@publicagenda.org</a>.

# MAIN FINDINGS



Primary care doctors and people with Medicaid agree that trust should be mutual. Both feel equally responsible for building it and both feel that it takes time to develop. Doctors overwhelmingly trust patients with Medicaid unless that trust is broken. But more people with Medicaid express wariness, with nearly 4 in 10 saying doctors need to earn their trust.

Previous research focuses largely on patients' trust in providers. But this research finds that most primary care doctors and most people with Medicaid believe that in order for doctors to provide high-quality care, it is important that they trust their patients; see figure 1. Both groups also understand the importance of patients trusting doctors; see figure 2.



#### Majorities of primary care doctors and people with Medicaid understand the importance of patients trusting doctors. Figure 2. Percent of people with Medicaid and primary care doctors who treat people with Medicaid who agree or disagree that if a patient with Medicaid trusts a primary care doctor, it is easier for the doctor to provide them with high-quality care: ■ Strongly agree ■ Somewhat agree ■ Somewhat disagree □ Strongly disagree People with Medicaid 36% 49% 12% 2% 64% 30% Primary care doctors Base: People with Medicaid, N=1,008; primary care doctors who treat people with Medicaid, N=402. Numbers may not add up to 100 percent owing to rounding and the less than 1 percent of respondents who refused the question and are not represented in the figure.

People with Medicaid in focus groups talked about the importance both of trusting their primary care doctors and of their primary care doctors trusting them, and of the mutually reinforcing nature of trust:

"If you want them to take certain steps for you, then they do have to trust you, and know that you're committed to your care as much as they are." —Person with Medicaid; in his 30s; Black; Philadelphia, PA

"It's important for your doctor to trust you when you go for a checkup. It's important for you to be completely honest with your doctor. That's the only way they could trust you, and that's the only way they can help you with whatever medical problem you have." —Person with Medicaid; in her 20s; Black; New York, NY

"Yes, it's important that I trust my doctor, but it's very important that they trust me, too. Otherwise, they're not going to prescribe the medication that I continuously need." —Person with Medicaid; in her 30s; white; New York, NY

Primary care doctors in the focus groups also described the importance of mutual trust in their relationships with patients with Medicaid:

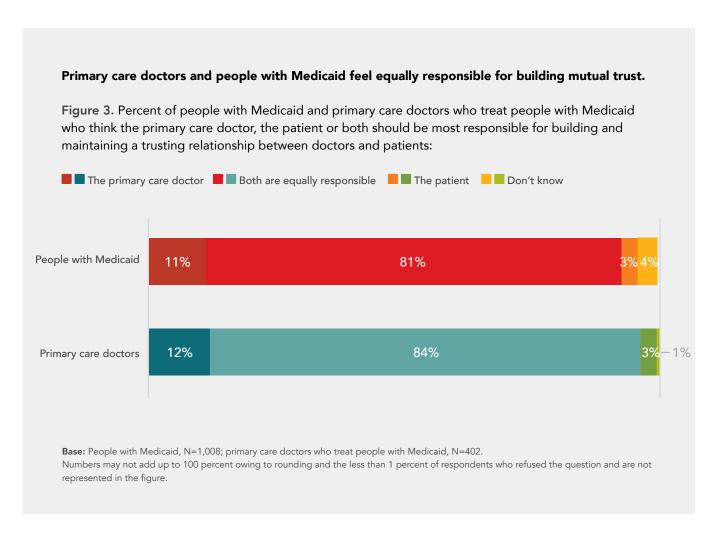
"If I don't trust them, then I don't have compliance and I'm not spending my time. Because it's a waste of time if they're untrustworthy." —Primary care doctor; in his 40s; white; Philadelphia, PA

"You can't tell them anything if they don't trust you. You can't advise. You're paralyzed. They may as well change doctors." —Primary care doctor; in her 50s; white; New York, NY

"If they're not going to trust my opinions, then there's no point in even treating them because they're not going to listen to what I say and do what I say." —Primary care doctor; in his 60s; white; Philadelphia, PA

#### Primary care doctors and people with Medicaid feel equally responsible for building mutual trust.

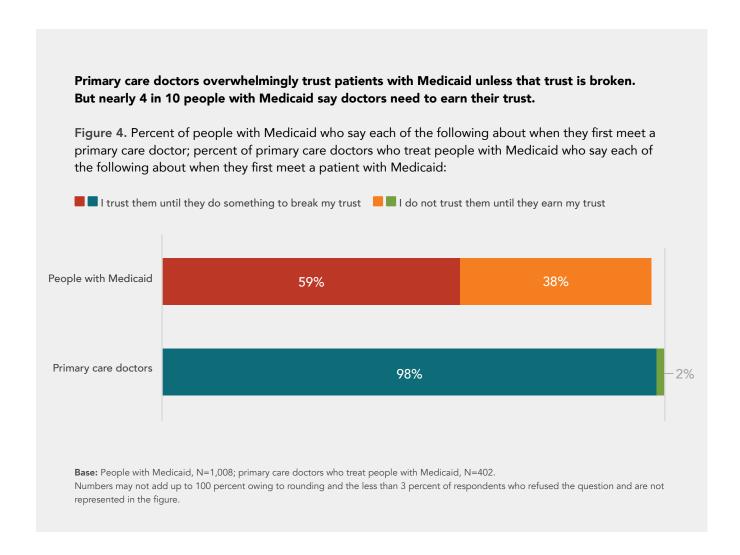
Not only do both primary care doctors and people with Medicaid agree that trust must be mutual, but majorities of both groups feel equally responsible for it; see figure 3.



# Nearly all primary care doctors trust patients with Medicaid unless that trust is broken. But nearly 4 in 10 people with Medicaid say doctors need to earn their trust.

The vast majority of primary care doctors say that when they first meet a patient with Medicaid, they trust that patient until they do something to break their trust. But nearly 4 in 10 people with Medicaid express wariness, saying that they do not trust a new primary care doctor until that doctor earns their trust; see **figure 4**. One primary care doctor in the focus group recognized that he needs to earn the trust of patients with Medicaid:

"As a result of the trust, you have good outcomes because the patient will adhere to the regimen, will come back to see you, will trust your judgment. But you have to gain the trust." —Primary care doctor; in his 60s; white; New York, NY



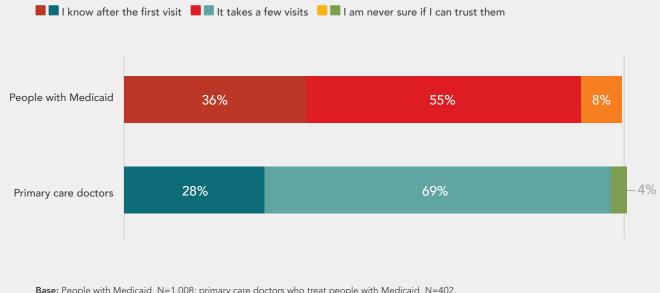
#### Primary care doctors and people with Medicaid both feel that it takes time to know if they can trust each other.

