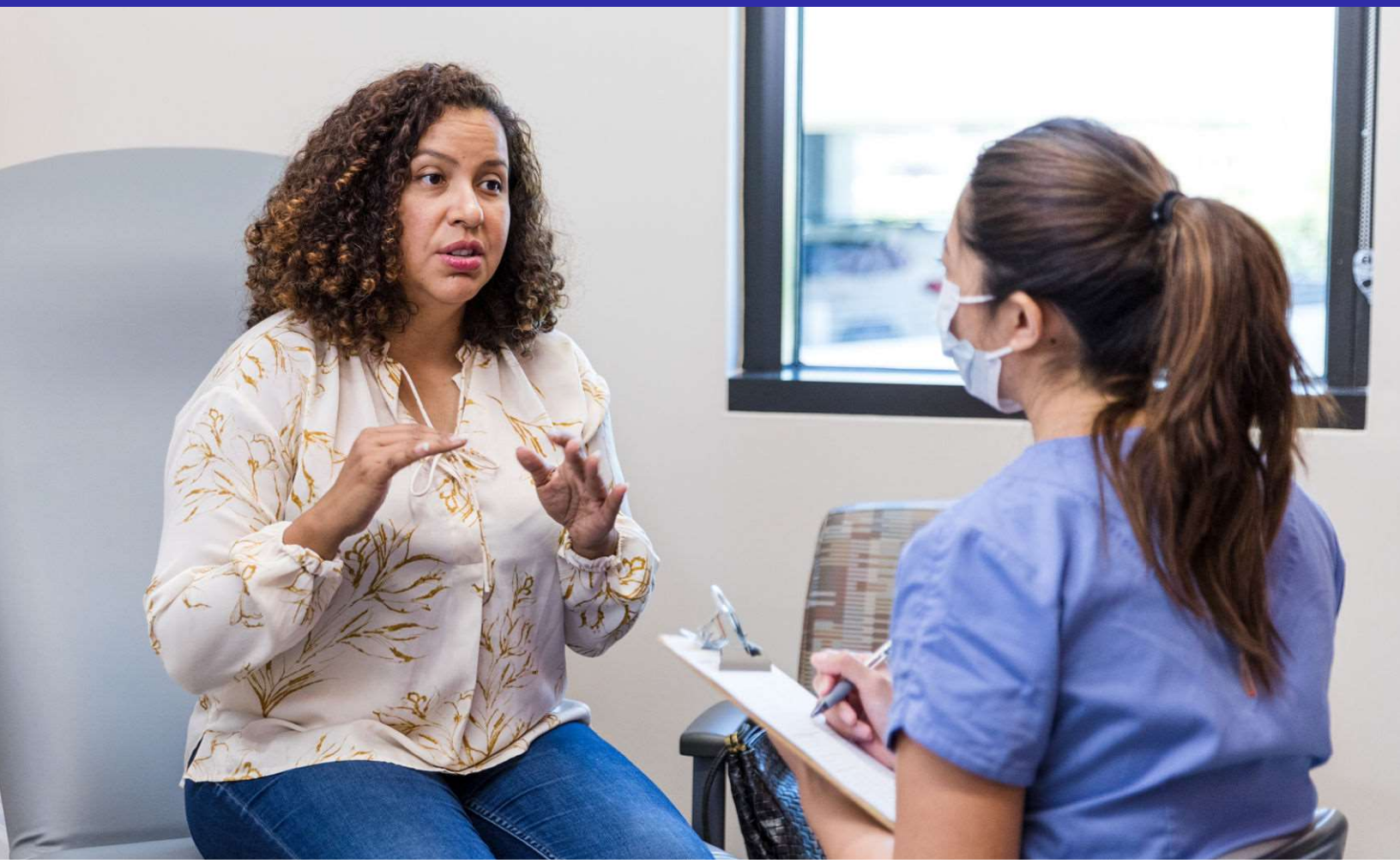
Complex, time-consuming, and frustrating: Searching for in-network diabetes care with marketplace insurance

By Rebecca Silliman, Erin McNally, Cruz Vargas-Sullivan, and David Schleifer



Public Agenda

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Overview

How difficult is it for people with marketplace insurance to find in-network health care providers, and how do delays and challenges in accessing care affect people's lives? This report is based on in-depth qualitative research that followed fifteen people covered by insurance plans purchased on state and federal marketplaces as they tried to find in-network diabetes care providers.

Overall, participants in this research struggled to find in-network diabetes care providers who were located close to them and had appointments available in a reasonable timeframe. They felt that there were not enough in-network diabetes care providers covered by their insurance and wanted their plans to include more in-network providers. Participants found the process of searching for providers to be complex, time-consuming, and frustrating. They reported that the search process and delays in getting care negatively affected their physical and mental health, work, relationships, and finances. They cited a need for centralized, continuously updated directories or systems to find prospective providers, check which insurance plans they accept, find their locations, and seamlessly book appointments.

