Oh, finally—this is my stop. It's so tiring that the buses get more and more off-schedule as the day goes on, but what can I do? It's not the bus drivers' fault, and I definitely cannot afford a car.

FACT:

Transportation is the 2nd largest expense for most families, particularly for those who are low-income, for whom it's about 42% of their budget.¹
Scene Two: At the Clinic

Better get going then.

Hi! Please fill these out and bring them back when you're done.

Thanks!

Here for a clinical trial? Please wait here!
FACT:
Almost 6 million Americans aged 60 & over, including
2.5 million Spanish Speakers who are 65 & older,
are not able to read or write English well.² Federal
regulations state that informed consent must be in a
language understandable to the patient. The preferred
method is to provide consent forms in the participant’s
language.

Oh, sorry! Would it be easier for you to read the
same document in Spanish?

I have some translated ones right here.

Yes, thank you very much.

Excuse me, do you know what these words
mean? I’m not so good with medical words.

Hmm...

FACT:
The difficulty of informed consent documents & its
legalese wording often imposes barriers to a
patient’s comprehension of information that is
needed for them to be able to make an
informed decision.³ Because of this,
live-translators are usually needed.
Certified translators are essential as
miscommunication may occur if
family members or ad hoc
translators are used.⁴

Oh, I can help you with that!
Muchas gracias. I've lived here for 30 years now, but I still feel like an immigrant. I'm reminded every day. I feel invisible.

Sorry for listening in, but what do you mean?

If you look like me or him...

(Nods)

Or these two ladies here...

(Nods)

People assume things.

Yes. I was an engineer back in Mexico but I can't read or write English very well, so I cannot even use my education here. So people make assumptions.

They think I don't belong here, but I don't consider Mexico my home anymore. I feel like I am an American.
The only work I could get was so hard on my body—that gave me a bad heart. I'm only 50 but I get so tired & achy & I had to take painkillers all the time.

I'm still working too, & every day they tell us to work faster & faster but it's unsafe—I see people getting caught in the machinery all the time but we're not allowed to report or they'll call immigration.

That actually leads to one of the reasons why I signed up for this trial. I'm so glad that these researchers are providing food or compensating it for us.

FACT:

Many low-income neighborhoods are "food deserts" because they lack access to a full-service supermarket & are instead dominated by "junk" & unhealthy food options. This food insecurity impacts nutrition, brain development, learning, behaviour, & leads to an increased risk of diabetes, obesity, & cardiovascular issues in the long run.
Yeah, you're right. And I definitely understand that, healthy options are difficult to find in my community, too.

I cannot even count the number of times I've been told that, too. I've lived here all my life, I'm American, but people tell me "Go back to your country," all the time.

AISHA

Yes, my whole family is American. Farming is all we know, we've been doing it for generations. I don't like the city because of the noise, the people, and so little sense of community. But, it's so difficult for us to get any medical help.

FACT:

Rural residents have many transportation difficulties when trying to reach health care providers, often traveling great distances to reach a doctor or hospital. Public transport often does not provide frequent or practical service in rural areas.

This clinical trial alone took me 40 minutes to get here. There are ridiculously long waiting lists to see any specialists. We can't go to the city easily because the bus routes aren't that practical.

I mean, it's great that these researchers are funding our public transportation and someone's actually helping us with navigating all the financial costs.

That definitely reduces a lot of stress I have about additional costs. But it's a deeper problem that should be addressed by the government, too.
Yeah, I have to take public transportation as well because I can’t afford a car.

I’ve been so late to many doctor’s appointments & they just end up not taking me in, so I have to reschedule &... well, it’s such a big hassle.

I’m sorry, we can’t see you today.

I’ve been so late to many doctor’s appointments & they just end up not taking me in, so I have to reschedule &... well, it’s such a big hassle.

No make up if you’re 15 min late.

I’ve been so late to many doctor’s appointments & they just end up not taking me in, so I have to reschedule &... well, it’s such a big hassle.

Having a full-time job & being the only caretaker for my son is also so difficult. I can’t afford a sitter so I was really concerned about what I’d do about my boy Malik if I was coming here. I’m really glad they’re compensating at least a little for that.

Yes, I hear you— it’s so tough. I have a little girl back home so I know how hard it is to juggle everything.

(nods)

I was actually not going to sign up for this because I know clinical trial sites are usually far away from home, but they said they’ll be moving closer to the patient population & I didn’t need to travel so much. That changed my mind.

FACT:

Sites for clinical trials are usually selected so investigators are located, as opposed to where the patients are, creating difficulties in patient recruitment.

That’s really great!

I guess my point is that I’m tired of pretending the reason families like mine don’t have the same opportunities for good housing or jobs or education isn’t because of race. Black communities have been facing discrimination for decades, & we remember everything.

Tuskegee Syphilis Experiment Exposed
Tuskegee is still present in our minds even today. When I was signing up for this clinical trial, my grandpa was adamant I research everything thoroughly beforehand.

So I was surprised when the researchers were so transparent! I think it was definitely easier to trust them because my general doctor also approved of them.

Yes, that’s something I’ve never seen before in other researchers.

We’re Muslims, we’re proud of our rich culture, and when things get hard, we have that to fall back on.

See, my culture really values family and a sense of community.

We have community gatherings a lot and we often meet around food and just some friendly conversation.

The researchers in this study actually came to our community and were very friendly. They set up tables at a few of our community events and town hall meetings and explained everything to us so thoroughly. It felt like they were really trying to get to know us and empathize with us.

That definitely made more open to doing this. I’m glad that the researchers really tried to get to engage with our culture.
Family is so important to my culture, too.

Sandy: But it's not always so easy. You know? It's been hard for me to even accept that I need to seek help. In the Asian cultural environment I grew up in, mental health was never talked about.

Right. If you don't talk about it, you can pretend it doesn't exist.

It's the same in Latino families as well.

Right. And when I finally got the courage to go get some help, the first doc. I saw just didn't understand my experiences.

He kept insisting that my family should help with my recovery, but I didn't even tell them that I was there because I knew they'd disapprove.

FACT:
A lack of diversity in the medical field makes it particularly difficult for researchers to empathize with underrepresented minorities & less likely to serve in these areas. Having cultural competence is vital to encompass the knowledge, skills, & attitudes required to bridge cultural, ethnic, & linguistic gaps. 12

Plus, there are so few behavioral providers to choose from anyway.

Right? If only there were more doctors that looked like us, or understood how it's different for us.
or if they Spoke our language at the very least.

There are so few that are from my culture in the first place, & they're not necessarily bad doctors, it's just I never feel entirely comfortable talking to them, which makes it even harder.

That's why when they were recruiting for this study, I signed up because I actually saw a researcher who was also Korean!

It was definitely a weird experience. It's been a long time since I've seen someone of my background involved in medical work.
Yeah. It seems like everything is stacked against us.

But it's definitely great that these researchers are starting to acknowledge that there's something wrong with the way things work right now.

Mm-hm. They've done a few things that have helped us actually participate & be able to come to these trials. Who knows - maybe people like us will actually be better represented, at least in this study?

Hm. Maybe. They've certainly done a lot differently, but I think there's still a long way to go.

Thanks for being so patient, everyone. We're ready to start the sessions now.


13. Quinn SC et al., Building trust for engagement of minorities in human subject research: Is the glass half full, half empty, or the wrong size? Am J Public Health 2013 Dec;103(12):2119-2121.