While the vast majority of primary care doctors say that they trust patients with Medicaid until they do something to break their trust, most of them also say it takes a few visits to know whether they can trust those patients; see figure 5. In other words, while these doctors' default setting is to trust their patients with Medicaid, most also say it takes some time to know whether they can trust them. Similarly, just over half of people with Medicaid feel that it takes a few visits to know whether they can trust a primary care doctor; see figure 5.

These primary care doctors feel similarly about patients with other types of insurance—namely, that it takes a few visits to know whether they can trust them; see figure 6. While all of the primary care doctors included in this survey treat patients with Medicaid, only 6 percent say that people with Medicaid account for more than half of their patients. Seventy-three percent of them say that only up to a quarter of their patients are covered by Medicaid, and 21 percent say that a quarter to half of their patients are covered by Medicaid.

#### Primary care doctors and people with Medicaid say it takes a few visits to know whether they can trust each other.

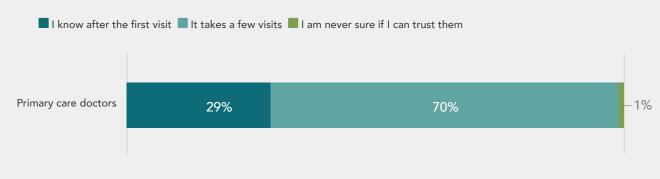
Figure 5. Percent of people with Medicaid who say how long it would take them to know if they could trust a primary care doctor whom they had never met before; and percent of primary care doctors who treat people with Medicaid who say how long it would take them to know if they could trust a patient with Medicaid whom they have never met before:



Base: People with Medicaid, N=1,008; primary care doctors who treat people with Medicaid, N=402. Numbers may not add up to 100 percent owing to rounding and the less than 1 percent of respondents who refused the question and are not represented in the figure.

#### Most primary care doctors believe it takes a few visits to know whether they can trust patients with insurance other than Medicaid.

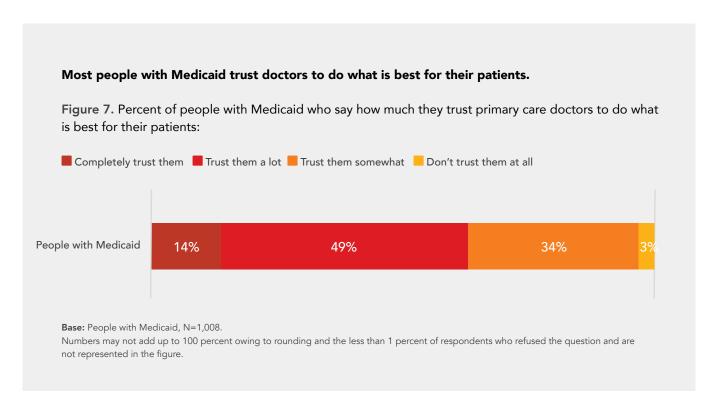
Figure 6. Percent of primary care doctors who say they know whether they can trust a patient with insurance other than Medicaid after the first visit, after a few visits or never:



Base: Primary care doctors who treat people with Medicaid, N=402.

Primary care doctors and people with Medicaid agree that in order for doctors to gain patients' trust, good listening and communication are top priorities. But the two groups have different priorities regarding other ways doctors can gain patients' trust. People with Medicaid prioritize doctors following basic safety protocols, while doctors think it is more important to consider their patients' finances and lifestyles. Few people with Medicaid say that a doctor's race or gender affects their trust.

Patients benefit in many ways when they trust their providers. 16 This survey found that 63 percent of people with Medicaid completely trust doctors or trust them a lot to do what is best for patients; see figure 7. However, that means that one-third of people with Medicaid trust doctors only somewhat or not at all.<sup>17</sup>



Primary care doctors and patients with Medicaid agree that listening and communicating is the single most important thing doctors can do to gain patients' trust. But beyond communication, their priorities differ.

As noted above, about half of people with Medicaid say that it takes a few visits to know whether they can trust a doctor. How, then, can primary care doctors gain these individuals' trust? According to both primary care doctors and people with Medicaid, listening and communicating effectively is the most important thing doctors can do

to gain patients' trust; see figure 8. However, these two groups may have different understandings of what good communication means; see page 20.

People with Medicaid in focus groups described the importance of primary care doctors listening and communicating effectively—as well as the frustration they feel when doctors fail to listen. Focus group participants often attributed those failures to doctors rushing through appointments:

"They're rushing in and out, and just signing the script and not wanting to listen. They should listen and give you feedback and not just say, 'Here I'll give you this medicine.'" —Person with Medicaid; in her 30s; white; Philadelphia, PA

"You try to tell them something and they'll cut you off. I'm like, 'Wow, can I finish and tell you what's going on with me?' It's like they don't want to hear. Like they already had an answer. But they didn't let me finish laying out the problem." —Person with Medicaid; in her 40s; Black; Philadelphia, PA

"It's really a matter of the tone. That tone can really determine how much you're going to tell your doctor, because if they say something in a condescending way, you're going to just shut down. And that can be detrimental to you." -Person with Medicaid; in her 40s; Latino/a; Philadelphia, PA

But beyond listening and communicating, people with Medicaid and primary care doctors prioritize different behaviors for building trust. After listening and communicating, the two behaviors that people with Medicaid most commonly rate as priorities for doctors to build trust with them are being honest and being thorough and careful. But most primary care doctors say that including patients in decision-making and considering patients' finances and lifestyles are more important to building trust with their patients with Medicaid than being honest, thorough and careful; see figure 8.

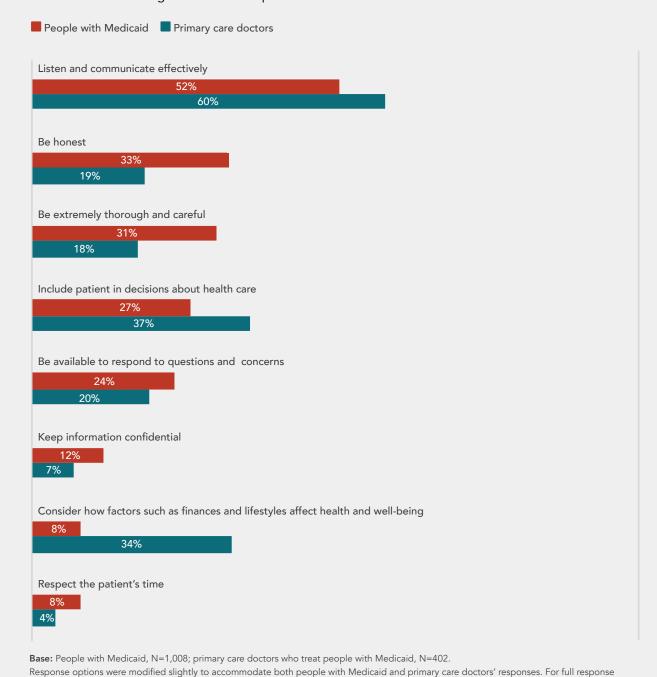
A person with Medicaid in a focus group described the frustration of dealing with a doctor who was not thorough or careful. The focus group participant said she eventually changed doctors.