All fifteen participants in this study were searching for diabetes care providers either because they were newly diagnosed with Type 2 diabetes, had an existing diagnosis but were no longer receiving adequate care from their current provider, or because their current provider no longer accepted their insurance. The participants answered weekly structured prompts from October 11 to November 14, 2022, as they searched for providers, tried to figure out which were in network, and tried to schedule appointments.[1] A companion study follows people covered by marketplace plans as they tried to find and schedule appointments with in-network mental health care providers. The methodology section of this report provides more information about how this study was conducted.

Key findings

1. **Only one of the fifteen participants successfully scheduled an appointment with an in-network provider that took place during the study.** Most participants had already spent time searching for a diabetes care provider prior to the start of this study, including ten who had been searching for three or more months. Nine of the fifteen participants were able to schedule appointments, but only one had his appointment during the study period and said that his provider was in network.

2. **Of the eight other participants who scheduled appointments, only three knew for sure that the provider was in network.** Eight participants made appointments that were scheduled to take place after the study period ended. Three of them knew that the provider would accept their insurance. Four were not sure if the provider would accept their insurance or not, and one knew that the provider would be out of network but scheduled anyway. Seven of those who scheduled nonetheless said it was difficult for them to find a diabetes care provider.

3. **Most participants who scheduled said they would have to wait too long or travel more than one hour each way for their appointment.** Six of the nine participants who made appointments said they would have to wait over one month for their appointment. Four of those who scheduled said they would have to travel over an hour to get to the doctor's office. Some participants made tradeoffs in order to schedule with a provider located closer to them, such as deciding to wait months for an appointment.

[1] While this project was designed to illustrate the experiences of these participants as they searched for a diabetes care provider, the challenges they encountered, and how delaying medical care for their diabetes affected different aspects of their lives, it was not designed to be representative of everyone's experiences finding a diabetes care provider.

4. **The process of searching for an in-network diabetes care provider or delays in getting care negatively affected all participants, impacting their physical and mental health, work, relationships, or finances.** Even participants who scheduled appointments reported negative effects. Most said that their productivity at work was affected, either because of unmanaged diabetes symptoms or because of time spent during work searching for and trying to contact providers. Participants also reported mental health impacts of searching and delayed care, including frustration, depression, and anxiety. Seven participants were impacted across all domains: physical and mental health, work, relationships, and finances.

5. **For all participants, whether they scheduled or not, trying to find an in-network diabetes care provider was complex and time-consuming, requiring them to piece together information across a variety of sources.** Participants described a continuous cycle of trying to identify providers, checking to see if they would be covered, looking for patient reviews and other information, and trying to book appointments. Many participants expressed frustration at spending hours searching for providers, only to find out that the next available appointment was months away or that the provider they had identified was out of network, leaving them to start searching all over again.

6. **Although six of the participants were unable to schedule appointments, it was not from a lack of trying. Most faced "chronic challenges," i.e., challenges experienced multiple weeks in a row.** Five of the six participants who were unable to schedule appointments spent three or more hours searching every week for three weeks. Only three of those who scheduled spent that much time searching. Those who did not schedule consulted on average about four different sources, while those who scheduled consulted about three. Additionally, five of the six participants who did not schedule experienced at least one challenge chronically.

7. **To facilitate access to in-network diabetes care, participants cited a need for more providers, more providers who would take their insurance, and better systems for scheduling.** Participants wanted up-to-date, centralized systems for finding out which providers are in network, which have appointments available, and where they are located. They wanted that information to be integrated into a streamlined system for making appointments. Because they felt there were not enough in-network, conveniently located diabetes care providers with appointments available, some cited the need to train more providers and to incentivize existing providers to travel to patients' communities.

To learn more about these findings, go to **https://www.publicagenda.org/reports/netad-2023/** or email **research@publicagenda.org.**

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Before the study, most participants had already spent time and faced challenges searching for a diabetes care provider. Most had already been negatively affected by the search process.

Prior to the study, ten of the fifteen participants had already been searching for a diabetes care provider for three or more months. Only one said they had been searching for less than one month. Eleven had spent three or more hours searching over the last 30 days. Only two said they had not searched at all in the previous 30 days.

All participants were covered by insurance plans purchased on state and federal marketplaces and were trying to find either a primary care physician or an endocrinologist. A few indicated they were also interested in finding an ophthalmologist, gastroenterologist, neurologist, or mental health provider to help with their diabetes care.

Ten of the fifteen participants had used two or more types of sources to identify potential diabetes doctors before the study began; see **Figure 1.**

Some participants had also checked to see if a prospective provider was in network, while a few indicated they had looked for additional information about a provider. One participant indicated that they had already tried to make an appointment, but it turned out that the provider had no availability at all.

Typical steps in searching for a diabetes care provider:

- ✓ **Identify** names of prospective diabetes care providers.
- ✓ **Check** to see if prospective providers are in network.
- ✓ **Look** for additional information about providers, such as location or patient reviews.
- ✓ **Try** to make an appointment.

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Before the study, most participants had already used multiple sources to identify prospective diabetes care providers.

