

Collaborator vs. Consumer: Closing the Gap in Research and Data Sharing

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True collaboration in the research system requires a long-term investment to build a proper network.

The perceived drawback to collaboration is simply time. Collaborative efforts take a long time to show value because these groups do not have the kind of absolute control needed to move quickly.

It is important to be patient in this process. Don't confuse the short-term adoption of the consumer model with the long-term adoption of the collaborative model. It's not a business; it's a network.

Part of making collaboration more effective is realizing information must be gathered from hundreds of thousands or millions of people in order to make interesting statements about the population as a whole.

We either need a little data from an enormous amount of people

or an enormous amount of data from a small group of people. To accomplish either of these things, we have to change the way you think about collaboration.

Three things need to come together in collaborative models for research:



1

Team science

Most people think of team science

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as taking labs from different institutions that work on the same topic and putting them together to work on a project. However, the members of this network are not always prepared to work together. Just because teams are working on the same topic, doesn't mean those teams will work well together. These groups need facilitators, like Sage Bionetworks, to teach them the necessary skills to overcome their differences, work effectively together and get out of their way.



2

Open vs. closed data

There is a huge impact associated with making data open, particularly human data. Human data cannot be open without informed consent. More generally, there are innovation costs to both openness and closure at the right and wrong times. Making data open too early in the research process may limit the creativity of other groups. Scientists in this situation are afraid to take chances

and make mistakes, so they follow the models of the front-runners in the research process. This greatly reduces diversity in methods, models and, ultimately, treatments for patients.



3

Human engagement

We have to treat people who enroll in studies as people. Make sure people are asked what they feel, what they like, what they don't like. It's unfortunately not far from subject to mouse. People need to be treated with empathy.

Take a rare disease group for example: If researchers want to get the kind of data that allow complete analysis, they have to become part of the patients' lives. Patients cannot come in every now and then and give a few vials full of samples and be on their way. Researchers have to be part of their lived experience. Patients will not allow researchers to become deeply involved in their lives

if they are being treated like a subject.

This investment is critical because patients can point scientists toward what questions to ask, what elements to measure and where intervention is needed.

The best way to move collaborative efforts forward and reduce costs is through standardized sharing platforms. At Sage Bionetworks, we cannot be successful until communities form outside of us and use our platforms to build their own trials and projects.

This sharing should include more than methods and models. It must also include mistakes. Researchers should not be afraid to reuse, repurpose and learn from each other.

Important data are gathered by surveys and wearables, but also on every individual's cell phone. More and more sensors are moving into our lives, and they are not moving in because of health. Apple, Amazon and other tech companies already use technology that can monitor a consumer's heart rate or detect signs of depression based on pauses and sighs in a consumer's speech.

These kinds of things will be used for health within 10 years. So the question becomes: What's that system going to look like? What's our citizenship inside that system? Will it empower new researchers?

Individuals must be welcomed as collaborators — and not just sources and consumers — in data and research. Transparency must be present in data to show people how their data are being used. We must ask ourselves: Will I be a citizen or will I be an oil-well for data?