"One time I had strep throat. I was sure I had this when I went to the doctor, because I looked inside my own throat. He said, 'You're fine. You just have a cough, and that's it.' But he didn't even look. I said, 'Are you sure I don't have strep throat? Because it's really painful and I saw some white spots.' Then he looked, and he said, 'Oh, yes, you do have it.'" —Person with Medicaid; in her 40s; Asian; New York, NY

In other words, when it comes to building trust, people with Medicaid want primary care doctors to take care of the basics: honesty, thoroughness and being careful. But primary care doctors do not necessarily see those behaviors as priorities for building trust. These dynamics come out even more strongly when people with Medicaid ranked doctors' behaviors that can damage trust, where following basic safety protocols emerged as a top priority; see page 15.

Primary care doctors and patients with Medicaid agree that listening and communicating is the single most important thing doctors can do to gain patients' trust. But beyond communication, their priorities differ.

Figure 8. Percent of people with Medicaid and percent of primary care doctors who treat people with Medicaid who selected each of the following items as one of the two most important things a primary care doctor can do to gain the trust of a patient with Medicaid:



options, please see full methodology.

More primary care doctors think they can gain the trust of their patients with Medicaid by considering how their finances and lifestyles affect their health. Few people with Medicaid share those priorities.

Health care providers are increasingly screening for and attempting to address social needs such as housing, food security and education.18 A third of primary care doctors in this survey rank considering how finances and lifestyle factors affect patients' health as one of the most important things they can do to gain the trust of their patients with Medicaid. But very few people with Medicaid rank that among the most important things a doctor can do to gain their trust; see figure 8.

Public Agenda's previous qualitative research with low-income parents in New York City found that those focus group participants were concerned that discussing social needs with their children's pediatricians could be time-consuming distractions from the pressing health concerns that brought them to the pediatrician's office in the first place. 19 While that research was specific to pediatric care, it serves as a reminder that discussing social needs in health care settings is not likely what motivates a patient to make a doctor's appointment.

Most people with Medicaid say that basic safety errors—such as prescribing medications without checking what else patients are taking or ordering unnecessary tests—would make them trust a primary care doctor less and try to find a new one. But few primary care doctors view those safety measures as priorities for building trust.

Continuity of care leads to better health.20 Therefore, the survey of people with Medicaid asked about several hypothetical negative behaviors that primary care doctors might engage in. It asked people with Medicaid whether each behavior would damage their trust so much that they would try to find a new doctor.\* The survey of primary care doctors used positive or inverse versions of those hypothetical behaviors and asked doctors to rank which were the three most important for gaining the trust of patients with Medicaid.

Although preventable harms from medical error remain unacceptably frequent, relatively few primary care doctors ranked basic safety protocols among their three most important trust-building behaviors.<sup>21</sup> These providers may indeed value patient safety, but when they were forced to choose, their priorities for building trust lay more with interpersonal aspects of care.

People with Medicaid, however, rank basic safety protocols as priorities. For example, three-quarters of people with Medicaid say that if a primary care doctor failed to admit a mistake, they would trust that doctor less and try to find a new one. Only 3 percent of PCPs said that admitting a mistake is among the top three things they can do to gain the trust of Medicaid patients; see figure 9.

Furthermore, 70 percent of people with Medicaid say that if a primary care doctor failed to check which other medications they were taking before prescribing something new, they would trust that doctor less and try to find a new one. Despite the dangers of polypharmacy, only 18 percent of primary care doctors ranked checking which other medications patients were taking before prescribing something new as one of the top three things they can do to gain the trust of Medicaid patients; see figure 9.

About two-thirds of people with Medicaid also say that if a primary care doctor prescribed medications or tests that were not necessary, they would trust that doctor less and try to find a new primary care doctor. Yet despite efforts to reduce the use of low-value care, just 16 percent of PCPs ranked only prescribing medications and tests that are really necessary among the top three things they can do to gain the trust of patients with Medicaid; see figure 9.

<sup>\*</sup> The survey found that most people with Medicaid (79 percent) say it is easy to find a primary care doctor who accepts their insurance. Only 16 percent say it is difficult.

The high priority that people with Medicaid place on basic safety and avoiding unnecessary care is consistent with findings from Public Agenda's representative survey of people in New York State.<sup>22</sup>

Primary care doctors and people with Medicaid are generally on the same page when it comes to the importance of doctors treating patients like people with unique needs—three-quarters of people with Medicaid say they that if a primary care doctor failed to do so, they would trust that doctor less and try to find a new one. A relatively high percentage of primary care doctors say treating patients like people with unique needs is one of the three most important things they can do to gain the trust of people with Medicaid; see figure 9.

#### Both primary care doctors and people with Medicaid value shared decision-making as a way to build trust.

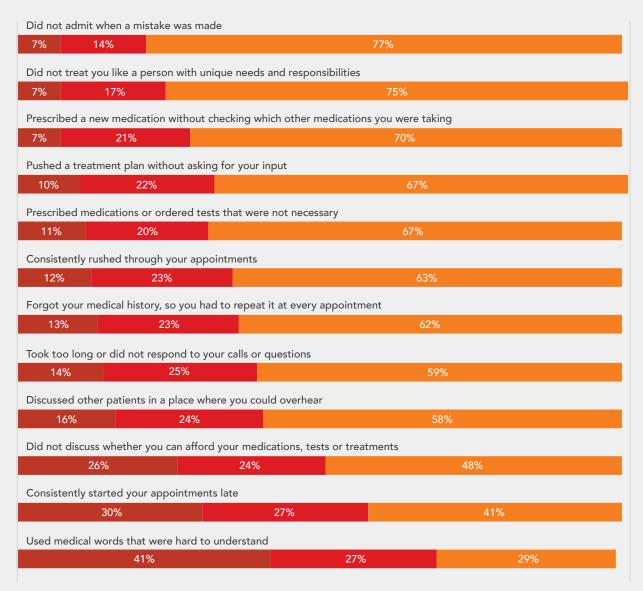
Shared decision-making has many benefits for patients and providers. It can lead to the creation of treatment plans that reflect patients' goals, can increase patients' and physicians' satisfaction and can improve patient outcomes.<sup>23</sup> In both batteries of survey questions for primary care doctors about trust-building, relatively high percentages of doctors ranked shared decision-making as a top priority for building trust with Medicaid patients; see figure 8 and figure 9.

While few people with Medicaid (27 percent) rank shared decision-making among their top priorities for building trust (see figure 8), two-thirds of them say that if a primary care doctor pushed a treatment plan without asking for their input, they would trust that doctor less and try to find a new one; see figure 9.

#### People with Medicaid say their trust would be damaged if a primary care doctor made basic safety errors.

Figure 9a. Percent of people with Medicaid who indicate how they would react if a primary care doctor did each of the following:

- It would NOT affect my trust in them
- I would trust them less but continue to see them
- I would trust them less and try to find a new primary care doctor



Base: People with Medicaid, N=1,008.

Numbers may not add up to 100 percent owing to rounding and the less than 2 percent of respondents who refused the questions and are not represented in the figure.