Figure 1. Number of participants who said, prior to the start of the project, that they had used each of the following to identify prospective diabetes care providers:

9	**Online searches**
5	**Insurers**
7	**Primary care providers**
6	**Friends and family**
1	**Support groups**

Base: All participants, N=15

"I have not been successful in scheduling an appointment because many of the doctors in this area are booked through next year." Kari, Black, in her 40s, Florida[2]

[2] Quotations have been minimally edited for clarity. The names used in this report are pseudonyms. The photos are representations and are not actual images of the participants.

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Prior to the study, many participants had already faced at least one challenge in finding a provider. Five of the participants had already found it difficult to find a provider in an acceptable location. Four indicated that it was challenging to find a specifically in-network provider and four said that finding reliable information about providers was difficult; see **Figure 2.**

"My insurance coverage wasn't enough to get me a diabetes doctor and my location prevented me from getting one. And when I did find one, I couldn't pay for the service."

Donovan, multiracial, in his 20s, Indiana

Most participants had already faced at least one challenge in searching for a diabetes care provider.

Figure 2. Number of participants who said, prior to the start of the project, they had faced each of the following when searching for diabetes care providers:

5	**Distant or inconvenient location**
4	**Difficult or overwhelming to find reliable information**
4	**Providers do not accept my insurance**
3	**Search process too time-consuming**
3	**Difficult to find a cultural, linguistic, or personal fit**
2	**Too expensive**
2	**Workable appointments timesnot available**
2	**Doctors or insurers are slow or unresponsive**
2	**Other**
3	**Did not respond or no challenge**

Base: All participants, N=15

"The most frustrating part about finding a doctor is the overwhelming information. There's a lot of information out there and getting suggestions from friends and also from my primary doctor, and checking out things online and reading stuff—it gets overwhelming. It can make the decision process a bit difficult."

Edward, Black, in his 20s, Ohio

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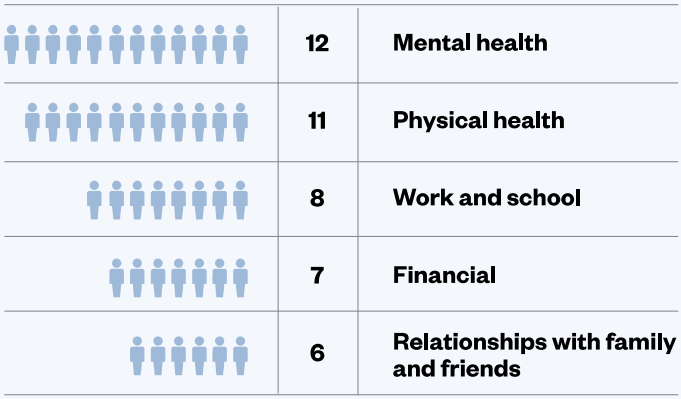
Prior to the start of the study, most participants said delays and challenges in searching for a diabetes care provider had already affected their mental health, causing them to feel anxious or depressed. Most said their physical health had already been impacted because they had to self-manage their diabetes symptoms. Around half indicated that not being able to find a diabetes care provider had affected their work in some way, usually by making it difficult to focus. Slightly fewer said it had affected their finances or relationships; see **Figure 3.**

"Finding a diabetes doctor has affected my physical health negatively. It is hard keeping my diabetes symptoms under control. Sometimes I experience high blood pressure and some kind of temporary blindness." Donovan, multiracial, in his 20s, Indiana

Nearly all participants reported that searching for a diabetes care provider and delays in accessing care had already impacted them before the study began.

Figure 3. Number of participants who said delays in finding care affected them in the following ways:



Base: All participants, N=15

"This has affected my mental health mostly because I kept getting frustrated in whole process and feeling super stressed out. This resulted in me eating more and being more depressed." Gordon, white, in his 20s, Illinois

Despite most participants saying that the process of searching for a diabetes care provider had already been difficult, most were confident they would find the right provider for them during the study. Among those who were not confident, most said there were just not enough providers available near them.

"There aren't enough doctors to choose from in my location. So, no, I won't have a doctor soon." Susana, white, in her 60s, Kansas

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The three-week search for an in-network diabetes care provider

For three weeks, participants documented their experiences searching for a diabetes care provider. At the end of those three weeks, nine of the fifteen had scheduled an appointment. All of those who scheduled had made appointments with their desired type of provider.

Most of those who scheduled appointments did so in the second week of the study:

