



SHARE

AND SHARE ALIKE

IT'S THEIR DATA, TOO

INTERVIEW BY ELAINE VITONE

If you volunteer for a research study, typically, what you walk away with is a bit of cash in your pocket, and that's about it. The researchers, however, gain data, the stuff that scientific discoveries are made of. Even though it is, after all, *your* data—your blood samples, your survey responses, your time and trouble—sharing study data with volunteers is generally not the default.



Massart

“But it absolutely should be,” says **Mylynda Massart**, an MD, PhD assistant professor of family medicine and core director for engaging special populations at Pitt’s Clinical and Translational Science Institute (CTSI).

She acknowledges: It is hard. “Return of results,” in scientist parlance, creates layers of additional work (including institutional review board approval). All that added staff time means added costs, too. And with sensitive information like genomics, there are many more layers still.

So yes, it’s hard, Massart says—but it’s worth it.

“We use this word, *reciprocity*,” she explains, the idea being that research is really a partnership, and participants truly are partners. “We are in an era where trust is very fragile, and for valid reasons. We need to earn that back, and reciprocity is a way to do that.”

Massart and her CTSI colleagues are engaged in what may be the largest-ever undertaking in research reciprocity. The All of Us study, as it’s called, is a historic effort to create a cohort of 1 million people. It’s the centerpiece of the National Institutes of Health’s Precision Medicine Initiative.

Each study volunteer’s genome will be sequenced and, if the participant wishes, these data will be shared with them. (“The opt-in part is important,” Massart stresses.) The years-long process of laying the study’s groundwork—which includes a network of genetic counselors to help participants understand what certain genomic testing results mean for their health—has been no easy feat.

Recently, Pitt Med talked with Massart about the tradeoffs and triumphs of reciprocity, a new research model for which she and her All of Us colleagues hope to set the gold standard. “Success is a strong motivator” for other scientists to board the return-of-results train, she says. “If we succeed in doing this for a million people across the country, that’s gonna be huge. People are gonna say, ‘How did they do that?’”

When you say research should be a “partnership,” what does that mean, exactly?

There should be value exchanged, and value can have many different forms. Historically it’s just been financial compensation, but now we’re recognizing that there’s actually huge value in returning results to participants, because they get to learn about themselves. And it turns out we are interested in ourselves. These are like our medical selfies.

Are there resources you can recommend for researchers who are interested in adopting this model in their studies?

Having gone through this process here at Pitt, we [CTSI] would be able to provide guidance for anyone consulting us. And the NIH’s National Human Genome Research Institute now has a website for return of research results.

What would you say to researchers who are hesitant to go this extra mile in returning results to participants?

Engagement is worth it. And especially long-term engagement. If you’re asking someone to participate in something over time, we should have ongoing return of value. We need to stop expecting that we can do research without it. We’re sitting in our academic ivory towers, thinking everyone is going to think our research is so important, and come running in to sign up? That’s just not logical. People are busy.

Tell me about the ethical component to this.

In graduate school I was in a study where I was a normal control for a brain. I did two brain MRIs a year apart. And they were not obligated to tell me if they had found a brain tumor or not. My brain, my MRIs, right? Is that really ethical? As scientists and clinicians find something, especially something that could be intervened on and change the outcome, don’t we have a moral obligation to inform that patient?

Also, can we engage patients and understand their social determinants of health and their needs that may not currently be met, and then match them with supports? That is also returning value. If you participate in a research study, and I learn that you don’t have a primary care provider, can we connect you with one?

If I find out that you don’t have food, can I connect you to a social worker who can help you complete the application for food stamps? People are starting to recognize that we actually do have a moral obligation there, too.

What’s your wish list for the way forward?

Hopefully in the future we will start seeing grant opportunities actually require [return of results]. There’s momentum there.

I hope folks are starting to think: What value am I giving my research participants? Yes, I’m paying them, but is that money actually respectful and meaningful? And I hope that, early on, [researchers] are engaging community members representing their target populations and asking that question: What is valuable to you and your community members? Or your family? Is it \$100, or is it something else?

What are some examples of what that might look like?

Maybe it’s having a social worker at the recruitment site who can help provide access to resources. Or maybe community members are saying, *We need more community gardens*. Well, let’s find some community gardens. Or: *We don’t have enough nurses in our public schools anymore; so when someone gets hurt on an off day, they go to the school office*. Well, [let’s help find a nurse].

It’s about having the dialogue to learn what the value is, and then returning that. It doesn’t have to start with returning genomics. It can truly be our time, our knowledge, our support, our interest.

We have this community vaccine collaborative [at Pitt]. We are engaging with community groups, and our return of value is just being there for people. Just saying, “If you have a question, you can message me. And then you’re not having to call 16 operators and hope someone gets the message.” So that when something happens, they think, “Oh I’m going to call Dr. So-And-So at Pitt. I’ll have an answer for us tomorrow.” That’s the space that Liz Miller is really trying to get folks to recognize. [See page 16.]

It’s the whole lasting relationship. The whole give and take. ■