#### Few primary care doctors prioritize basic safety measures as ways of building trust.

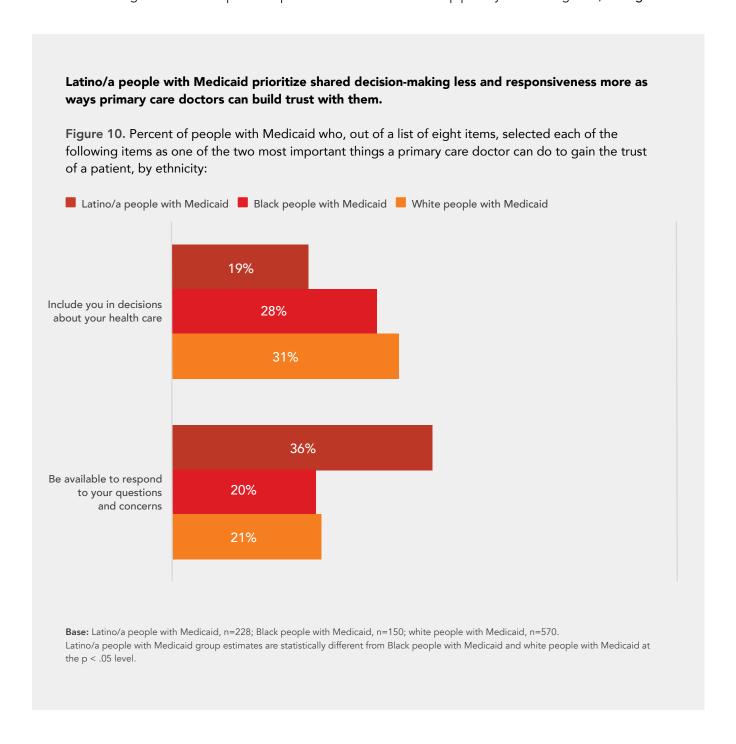
Figure 9b. Percent of primary care doctors who treat people with Medicaid who selected each of the following items as one of the three most important things they, as a primary care doctor, could do to gain the trust of patients with Medicaid:

Admit when a mistake was made  3%
Treat them like a person with unique needs and responsibilities  56%
Check which other medications they were taking before prescribing new medications  18%
Discuss treatment plans with them and ask for their input  58%
Only prescribe medications or order tests that are necessary  16%
Ensure they are not rushed through appointments  22%
Remember their medical history, so they do not have to repeat it at every appointment  14%
Respond to their calls and questions in a timely manner  35%
Only discuss patients in a place where other patients cannot overhear  4%
Discuss whether they can afford their medications, tests and treatments  29%
Consistently start appointments on time  6%
Use medical terminology that is easy for them to understand  33%

 $\textbf{Base:} \ \text{Primary care doctors who treat people with Medicaid, N=402}.$ 

#### Latino/a people with Medicaid prioritize shared decision-making less and responsiveness more as ways primary care doctors can build trust with them.

Fewer Latino/a than Black or white people with Medicaid say that being included in decisions about their health care is a priority for primary care doctors to build trust with them. Latino/a people with Medicaid also differ in how much they prioritize primary care doctors' responsiveness. More Latino/a than Black or white people with Medicaid rank primary care doctors being available to respond to questions and concerns as a top priority for building trust; see figure 10.



#### People with Medicaid and doctors may have different visions of what good communication means.

As noted earlier in this section, both primary care doctors and people with Medicaid prioritize listening and communicating effectively as a way to build trust. But these two groups may have different ideas about what good communication means. Only 29 percent of people with Medicaid say that if a primary care doctor used medical words that were hard to understand, they would trust that doctor less and try to find a new one. In fact, 41 percent of them say that their trust would not be affected at all if a doctor did so; see figure 9.

However, a third of primary care doctors say that using medical terminology that is easy for patients to understand is one of the three most important things they can do to gain the trust of patients with Medicaid; see figure 9. This contrast suggests that doctors may think they need to simplify their language for patients with Medicaid. But those patients may expect some complexity in their doctors' language, may not care much about that complexity or may not want doctors to talk down to them.

Several people with Medicaid in focus groups talked about how much they dislike it when doctors simplify their language for them:

"The thing I love most about my PCP is that he treats me like an intelligent enough person to receive some of the more complex explanations for things. The thing that bothered me most in the past about doctors is feeling like there's this big gap of authority between us. I would feel like they're just dumbing things down for me in an insulting way." —Person with Medicaid; in her 20s; multiracial; New York, NY

"I've had doctors assume because I was a patient I can't comprehend what they would say or whatever, which is ridiculous." —Person with Medicaid; in his 20s; biracial; Philadelphia, PA

A primary care doctor in New York City explained how she tries to communicate with patients without condescending to them:

"I don't talk down to them. That sounds a little bit paternalistic. It's knowing where they're coming from."

-Primary care doctor; in her 40s; Asian; New York, NY

#### Few people with Medicaid feel that a doctor's race or gender affects their trust.

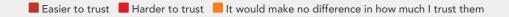
Personal connections matter to people with Medicaid. Half of them say that they find it easier to trust a doctor who was recommended by someone they know. But far fewer say it would be easier to trust a doctor who is the same gender or race as they are; see figure 11.

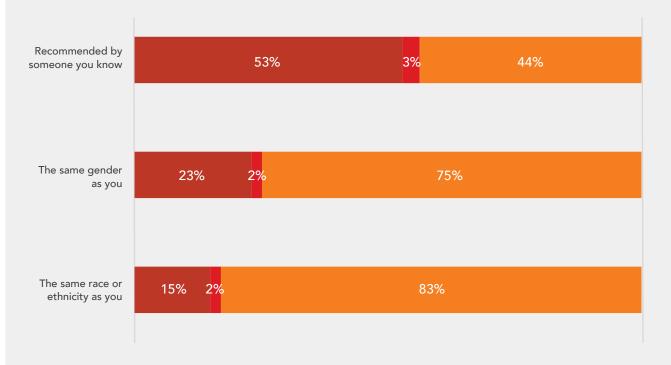
However, more Black and Latino/a people with Medicaid (18 percent and 22 percent, respectively) say it would be easier to trust a primary care doctor of the same race or ethnicity, compared with only 10 percent of white people with Medicaid who feel that way. Similarly, more women (31 percent) than men (14 percent) with Medicaid say it would be easier to trust a primary care doctor of the same gender.

Other research has shown that a perhaps surprisingly small percentage of Black and Latino/a people prefer physicians of the same race, although those preferences are stronger among those who are more aware of racism.<sup>24</sup>

#### Half of people with Medicaid would find it easier to trust a doctor recommended by someone they know. Few say a doctor's race or gender would affect their trust.

Figure 11. Percent of people with Medicaid who would find it easier or harder to trust a primary care doctor who is recommended to them, the same gender or the same race or ethnicity:





Base: People with Medicaid, N=1,008.

Numbers may not add up to 100 percent owing to rounding and the less than 1 percent of respondents who refused the questions and are not represented in the figure.

Nearly 4 in 10 people with Medicaid say they have been treated by a primary care doctor whom they did not trust. Most people who have had those negative experiences say that as a result, they have behaved in ways that could negatively affect their health, such as stopping medications or delaying care. More of those who have been treated by a doctor they did not trust also say they have behaved in ways that could damage doctors' trust in them.

