

Forms of Trust Identified through Focus Group Transcript Analysis and Supporting Quotes

FORM OF TRUST 1: Trustworthiness and use of genomic findings for reproductive and health decision-making

"That knowing... if you had known about that gene for schizophrenia, you know, how that would influence your decision to have children or not. And I guess at the same time, I just... With any kind of genetic testing, that idea of nature versus nurture... I mean, just because you have a gene doesn't mean it'll necessarily happen."

"If you do have that gene, it might make you think of other routes. Which I think is, you know... it can be a good thing. But at the same time, I think that making that decision based off the probability of you having that, or whatever, also takes away the chance of, like, a miracle baby. Because like PARTICIPANT:, is that right? ...You know, just because you have that gene, or just because you have a 90% probability, doesn't mean that it's gonna' turn out that way."

"And I'm sure it can stir up emotions within people. And I think that someone that has a less formed self-identity, and a less positive self-identity, especially relating to adoption... it might not be the best idea at that point. Because who knows what it can do to their self-confidence, and how they're feeling about their identity, and where they came from. And, you know, "This is in my history... and that's bad... so that makes me bad" kind of situation. Whereas if you have someone that is more confident and okay with having that information, I think they would do a lot better with hearing those results than the latter, so."

FORM OF TRUST 2: Trust in the protection from misuse and abuse of genomic data

"And so I don't know if something like that is possible with the DNA you take from us. But anything's is possible nowadays, especially the way technology advances. So to know that information... that genetic material is secure and is only being used for your purpose, not anybody else's. And I know you have informed consent and things like that, nowadays. But, I mean, it's something that was also just recently in the headlines."

"That information would have to be really, really, really strictly confidential between you and your doctor. And as it is now, insurance companies know everything about you, because that's the only way the doctor can get paid."

"I think that as long as you make the informed consent as detailed as possible, so that people are pre-warned about the results that they're going to give... as long as you cover that basis, then I think that you're fine. Because as long as people have a forewarning about what they're getting into, then they should be able to handle what the results are."

FORM OF TRUST 3: Trust in the research study, with particular attention to whether the research was guided by individuals with personal connections to adoption

"...for me comes back to one of the adoption issues of just trust. So if somebody else is gonna' have access to all of this... and how much of it is gonna' be fully given to me? How much is gonna' be withheld? I go into that mindset of knowing, again, someone else is controlling parts of what's mine. And so for me, the easy answer – and without getting too, like, into this easy answer – is I'm just not gonna' do it. Because it just feels safer that way. And so when you engage in something like this, for me it feels very vulnerable. And so that would be the risk of having that out there; trusting or not trusting how much of it's going to be given to me honestly or withheld for research, or those sort of pieces. And then once I have the information, like, the list of medical conditions or this... Then what do I do with it?"

"...the fact that there's people involved in this research that are adopted, or that have adopted... That investment helps me to have trust in the project. I think when you have that – somebody involved with it that has a personal investment – it, generally speaking, has a tendency to, for me, to want to participate more than, for example, outsiders. An example of that is when some of us are invited to speak with groups, or adoptive families or schools... to be "used" versus to be "engaged with," I feel, like, are two different things. So that... I think that may make a difference in the research, or how it's presented back to you. Saying, "We're a part of this too. This isn't just a job that we're doing..." but there's a... this is a personal investment of some sort. I think... for me at least, that feels safer."

"I'd rather have somebody who's more interested in me, kinda' thing – not just running a business. So if adoptees and the community is in this program, I definitely would feel more comfortable with it. Because there's already that kind of trust bond, being an adoptee community kinda' thing"

"So then, I would hope for some sort of a legal agreement between, like, participants and the researchers to... whether it's scripted or something we agree on one-on-one... is what I would want out of this. So as a participant... regardless of what you find, regardless of how difficult it is to bring to us or whatever, I want to have verification that it would be given to me. 'Cause otherwise, if there's not that 100 percent transparency for me, I wouldn't participate."