One scheduled in the first week

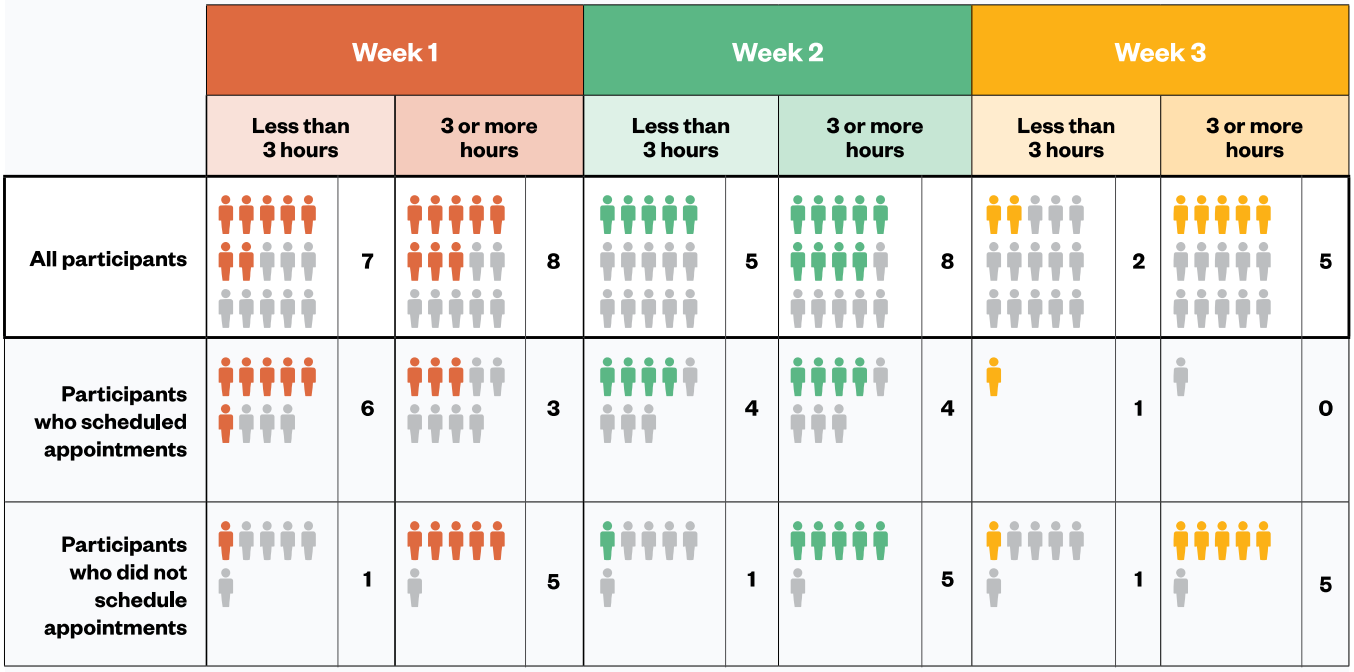
Seven scheduled in the second week

One scheduled in the third week

Each week, half or more of the participants said they searched for three or more hours. Those who were unable to schedule actually spent more time searching than those who scheduled. Specifically, five of the six participants who were unable to schedule reported that they spent at least three hours every week for three weeks searching for a diabetes care provider, including searching for over five hours at least one week. None of the participants who were able to schedule spent three or more hours searching for two weeks in a row; see **Figure 4.**

Participants who were unable to make appointments spent more time searching than those who did make appointments.

Figure 4. Number of participants who spent less than or more than three hours searching for a diabetes care provider, by week:



Base: All participants, N=15; Participants who scheduled an appointment week 1, n=9; Participants who scheduled an appointment week 2, n=8; Participants who scheduled an appointment week 3, n=1; Participants who did not schedule an appointment, n=6.

Searching for a diabetes care provider required participants to piece together information from a variety of sources.

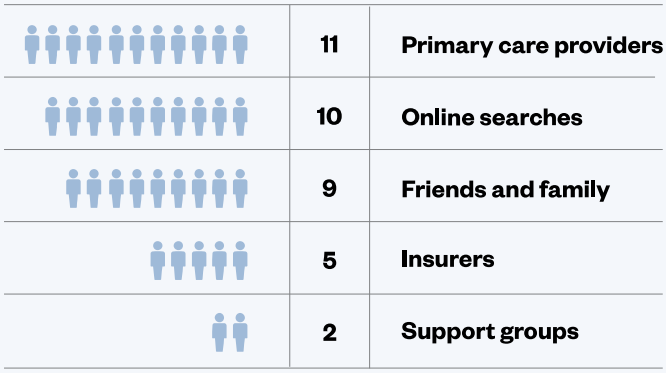
Across the three weeks of the study, the search for a diabetes care provider was nonlinear and repetitive. Participants were continuously identifying names of providers, checking to see if they were in network, looking for additional information, and trying to book appointments. Participants often repeated these steps within and across the weeks of the study.

However, not all participants completed every step and not all completed them in the same order. For example, some participants used their insurance company's website to identify potential diabetes care providers and check whether they were in network. Others only consulted their insurance company's website after they identified potential providers.

Across the three weeks, participants used an average of three different sources to identify prospective diabetes care providers and most switched sources from one week to another. Those who were unable to schedule an appointment consulted on average one more source than those who did schedule. The most common sources used to identify prospective providers were Google searches, recommendations or referrals from primary care physicians or other current doctors, and recommendations from family or friends; see **Figure 5.**

Participants used multiple sources to identify diabetes care providers. Only five used their insurers. More used primary care physicians, online searches, and friends and family.

Figure 5. Number of participants who said they used any of the following sources to identify diabetes care providers:



Participants who scheduled appointments used on average three sources.

Participants who were unable to schedule used on average four sources.