People who are more trusting of their health care providers tend to be more satisfied with their treatment, behave in ways that benefit their health, report fewer symptoms and have a higher quality of life.<sup>25</sup> But 38 percent of people with Medicaid say that they have received care from a primary care doctor whom they did not trust.

Previous research has found that Black Americans tend to be less trusting of physicians and hospitals than white or Latino/a Americans.<sup>26</sup> But this research actually found that more white (44 percent) than Black (28 percent) or Latino/a (33 percent) people with Medicaid report that they have received care from a primary care doctor whom they did not trust.

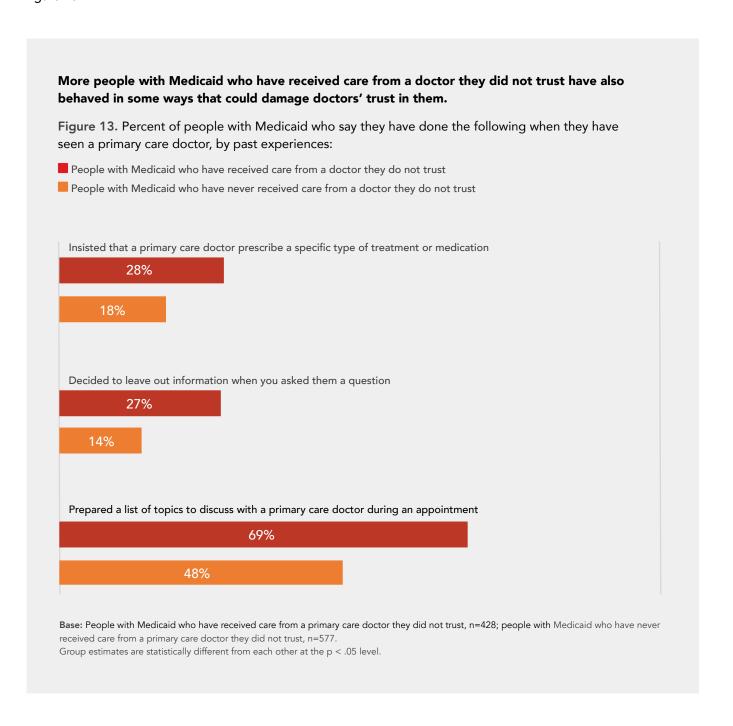
Most people with Medicaid who have received care from a primary care doctor they did not trust say that as a result, they have behaved in ways that could negatively affect their health.

Most people with Medicaid who have received care from a primary care doctor they did not trust say that as a result, they have behaved in ways that could negatively impact their health, such stopping medications prematurely or delaying getting care; see figure 12. Eighty-four percent of them say they have switched primary care doctors as a result, which could disrupt the continuity of their care but could mean that they found doctors whom they trusted more.

Most people with Medicaid who have received care from a primary care doctor they did not trust say that as a result, they have behaved in ways that could negatively affect their health. Figure 12. Percent of people with Medicaid who have received care from a primary care doctor they did not trust who say they have done each of the following because they did not trust a primary care doctor: Switched primary care doctors 84% Delayed getting care 66% Stopped taking medication or stopped following a primary care doctor's instructions 50% Base: People with Medicaid who have ever received care from a primary care doctor they did not trust, n=428.

#### More people with Medicaid who have received care from a doctor they did not trust have behaved in ways that could damage doctors' trust in them.

As Finding 4 explains, primary care doctors say that they trust patients less who engage in behaviors such as insisting that they prescribe a specific medication or leaving out information in response to questions. Yet more people with Medicaid who have received care from a doctor they did not trust say they have engaged in precisely those and other behaviors that can damage doctors' trust in them. On the other hand, more of them also say they have prepared a list of topics to discuss during an appointment, which primary care doctors actually say builds their trust in patients; see figure 13.

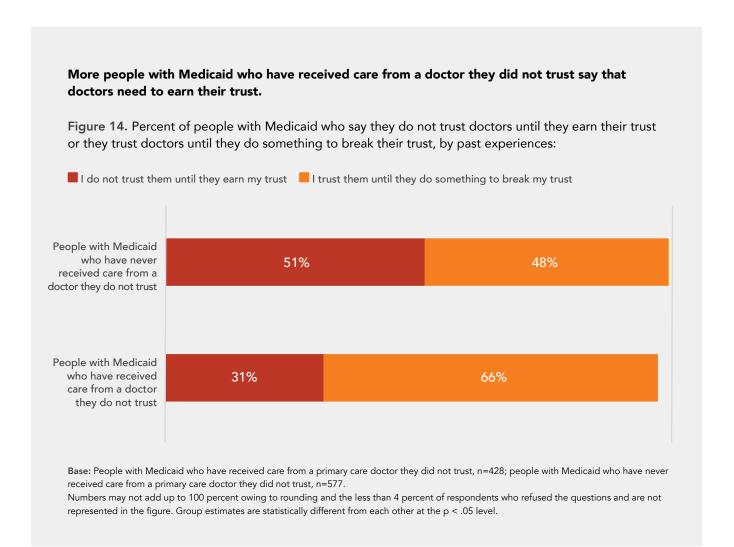


#### Among those who have received care from a doctor they did not trust, fewer say they trust doctors to do what is best for their patients. More say that doctors need to earn their trust.

People with Medicaid who have had these negative experiences may generally be more wary overall and may therefore be more likely to say they have mistrusted a doctor. Or they may have had truly negative experiences that changed how they perceive health care providers. Whichever direction the causal arrow points, this group of people provides a window into the complex nature of trust.

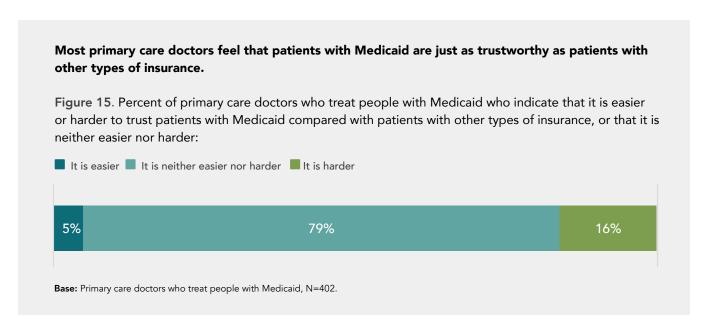
For example, only 50 percent of those who have received care from a doctor they did not trust say they completely trust doctors or trust them a lot to do what is best for their patients. By comparison, 71 percent of those who do not report such negative experiences say they completely trust doctors or trust them a lot. Also, more of those who have received care from a primary care doctor they did not trust (31 percent) think primary care doctors are less trusting of people with Medicaid, compared with only 14 percent of people who do not report that type of negative experience.

Similarly, half of those who report receiving care from a doctor they did not trust say they do not trust a doctor until he or she earns their trust, compared with only one-third of people who have not had that type of negative experience; see figure 14.



Primary care doctors largely feel that patients with Medicaid are just as trustworthy as patients with other types of insurance. But when patients with Medicaid are actively engaged in their care, such as by participating in decisions or voicing their health goals, primary care doctors trust them more. These doctors are less trusting, however, when patients with Medicaid leave out information, exaggerate symptoms or insist on specific treatments.

