

## Supplemental materials for

### *Challenges in Receiving Care for Long COVID: A Qualitative Interview Study Among Primary Care Patients About Expectations and Experiences*

Elena Gardner, MPH<sup>1</sup>

Alex Lockrey<sup>1</sup>

Kirsten L. Stoesser, MD<sup>1</sup>

Jennifer P. Leiser, MD<sup>1</sup>

Jeanette Brown, MD, PhD<sup>2</sup>

Bernadette Kiraly, MD<sup>1</sup>

Dominik J. Ose, DrPH<sup>1</sup>

<sup>1</sup> University of Utah Family and Preventative  
Medicine, Salt Lake City, Utah

<sup>2</sup> University of Utah Internal Medicine, Salt  
Lake City, Utah

## Supplemental Appendix

**Title of Study:** SARS-CoV-2: Identifying long-term symptoms and their impact on patients  
in primary care (IRB\_00139714)

### Interview Guide

#### Warm-up

- Introducing interviewer
- Note about recording, data protection, data usage, voluntary participation

#### Topic 1: Introduction

- Please introduce yourself briefly (name, age, marital status, time living with long-COVID, etc.)

#### Topic 2: Long-term symptoms

- What kind of long-term symptoms you are suffering from?
- When did the symptoms begin?
- Are the symptoms always the same?
- Which symptoms are the worst for you?

#### Topic 3: Impact

- How do the symptoms impact your personal life (hobbies, habits, social life, etc.)?
- How do the symptoms impact your relationship with the people in your household?
- How do the symptoms impact your ability to work?
- How do the symptoms impact your long-term goals?

#### Topic 4: Healthcare

- Prior to coming to the clinic today, were you seen for your symptoms by your usual doctor?
  - If yes, what was that experience like?
- How has your experience been so far in the healthcare system?

- What do you wish healthcare providers knew about your experience with long-COVID?
- What expectations do you have of your Primary Care provider?
- What needs of yours have not been met by the healthcare system?

#### **Close-up**

- Now, thinking back to our discussion today, what else has come to mind that you would like to mention?
- **Closing remarks:** Thank you very much for your participation today! We have received many interesting insights.

**Supplemental Table 1. Patient expectations**

Category	Themes	Supporting Quotes
Expectations for primary care providers (PCPs)	Knowledgeable clinicians	<p><i>"Define it. I mean, is it short-term, is it long-term? Is it something I'm gonna have to live with for the rest of my life?" (I2:273-288)</i></p> <p><i>"when I first went in, because it was so new, there wasn't a lot of data or information. ... I was kind of told 'we're gonna be learning more about this as it comes out.' And so, there wasn't really much direction, I just tried to figure it out." (I16:308-316)</i></p>
	Lowered expectations	<p><i>"I think I had high expectations when I first went in, um, but I don't now. I think this is just new for everybody so I'm not expecting immediate answers ... it's very frustrating" (I7:328-338)</i></p>
	Individual assessment	<p><i>"I wish they listened better. I feel like they're on a time parameter to get us in and out. And ... I don't know that ... they take the time to ask the right questions.... I don't want to just become a group of people where it's like 'Oh, I've had Covid, so they've got this, so they've got this, so'. I think curing us individually and taking action" (I11:571-632)</i></p> <p><i>"I want them to know me. That's my expectation. Much like as an educator, I know my students. I know if something is off or not. I know if it's the norm or not for them. And so, I would expect the same kind of expertise with the medical field." (I17:498-502)</i></p>
	Engagement	<p><i>"... the primary care provider didn't follow me through my process at all, right? Which I, kind of, would have expected" (I1:286-300)</i></p> <p><i>"I expect her to follow up on things. ... she made sure all the information was along with the referral ... and I just expect advocacy like that" (I14:553-563)</i></p>
Expectations for treatment	Collaboration with patient	<p><i>"... when you [the provider] walk into the exam room, check your ego at the door. ... my favorite doctor is my dermatologist. He actually asks my opinion. He goes, ... 'you seem like a smart guy. What do you think is going on?' and that's something doctors fail to ask" (I6:279-296)</i></p>

*“How about some natural things like supplements and stuff. Oh boy, doctors don’t wanna touch any of that” (I2:478-490)*

*“Support, and meeting with others so you don’t feel like you’re the only one that has this.” (I15:661-664)*

Communication across care team	<i>“It’s hard when one doctor puts you on a med that causes you to be tired, and then the next doctor gives you a med to not make you tired ... so, a little better communication, a little bit more, um, continuity between appointments and doctors” (I12:282-289)</i>
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Interdisciplinary knowledge sharing	<i>“And COVID somehow lives or is causing problems in between these specialties. So, at some point, I hope that there will be some, shared knowledge between these doctors on how to approach and treat COVID moving forward.” (I9:676-686)</i>
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Participants used several terms to describe primary care and primary care providers, including primary care provider, family practitioner, or general practitioner (GP) to describe their main clinician. Here, we use primary care physician (PCP) to capture all these terms. When participants refer to specialty care, they are referred to by name (i.e., pulmonology, neurology).