Base: All participants, N=15

Only five participants used their insurance companies to identify prospective diabetes care providers. But an additional two indicated that they used their insurance companies to confirm whether doctors who had been recommended to them or who they had been referred to were in network. A few participants also called prospective doctors' offices or checked doctors' websites to figure out whether their insurance would be accepted.

Among the fourteen participants who received recommendations or referrals from their current doctors or from friends and family, six also looked for additional information about the doctor who was recommended to them or who they had been referred to. They turned to online searches for reviews or in one case looked for lawsuits against the recommended provider. Others looked at the provider's profile on a hospital or practice website. One even tried to see if a recommended diabetes care provider used the same electronic health record system as his primary care physician so that sharing records would be easier.

Five participants, including three who were unable to schedule appointments during the study, tried to schedule with a prospective diabetes care provider at some point, only to be denied for one reason or another.

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Participants faced an average of two different challenges during their search for a diabetes care provider.

Fourteen of the fifteen participants faced at least one challenge in their search for a diabetes care provider. In most cases, participants faced different challenges from week to week. These ranged from difficulties finding a provider in a nearby or convenient location to difficulties with the search process itself, such as not having enough time to search or not knowing where to find reliable information; see **Figure 6.**

"The major problem I have is my work schedule. I'm actually working and I don't have time to research about the diabetes doctor." Donovan, multiracial, in his 20s, Indiana

Most participants found the search process complex and time-consuming, and most found it difficult to identify providers nearby or in convenient locations.

Figure 6. Number of participants who experienced one of the following challenges at least once in the three weeks of trying to find a diabetes care provider:

8	**Distant or inconvenient location**
8	**Search process is time-consuming**
4	**Difficult to find a cultural, linguistic, or personal fit**
4	**Workable appointments times not available**
3	**Doctors or insurers are slow or unresponsive**
3	**Too expensive**
2	**Providers do not accept my insurance**
2	**Difficult or overwhelming to find reliable information**
2	**Other**
1	**Did not respond or no challenge**

Base: All participants, N=15

"I was finally able to get in contact with a doctor. It turns out that it was just a physician who diagnosed diabetics and he wasn't actually a doctor to treat diabetes. So it was really frustrating, after much effort, to actually schedule an appointment—that's what it turned out to be. That was very frustrating because I knew that I was back to the drawing board again and I had to start all over again." Peter, Black, in his 30s, Michigan

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About a quarter of the participants indicated that they found it challenging to find a provider who was a good fit for them, including culturally or personally; who could be emotionally supportive; or who could explain things in relatable ways. About a quarter also indicated that they found it difficult to find appointments at times that worked for them.

Most indicated that available appointments were months away, while others indicated available appointments conflicted with their work schedules. Only three participants indicated having difficulties with unresponsive or slow doctors or insurance companies. But one who did have those difficulties got increasingly frustrated as the weeks passed and started to wonder whether the providers' unresponsiveness was indicative of how he would be treated as a patient.

"When he becomes my doctor, will he give me that attention? Will he give me that attention that I need, that emotional support? These are the difficulties I'm facing right now." Donovan, multiracial, in his 20s, Indiana

Although many participants documented different challenges from week to week, eight experienced "chronic challenges," i.e., the same challenge two or more weeks in a row. Five of the six participants who were unable to schedule an appointment faced at least one challenge chronically, including three who encountered two challenges chronically. By comparison, only three of the nine participants who made appointments experienced a chronic challenge.

Tradeoffs for those who scheduled

Nine of the fifteen participants were able to schedule an appointment with a diabetes care provider during the study. But "success" did not mean that the process was easy or without tradeoffs.

Of the nine who scheduled:

Five either know the doctor will not accept their insurance or are unsure if their insurance will be accepted.

Six will wait one to four months for their appointment.

Six believe they have to wait too long.

Four will have to travel one to two hours to see the doctor.

A distant or inconvenient location was a common chronic challenge for those who were unable to schedule. For example, throughout the three weeks of searching, one participant repeatedly said there were no doctors in her location and that she did not feel her car was reliable enough to drive the 90 minutes to the nearest diabetes care provider and 90 minutes back.

"The closest doctor for diabetes is an hour and a half away, one way. I'd have to commit at least three hours of driving in a day just to go see this doctor. Right now, I don't think I can spare the time, and my vehicles are not the greatest to go that far away from home. I'll have to stop and think about it, and maybe I can combine rides with friends or other people going that way. I haven't decided if I want to travel that far to see a doctor." Susana, white, in her 60s, Kansas

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Other chronic challenges encountered by those who were unable to schedule appointments included the complex and time-consuming nature of the search process itself, the high cost of care, difficulty finding reliable information about providers, and difficulty finding providers who were a good fit culturally, linguistically, or personally.

However, the chronic nature of these challenges may be due to the tradeoffs that these participants were unwilling to make. For example, one participant who chronically indicated the process was complex and time-consuming also recognized that he could have widened his search and possibly found a doctor more quickly if he was not prioritizing prospective providers' fit with his current medical team by relying on their recommendations.