Theoretically, patients should benefit if their health care providers trust them.<sup>27</sup> Most primary care doctors who treat people with Medicaid also treat people with other types of insurance, as discussed on page 10. And most of these doctors—80 percent—say they know whether a patient is covered by Medicaid when they see them. Yet for the most part, these PCPs feel that their patients with Medicaid are neither easier nor harder to trust than patients with other types of insurance; see figure 15.



Sixty-four percent of these primary care doctors say that most patients with Medicaid try their best to take care of their health. But this leaves a substantial 36 percent who do not think so. Furthermore, 59 percent of these doctors say that patients with Medicaid are more demanding than those with other types of insurance.

Several primary care doctors in focus groups talked about how demanding they felt patients with Medicaid can be, which some attributed to their belief that these patients do not pay any out-of-pocket costs for their insurance or for medical services and therefore feel more entitled:

"I'm here to take care of you if you have a problem. But I'm not here to give you all these things that you want because the government is paying for it." —Primary care doctor; in his 50s; Black; New York, NY

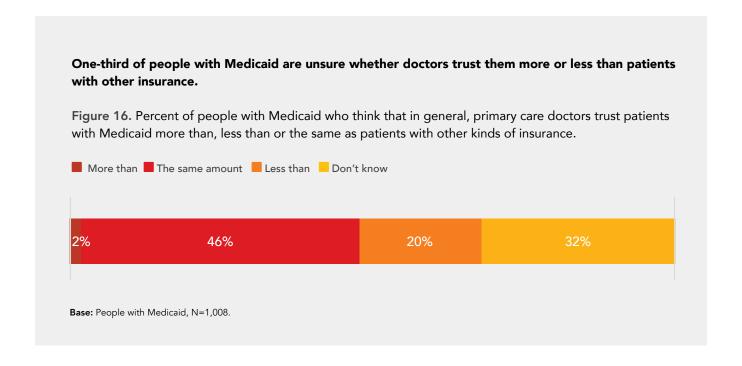
"With Medicaid patients, I have this one lady. What she comes in for is, 'I need you to give me services. Sign for this service, sign for that service, sign for this. I need that and I need a 24-hour aide. Medicaid is going to pay for it, so you're going to ensure that I get as much as I can."" —Primary care doctor; in his 50s; white; New York, NY

"Ninety percent of my no-shows are Medicaid patients. They just don't comply. They won't comply. And it's a big difference between other insurances. If they're working and they have to pay for insurance, then they care about their care. Unfortunately, there's a big percentage of Medicaid patients that don't. I don't know whether they have different priorities or they're more worried about the new iPhone because they're getting free health care." -Primary care doctor; in his 40s; white; Philadelphia, PA

#### Only half of patients with Medicaid think primary care doctors trust them as much as other patients.

Most people with Medicaid (73 percent) think their doctors know what kind of insurance they have. And only about half of them think that primary care doctors trust people with Medicaid as much as people with other insurance. Twenty percent of them think doctors trust them less, and one-third say they do not know; see figure 16.

In other words, although most primary care doctors say that their patients with Medicaid are relatively trustworthy, 1 in 5 people with Medicaid feel mistrusted by their doctors. More are unsure whether they are trusted or not. This could set up a dynamic of reciprocal mistrust for those patients, impeding good communication and shared decision-making.



Several people with Medicaid in focus groups described feeling mistrusted or disrespected by health care providers:

"Being on Medicaid is like a public kind of thing. I think that some doctors ain't going to respect people who are on Medicaid like they do private insurance." —Person with Medicaid; in his 50s; Black; New York, NY

"I'm not sure if it was because of Medicaid, but since I've had Medicaid, I've had more experiences of doctors not paying as much attention." —Person with Medicaid; in her 40s; Asian; New York, NY

"I think that African Americans at times we were sort of looked at negatively, like we don't care about our health. And then they see the fact that you might have Medicaid. I think sometimes it does factor into how they perceive you and how they treat you." —Person with Medicaid; in her 40s; Black; Philadelphia, PA

"I truly believe when you go into an emergency room, and they look at your insurance, they treat you a certain way. They're like, 'Oh, you have Medicaid. So, let's just put her in the room with the rest of everybody.' But if you have Blue Cross Blue Shield, 'Let me put you in a private room.'" —Person with Medicaid; in her 40s; Latino/a; Philadelphia, PA

#### Primary care doctors trust patients with Medicaid more when they are actively engaged in their care, such as by participating in decisions and voicing their health goals.

Primary care doctors express more trust when patients with Medicaid behave in ways that signal they are activated and engaged in their care. Previous research shows that people who are more activated and engaged tend to have better health outcomes and better experiences in the health care system.<sup>28</sup> This research reinforces the value of several of those behaviors for building trust. For example, when asked about the two most important things people with Medicaid can do to make doctors trust that they want to do what is best for their health, 56 percent of primary care doctors prioritize providing complete, honest information; see figure 17.

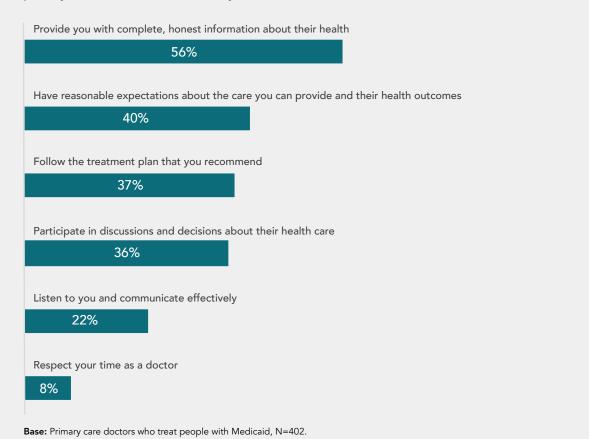
In focus groups, primary care doctors explained that they did not think patients could know exactly what symptoms or other factors are important or exactly how to explain their health concerns. Rather, they saw it as their job to be "good detectives," asking the right questions to draw patients out and piece together diagnoses:

"Either the patient doesn't know how to express themselves or doesn't know what's important. That's where we become detectives and have to ask the appropriate questions. In my experience, it's not because the patient is actively trying to deceive." —Primary care doctor; in her 50s; white; New York, NY

"Sometimes they actually don't know how to explain things. Sometimes they're very vague. And that's a reason why you have to dig." —Primary care doctor; in his 50s; Black; New York, NY

#### Primary care doctors trust people with Medicaid more when they provide complete information, have reasonable expectations, follow treatment plans and participate in decisions.

Figure 17. Percent of primary care doctors who treat people with Medicaid who selected each of the following items as one of the two most important things a patient with Medicaid can do in order for a primary care doctor to trust that they want to do what is best for their health:



About 1 in 4 primary care doctors rank several other behaviors among the two most important things that patients with Medicaid can do to make them trust that they want to do what is best for their health. These include having reasonable expectations about their care, following treatment plans and participating in discussions and decisions about their care; see figure 17.