**Supplemental Table 2. Interacting with providers**

Category	Themes	Supporting Quotes
Positive experiences	PCP listens	<i>“if I didn’t have my primary care that was with it – would actually listen to me – I would still be on my old asthma medication, and barely able to breathe.” (I5:687-689)</i>
	PCP is honest	<i>“[The clinician] was a little frustrated because he didn’t have the answers. And that’s obvious. And he was very honest and upfront with me, and that’s why he referred me to the clinic.” (I6:236-239)</i>
	PCP is supportive	<i>“[My PCP] is the one who suggested actually going to the long-haul COVID clinic. ... I think everybody was very supportive” (I7:220-233)</i>
	Longitudinal relationship with PCP	<i>“I just bawled. I was like, I’m so scared. She was like, ‘okay. We really need to get you into the COVID clinic’ ... you know, seeing her for years, she knows me.” (I14:430-432)</i>
Negative experiences	Dismissal	<i>“every time I would go in to see him [PCP] I’d say ‘this is what I feel’ ... he’s like ‘it’s just COVID.’ I’d say ‘well, I hurt ... and that hasn’t changed and gone away. It’s gotten worse’” (I11:496-499)</i>

*"I have had everything from, you know, 'this is as good as you're gonna be so just live with it.' I have had the 'you need to lose weight. That's the only thing that's wrong with you.' ... So, just a lot of ... resistance ... to even believing that it's a real thing." (I12:211-224)*

*"where I felt more frustrated is where other doctors, like lung specialists or physical therapists or even balance, uh, vestibular therapy therapists, um, say, 'there's nothing wrong with you. Your organs are fine. Your lungs are fine. There's nothing more we can do for you.' And – and they – and one of the doctors even told me, "This is all in your head. You are fine." (I19:396-402)*

Discouragement	<i>"[Initial experience in primary care] was pretty discouraging. In fact, I didn't call the long-Covid clinic for a few months after that [...] they gave me a referral and it just expired because I was just like, is this just gonna be the same thing?" (I8:241-248)</i>
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Inappropriate treatment	<i>"They [general practitioner] took a chest X-ray, said, 'We don't see anything.' They said, you know, 'try to get some rest. Come back in a week.' Still felt terrible in a week, went back and saw them. And they said, 'oh, well, we think you just have had a lot of life changes ... here's some Lexapro' ... and that did not help. So, I'm seeing a different GP now." (I9:477-481)</i>
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**Supplemental Table 3. Navigating the health care system**

Category	Themes	Supporting Quotes
Access and coordination	Lack of timely primary care	<i>"I even called one of the nurse lines and it wasn't very much help. That was really difficult because I couldn't explain my problems to them and they couldn't see me and that just got really frustrating, so, that's when I ended up going to the emergency room" (I7 275-289)</i>

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*"It seems like there's just a lack of concern for getting people in, and seen." (15:677-678)*

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Barriers to care

*"Like, I get the runaround. And I'm just like, do people not realize, like, literally my livelihood depends on me knowing what the hell is going on, and I can't remember....it's a nightmare. Because if you don't have like, breathing problems they're just like, oh well." (114:489-500)*

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Challenges with coordinating care

*"We're ... on MyChart with the nurse from his primary care doctor ... they're questioning, 'Why do you wanna see a gastroenterologist? Why do you wanna see a neurologist? The doctor has to know before he can refer you.' ... it's a lot of work." (12:427-439)*

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*"I did have to get a referral to go to the COVID clinic, and that was a little difficult. ... it was calling my primary physician ... and then having to follow up with both clinics." (11:254-266)*

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Diagnosis and treatment

Long wait times

*"They wanted to put me in a, like, sleep apnea – like a testing group. And so, when I made the appointment for that, it was already 3 months out. And then they called me the other day and said 'Sorry, that day's not going to work', so they set it again for January. So It will be a year since I got COVID to actually get that test" (11:323-334)*

*"I finally did get my sleep study and it was in February of last year. I had to wait nine months... and then it took another like, three, four months before they could get a CPAP because they were out of CPAP machines" (13:531-542)*

*"My PCP has to put in a note to say 'She's having these symptoms. You need to meet with a neurologist.' Well, it turns out I now have to wait six months because that was the soonest appointment. So, I don't know what it will be for cardiology. But for me, I was like that is completely unacceptable. ... I mean I hope I'm not dying from this, geez." (117:514-533)*

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Lack of treatment options

*"The doctor kind of gave a quote/unquote thing 'I will – let me just tell you right now I will not have any magic pills, I will not have any magic potions, and will not be recommending supplements or anything. The best we can do is send you with some referrals to specialists.'" (12:244-252)*

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*"I mean they're trying, I suppose, but there has been no solution. So, I'm at the point where I'm kinda like, eh, is it worth it to keep trying stuff?" (I10:305-312)*

Cost of care	High costs for few improvements in symptoms	<i>"Very recently I ended up with a bill for like almost 1,400 bucks. That's my part to pay, right. And before I was paying, you know, 100 here, 200 here, it was like little stuff. ... I'm like, who knows, almost 3,000 in the hole for nothing. ... so, I don't have the money to do this anymore." (I10:364-400)</i>
	Delayed care leading to emergency room admission and high costs	<i>"the first time I went to the emergency room, they didn't even ask me if I had COVID before. They just checked for a heart attack, and a stoke, and \$10,000 later, I'm out of there" ... Of course, at the time, I thought maybe I was having a heart attack or a stroke" (I13:192-208)</i>
	Challenging insurance claims process	<i>"I've had the insurance companies call me, 'why are you doing this? Who authorized this? Why do you need this?' and it's like this – I'm not a doctor. This is what they're telling me, they know better. And the longer they take to authorize it- it's putting me, you know, a couple months behind now of trying to get better" (I7:411-423)</i>
		<i>"I guess my appointment may have gone over an hour so they [insurance company] charged me extra for that, which I was not aware was a thing. ... the other thing is getting charged for tests when I thought that was covered." (I20:451-459)</i>

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