"I surfed the internet, asked friends and loved ones, and, to all end results, I wasn't having any reliable information." Rusty, Black, in his 40s, Texas

"I'm looking for someone who can relate to me better, on the personal level. And I just couldn't find that." Marcel, Hispanic, in his 30s, New York

Tradeoffs to address chronic challenges in accessing diabetes care

Three of the nine participants who were able to schedule appointments experienced at least one chronic challenge and made tradeoffs in response.

Donovan, multiracial, in his 20s, Indiana

Chronic challenge: Distant or inconvenient location.

Tradeoffs: Scheduled with a provider 30 to 60 minutes away who did not accept his insurance. Paid more out of pocket than expected.

Before the appointment: *"First, I was happy to have finally found one at my location and a good one at that. But reaching out to him, I discovered that he wouldn't accept my insurance. Right now, I don't have enough providers to choose from."*

After the appointment: *"It wasn't affordable, and I didn't expect to pay so much money from my pocket."*

Kari, Black, in her 40s, Florida

Chronic challenge: Workable appointment times not available.

Tradeoff: Scheduled an appointment three to four months away, which she felt was too long to wait.

"I do think it's gonna take an awful long time for the appointment until January, so I'm not really pleased about that. But overall, I'd rather be on a waiting list for the doctor."

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Taylor, Black, in his 30s, New York:

Chronic challenges: Workable appointment times not available and providers do not accept her insurance.

Tradeoff: Scheduled an appointment one to two months away, which she indicated is a little too long to wait. Unsure if they accept her insurance.

"The most difficult thing about scheduling an appointment with my diabetes doctor is actually finding a time that matches my schedule and also finding one that takes the insurance that I have."

Participants wanted plans to cover more diabetes care providers in their communities.

Some participants expressed surprise at the lack of in-network providers available to treat what they saw as a very common health condition. Some indicated that, in general, more doctors need to be trained to treat diabetes. Others suggested a need for incentives to get more doctors into rural areas or other communities where they believe that doctors do not want to live. About one-quarter of participants said that policymakers can do more to ensure that there are enough in-network diabetes care providers accessible to everyone who needs one.

Participants wanted up-to-date, centralized systems for identifying, learning about, and scheduling with in-network providers.

Participants had to use multiple sources to identify providers, find out if they were a good fit, find out whether they would be in network, and find out whether they had appointments available. They expressed a need for someone or something to centralize that information.

Despite having access to their insurer's directories, some wished for an up-to-date online hub, app, or directory to find prospective doctors' locations, check what insurance they currently accept, seamlessly book appointments, and coordinate referrals if needed. Others wanted a human liaison to provide recommendations, check insurance coverage and office locations, and make appointments. A few participants suggested that insurers, hospital systems, and individual providers should collaborate to deliver a streamlined, patient-centered search process. A few suggested policymakers can push insurers and providers to collaborate to streamline information and scheduling for patients.

"A collaboration with the insurance company and the hospital will really go a long way to make it easier on the patient." Maria, Black, in her 30s, New York

"If the parties that are involved, like the health care system, the insurance, the diabetes doctors are able to collaborate on having something which is a dedicated space for diabetes patients, like an app, a community based-website, or social media for diabetes patients, that would be great." Edward, Black, in his 20s, Ohio

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Searching for a diabetes care provider and delays in getting care negatively affected all participants, impacting their physical and mental health, work, relationships, or finances.

All participants were negatively impacted by the process of searching for a diabetes care provider and by delays in finding a provider. Even the nine people who scheduled appointments experienced negative impacts, although for two of them, the impacts were relatively minor.

Sometimes participants were clear about whether it was the search process itself that impacted them or whether they were impacted by not receiving proper medical care. But often participants portrayed the negative impacts of the search process and delays in care as intertwined.

Many said their day-to-day lives had been impacted because the complex, time-consuming search process ate up hours they could have used for other responsibilities. They said searching for a provider took focus and concentration away from other tasks. Some mentioned they altered their daily routines to accommodate searching.

Seven participants said that the search process and delays in getting care affected them across all five of the categories that were asked about in this study: physical health, mental health, work, relationships with family and friends, and finances. Some indicated that the negative impacts got worse as the weeks passed; see **Figure 7.**

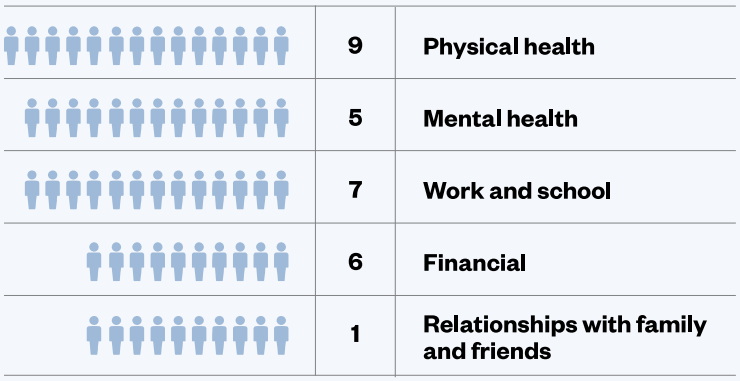
Only one "successful" appointment

Nine of the fifteen participants were able to schedule an appointment, but only one actually had their appointment during the study period and said that the provider was in network. He was also the only participant who found a provider less than thirty minutes away and said that the appointment was soon enough, the search process was easy, and that after the appointment he planned to continue seeing that provider. He did not appear to need to make any tradeoffs in choosing a provider and reported only minimal negative impacts from the search process or delays in getting care.