Several people with Medicaid in the focus groups talked about how much they appreciate being included in decisions about their care. However, they did not want to be presented with unlimited options or to be left to make decisions entirely on their own:

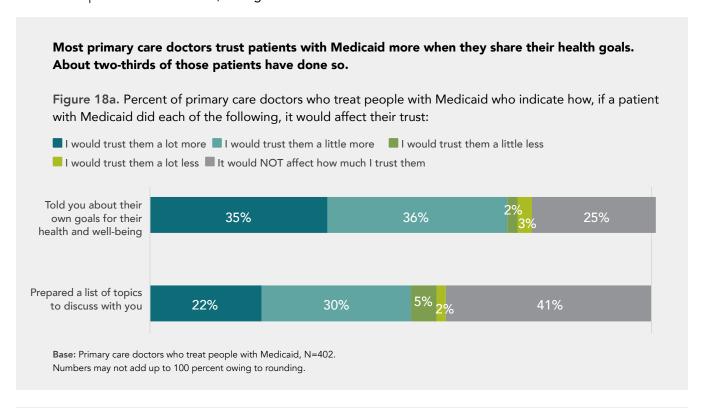
"I enjoy the options with explanation. As long as there's some type of explanation behind or attached to it, then I enjoy the options, because then I feel like they're doing their job, and they're getting me involved in my own care." —Person with Medicaid; in her 40s; white; New York, NY

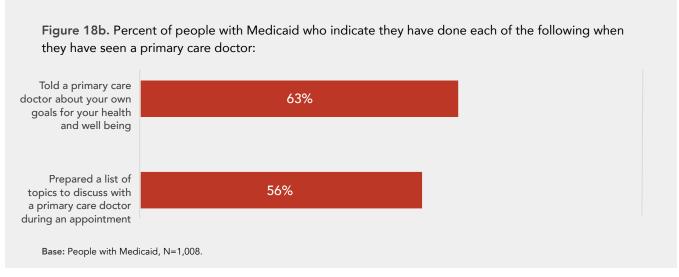
"I want to hear your own professional opinion, but at the same time, I do want options. A combination of the two helps." —Person with Medicaid; in his 30s; Black; Philadelphia, PA

"If there's more options, it's not that bad. But if he gives me too many options, you can get really flustered. If you know what I need, then you might as well tell me. If you give me options, I'm going to say, 'Well, what's the best option?" -Person with Medicaid; in his 30s; white; New York, NY

Most primary care doctors (71 percent) say they would trust a patient with Medicaid more who told them about their goals for their health and well-being. About two-thirds of people with Medicaid say they have actually done so; see figure 18.

About half of primary care doctors say they would trust a patient with Medicaid more who they prepared a list of topics to discuss at an appointment, and about half of people with Medicaid say they have actually done so. But a substantial 41 percent of those doctors say that preparing a list of topics would make no difference either way in how much they trusted their patients with Medicaid; see figure 18.





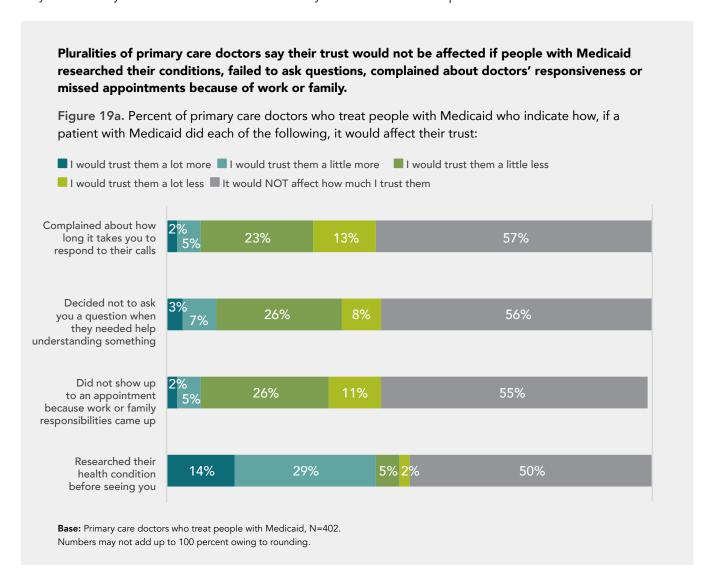
There are two activated, engaged behaviors that primary care doctors say would not affect their trust in their patients with Medicaid either way. About half of these doctors say their trust would not be affected if a patient with Medicaid researched their health condition before seeing a doctor, which about two-thirds of people with Medicaid say they have done; see figure 19.

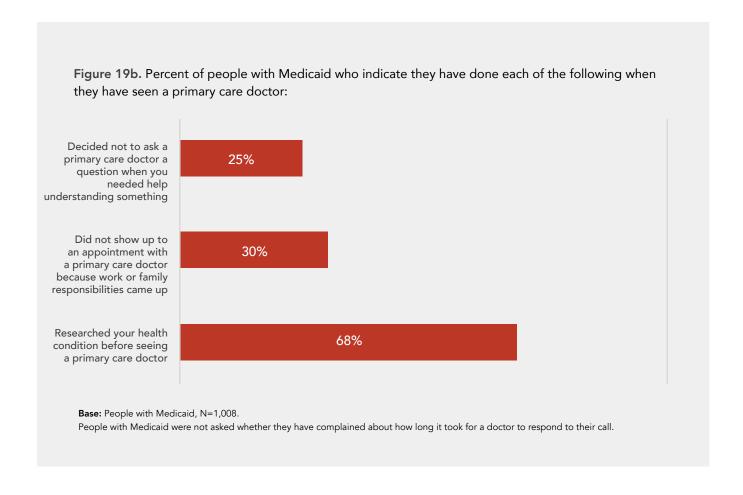
Several primary care doctors in focus groups, however, expressed frustration with patients researching their health before appointments:

"Don't let your Google search cloud my medical decision." —Primary care doctor; in his 50s; white; Philadelphia, PA

"It used to be the doctor said you need to do this and you did it. Now people will go on the internet, they'll talk to their neighbor." —Primary care doctor; in his 50s; white; New York, NY

In addition, just over half of primary care doctors say that their trust would not be affected if a patient with Medicaid decided not to ask them a question when they needed help understanding something. A quarter of people with Medicaid say they have decided not to ask a primary care doctor a question; see figure 19. The most common reasons why are that they felt embarrassed and because they did not think it was important.





#### Primary care doctors say they trust patients with Medicaid less when they leave out information, exaggerate symptoms or insist on specific treatments.

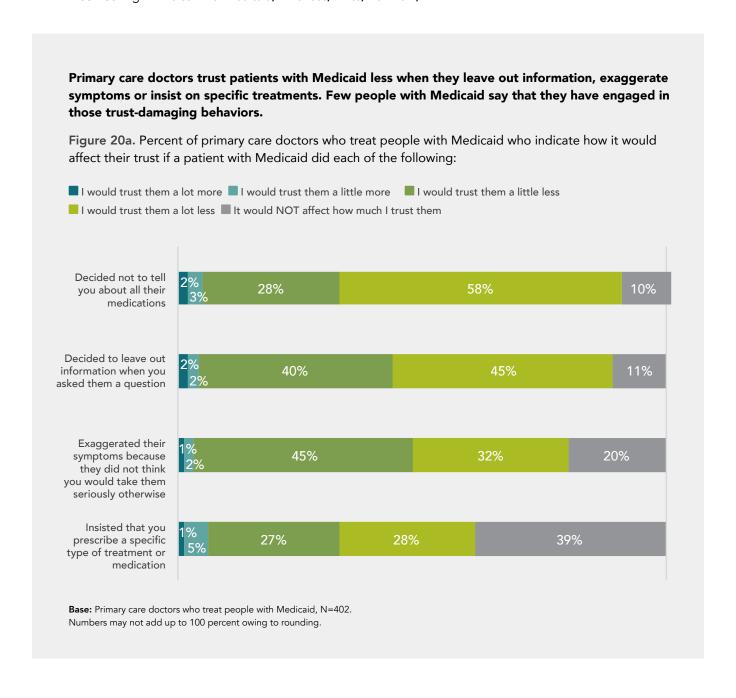
The behaviors that primary care doctors say can damage their trust in their Medicaid patients include leaving out information, exaggerating symptoms and insisting on specific medications or treatments; see figure 20. As discussed in Finding 3, more people with Medicaid who have received care from a doctor they did not trust say they have engaged in several of these trust-damaging behaviors.

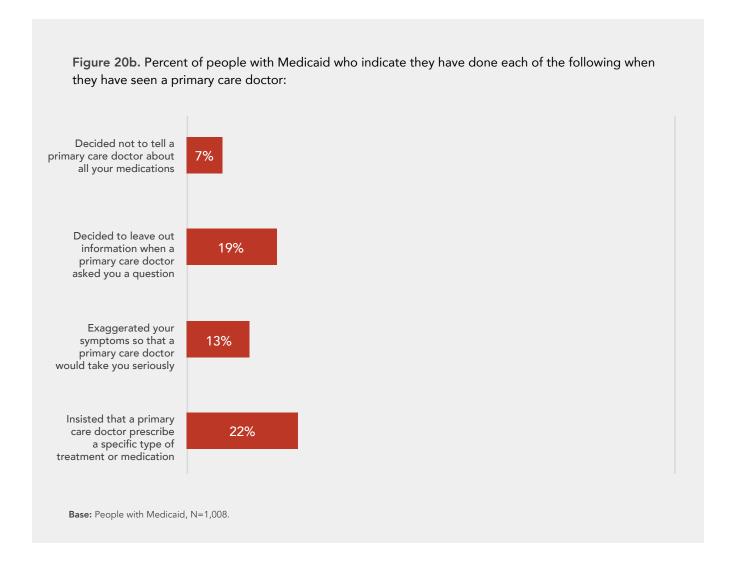
Fairly few people with Medicaid say that they have exaggerated symptoms or not told doctors about the medications they are taking. More of them, however, say they have decided to leave out information when a doctor asked them a question or have insisted a doctor prescribe a specific type of treatment or medication; see figure 20.

The most common reason why people with Medicaid have decided to leave out information or to not tell doctors about their medication is because they did not think that information was important: 50 percent say that is why they have done so. Determining what is or is not important can have safety implications: 39 percent of people with Medicaid who have decided not to tell a primary care doctor about their medications say they did not think it was important, again making that the most common reason why these patients have engaged in that trust-damaging and potentially dangerous behavior.

#### As a person with Medicaid explained in a focus group:

"I don't feel like I need to tell my doctor my entire life story, and yet I feel like I'm often meant to be completely open and honest about every single thing that they ask me. It's very intrusive. It's almost like I'm forced to now. If I don't answer the question, or I say I don't really want to discuss that, then I must be hiding something." —Person with Medicaid; in her 30s; white; New York, NY





# RECOMMENDATIONS FOR BUILDING MUTUAL TRUST IN PRIMARY CARE

There are currently few proven interventions in health care for building trust, although efforts are underway to gather promising trust-building practices.<sup>29</sup> One aim of this research is to shed light on what patients themselves—in this case, patients with Medicaid—believe can help build mutual trust with physicians, which can serve as the basis for future interventions.

Research on trust overwhelmingly focuses on patients' trust in providers. This research shows that primary care doctors who treat people with Medicaid largely understand that they need to trust their patients and most people with Medicaid understand the need for doctors to trust them. People with Medicaid who have received care from a doctor they did not trust disproportionately report behaving in ways that could damage providers' trust in them, illustrating the complex, multidirectional nature of trust.

Since primary care doctors who treat people with Medicaid also treat other types of patients, helping those doctors become more adept at trust-building could positively impact people with other types of insurance as well. And building more trusting relationships in primary care could set a higher bar for trust throughout the health care system. Recommendations based on findings from this research include:

#### By demonstrating that they take safety seriously, doctors can help build trust with patients.

People with Medicaid say their trust would be damaged if primary care doctors made safety errors such as prescribing medications without checking what patients are taking already or ordering unnecessary tests or treatments. They say that being honest, thorough and careful are top priorities for building trust. Primary care doctors must make clear to patients that they are doing everything they can to avoid errors and keep people safe.

#### Increasing patient activation and engagement may increase doctors' trust in patients.

Primary care doctors are more trusting of people with Medicaid when they participate in decisions and voice their health goals. While most patients with Medicaid say they have engaged in those and other activated, engaged behaviors, substantial minorities say that they have not done so. People with Medicaid who have left out information in response to doctors' questions often say they did so because they did not know that information was important, rather than because they were trying to hide something. Interventions aimed at building patient activation and engagement may have positive effects on providers' trust in patients—an outcome that future research on those interventions should measure.

#### Creating time and space in primary care practices for mutual communication can build reciprocal trust.

For both doctors and patients, the hustle and bustle of a busy practice may make it hard to slow down and communicate. Yet people with Medicaid see good listening and communication by primary care doctors as a way to build trust. In focus groups, they complained about doctors not listening and rushing them through appointments. Primary care doctors, meanwhile, trust people with Medicaid more when they provide complete information, participate in decisions and voice their goals. Structuring primary care practices to provide the time and space for good communication can help create the conditions for mutual trust.

#### Doctors can build trust by finding ways to discuss social determinants of health without alienating patients.

Discussing social determinants of health is not patients' top priority for building trust. More primary care doctors than people with Medicaid believe that considering patients' finances and lifestyles is an important way of building trust. Doctors need to find ways to discuss these sensitive topics without alienating or scaring patients who may worry that disclosing sensitive information could have unintended consequences for them or their families. In the context of a short, possibly rushed appointment, patients may want doctors to handle their chief complaints or concerns first. Putting patients' goals first can help build trust, which may be a prerequisite to addressing complex social needs.

#### Developing the evidence base for how and why doctors should build trust in patients can help move health care away from paternalism and toward centering patients.

Primary care doctors who treat people with Medicaid know that they need to trust their patients. Do other types of medical providers know this as well? Trust research thus far has focused almost solely on patients' trust in doctors. To move health care away from paternalism and toward centering patients, more research is needed about how providers' trust in patients correlates with decision-making styles, safety practices and patient outcomes. More research is also needed to explore variations in providers' trust in patients—comparatively across specialties, physician demographics and patient populations.

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