Although one other participant scheduled an appointment during the study with a provider he believed was in network, he was forced to cancel it because of an unexpected work obligation.

Challenges of the search process and delays in finding a diabetes care provider negatively impacted all respondent's lives. For most, the impacts got progressively worse.

Figure 7. Number of participants who say delays in finding care affected them in the following ways at least once across the three weeks:



Seven participants: impacted in all five categories

Four participants: impacted in four categories

Two participants: impacted in three categories

One participant: impacted in one category

Base: All participants, N=15

"It took me three to four hours and that was time to be more productive. I am extremely frustrated trying to spend time to run into walls with no progress."
Gordon, white, in his 20s, Illinois

"It has taken too much time out of my day that I could be working on other things. I have also not accomplished anything with all the effort to find a doctor. Spent a lot of time online and I can be doing other stuff instead of that and I'm not accomplishing anything"
Susana, white, in her 60s, Kansas

Nearly all participants indicated that their physical health was affected by the search process and delays in finding a diabetes care provider, with many indicating that their physical health was affected progressively more each week of the study. Some described untreated diabetes symptoms getting worse and some said that the search process made it harder to maintain proper diet and exercise routines.

Before scheduling: ***"The symptoms became so unbearable, a bit complicated that I had to spend more to manage it. Some of the symptoms that I have not been experiencing before came to play, like blurred vision."***

After scheduling: ***"Am experiencing an increase in urination and fatigue, coupled with the stress. Am actually finding it hard to do it by myself, for example, monitoring my blood-sugar level and taking the oral medication. I really need motivation."***

Donovan, multiracial, in his 20s, Indiana

After scheduling: ***"I have less time to cook when I spend time looking for a doctor. When I [cook], I can avoid all the nasty junk that goes into food you get outside your house."*** Cliff, white, in his 60s, New Jersey

Most participants also reported negative impacts on their mental health during the three weeks searching for a diabetes care provider due to the difficulty of accessing care. Even after some participants scheduled appointments, they experienced negative impacts on their mental health while waiting for appointments. Some indicated feeling frustration, depression, or anxiety.

Before scheduling: ***"I feel I have been overthinking lately."***

After scheduling: ***"It has made me quite anxious because I can't wait to start receiving proper treatment."***

Fred, Black, in his 30s, Michigan

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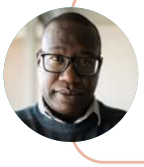

Never scheduled: ***"My friend's dad has had near-death experiences due to diabetes where he collapsed, so this keeps haunting me. Like I get worried sometimes."*** Rusty, Black, in his 40s, Texas

After scheduling: ***"My mental health is really affected. I feel more anxious and worried, most of the time depressed. I always have this sad feeling, like why do I have to live on meds? It's really challenging and depressing, and I sometimes feel rejected."*** Donovan, multiracial, in his 20s, Indiana

Never scheduled: ***"I have been stressed and annoyed because it shouldn't be this hard to find someone who will work for me."*** Susana, white, in her 60s, Kansas

Most participants found the challenges in searching and delays in accessing care affected their concentration or productivity at work. Some cited physical diabetes symptoms, such as headaches, while others described the challenges of trying to search for a provider or contact prospective providers. In some cases, participants indicated they took time off work to search.

"It has affected work, as I now worry about it while at work, and sometimes I try to get information online while at work." Taylor, Black, in his 30s, New York

"I have actually found it so hard to concentrate at my workplace because I am actually starting a new position at my firm. I need to be mentally stable and concentrate on the task at hand. But looking back on my health condition, I can't really concentrate because I need to manage my blood-sugar level by myself, run some tests, and decide on what to eat." Donovan, multiracial, in his 20s, Indiana

"My work in the past weeks has been greatly affected due to my inability to keep to schedule. I have spent more time with my search for a diabetic doctor, ignoring deadlines I had to meet at work. This has affected my credibility at work and with my employers." Peter, Black, in his 30s, Michigan

"When I am at work, I feel like I am not concentrating on work like I should. I am thinking about finding a doctor that is closer so I can get the care I need." Susana, white, in her 60s, Kansas

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Before the study began, relatively few participants reported experiencing negative impacts on their relationships with family and friends or on their finances. But by the end of the study, two-thirds reported their relationships were affected and two-thirds reported their finances were affected.

Many said their time was diverted from friends and family since they had to spend time looking for a diabetes care provider. Others acknowledged that their friends or family grew sick of hearing them continuously talking about the challenges of searching for a provider. In some cases, participants had to miss outings and gatherings with friends or family because they were self-managing their diabetes. Financially, most participants reported spending more on medication and food to manage their diabetes.

"I don't usually dine with my kids as I used to before." Fred, Black, in his 30s, Michigan

"They are very tired of hearing about my struggles with finding a doctor. I feel I am a broken record and only have one thing to talk about." Susana, white, in her 60s, Kansas

"The challenges in finding a doctor did really affect me financially regarding continuous spending on medications that were not really helping me enough." Edward, Black, in his 20s, Ohio

"Actually, I have spent more money. It's really frustrating as I recently purchased some new medications and food supplies for my diabetes." Peter, Black, in his 30s, Michigan

Most participants remained confident despite the challenges:

Seven of the eight participants who scheduled appointments for the future were confident that they had found a good provider.

Four of the six participants who did not schedule appointments remained confident that they would find a provider who was a good fit for them.

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Methodology

This report summarizes findings from a diary study conducted October 3 to November 14, 2022, with fifteen adult Americans, 18 years and older, whose health insurance was purchased from a state or federal health insurance marketplace.[3] All participants had either been told they had prediabetes, or suspected or were told they had Type 2 diabetes. At the start of the project all participants were trying to find a doctor or other health care provider to treat their Type 2 diabetes or symptoms caused by their diabetes. Participants were financially compensated for their time. Heartland Institutional Review Board reviewed and approved the diary study.

The first week of the diary study, participants were asked questions about the type of doctor they were searching for to treat their diabetes and their previous experiences trying to find a diabetes care provider. The following three weeks of the diary study, participants were asked to document the steps they took to search for a diabetes care provider and the challenges they encountered along the way. If they were able to schedule an appointment, they were asked about the appointment. Participants were also asked to reflect on how, if at all, delays in finding a diabetes care provider or delays in seeing a diabetes care provider had affected them across multiple dimensions of their lives, including financially, day to day, work, or school; relationships with friends or family; and their physical and mental health. During the last week of the project, participants were also asked a series of questions about their views on the health care system overall and how they believe it can be improved.

The diary study protocol was developed by Public Agenda and combined a mix of structured open-ended response questions and multiple-choice questions. The diary studies used a web-based platform called QualBoard and participants logged in weekly to document their responses. Sago, previously known as Schlesinger Group, recruited the diary study participants to Public Agenda's specifications and managed technical aspects of QualBoard. While a few questions required participants to respond via video, for most questions, participants had the option to respond via text or video.

By identifying commonalities among participants' responses, Public Agenda coded qualitative responses into quantifiable data to track responses across the study. Although qualitative responses were quantified, the data only represents what participants explicitly mentioned in response to open-ended questions and may not be representative of everything they did or experienced. For example, while seven participants specifically indicated that they checked to see if a diabetes care provider was in network, others may have done so but did not specifically mention it in response to this question:

What, if anything, have you done over the last seven days to try to find a diabetes doctor? Think about all the different things that you may have ever done over the last seven days, such as:

- Trying to find out which diabetes doctor takes your insurance
- Trying to schedule appointments
- Calling your insurance company or using your insurance company's website searching online for providers
- Asking your primary care provider for a referral
- Getting recommendations from family or friends
- Anything else you might have done to try to find a diabetes doctor

[3] Sixteen participants were recruited to complete the diary study. However, upon reviewing the data, it became apparent that one participant did not have any insurance and his responses were therefore removed from the analysis.

To inform the development of the diary study, Public Agenda designed and conducted three demographically diverse online focus groups in May 2022 with people who needed medical care for Type 2 diabetes or had been diagnosed with Type 2 diabetes in two or fewer years prior. All focus group participants had also tried to make an appointment with a doctor or other health care professional for Type 2 diabetes in two years or fewer prior to the focus groups. Fieldwork National Recruiting Center recruited participants for two of the focus groups and Sago, previously known as Schlesinger Group, recruited participants for one of the focus groups. All focus group participants were recruited to Public Agenda's specifications. Participants were financially compensated for their time. Focus group video responses were transcribed by a professional transcriber, Kelsey Transcripts. The focus group portion of this study was not reviewed by Heartland Institutional Review Board.

For more information about this study, go to **https://www.publicagenda.org/reports/netad-2023/** or contact **research@publicagenda.org**.

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Sample characteristics

Gender

Male	**12**	
Female	**3**	

Age

20-29	**3**	
30-39	**7**	
40-49	**2**	
50-59	**0**	
60-64	**3**	

Race/ethnicity

Black	8	
Latino	1	
White	5	
Multiracial	1	

Income

Under $50,000	1	
$50,000 to under $100,000	10	
$100,000 or more	4	

Education

High school/GED or less	1	
Some college/2-year degree/trade school degree	4	
4-year college degree or more	10	

Location

Northeast	4	
Southeast	1	
Midwest	7	
Southwest	2	
West	1	

Public Agenda is a research-to-action nonprofit organization dedicated to creating and sustaining a stronger democracy. Through research, public engagement, and communications, we amplify public voice in institutional and government decision-making. The organization was founded in 1975 by the social scientist and public opinion research pioneer Dan Yankelovich and former secretary of state Cyrus Vance. Find Public Agenda online at **PublicAgenda.org**, on Facebook at **Facebook.com/PublicAgenda** and on Twitter at **@PublicAgenda**.

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