Director’s Blog: Something Interesting is Happening

By Thomas Insel (http://www.nimh.nih.gov//about/director/bio/index.shtml) on June 5, 2015

Tom Goodwin made an intriguing observation in a recent Techcrunch.com essay : “Uber, the world’s largest taxi company, owns no vehicles. Facebook, the world’s most popular media owner, creates no content. Alibaba, the most valuable retailer, has no inventory. And Airbnb, the world’s largest accommodation provider, owns no real estate. Something interesting is happening.”

Something interesting may also be happening in the world of clinical trials. Precision medicine has become the buzzword of 2015, beginning with President Obama’s announcement in his State of the Union speech in January, “I want the country that eliminated polio and mapped the human genome to lead a new era of medicine -- one that delivers the right treatment at the right time.”

At NIH, the Precision Medicine Initiative is developing in two different programs. The National Cancer Institute just launched a massive clinical trial at over 2,400 sites in collaboration with 20 private sector partners. This program will try to match patients to best treatments based on the molecular fingerprint of their tumors. A second project, still under discussion at NIH, is a plan to create a cohort of 1 million people for longitudinal study.

This million person cohort is beginning to take on something of the Uber, Facebook, and Airbnb spirit. Like these innovative companies that have grown up in a new share economy where trust is the most important currency, the new cohort study could be a very different kind of biomedical research, also based on trust and empowered not by NIH or academic investigators, but by volunteers who want to crowd source their medical data. Would a million people create an information commons, sharing their personal genomic data, medical data, cognitive data, and behavioral data? Of course, this is happening already but not all in one place. Hundreds of thousands have already sent data to PatientsLikeMe and 23andMe . Imagine if we could add “largest clinical trial with no principal investigator and very little funding” to the list of largest taxi service with no vehicles and largest accommodation provider with no real estate. Now that would be interesting!

But would this very interesting revolution include people with mental illnesses? The PatientsLikeMe mental health and behavior forum has over 61,000 members, including people who self-identify as having schizophrenia (http://www.nimh.nih.gov//health/topics/schizophrenia/index.shtml), depression (http://www.nimh.nih.gov//health/topics/depression/index.shtml), or social anxiety (http://www.nimh.nih.gov//health/topics/social-phobia-social-anxiety-disorder/index.shtml). Recovery Record reports over 300,000 people with eating disorders signed on to its registry. The Interactive Autism Network has been a meeting place for thousands of families with autism to share their experiences and learn about the latest research. While some may have thought that stigma or denial would keep people with mental illnesses or neurodevelopmental disorders from creating registries, many thousands of people with these conditions have already joined the movement for patient-driven research.

There are still many questions about where this new movement will take us. Are these registries representative of the entire population? How will privacy be protected? Who will ensure the quality of the data? What questions will and will not be answered by this approach? Uber and Airbnb were greeted with skepticism, and questions continue to emerge. Likewise, these are still early days in the patient-driven research movement.

Although the Precision Medicine Initiative at NIH is still under development, one consistent message has been that we will be creating not only a new cohort but a new culture for biomedical research. Research driven by patients, or maybe I should say “volunteers,” could create a research platform that might not look like academic research or private sector research. As people share their experiences with treatments that work or don’t work, they may see patterns that were never evident in randomized clinical trials. I don’t know where this will lead. But isn’t that exactly the potential of a new kind of clinical research – built by and for the people who have the most at stake?

Publications by the Director

Selected publications by NIMH Director Thomas Insel (http://www.nimh.nih.gov//about/director/bio/publications/index.shtml)

Science News

Medicaid supports new psychosis treatment (http://www.nimh.nih.gov//news/science-news/2015/medicaid-to-cover-new-treatment-for-first-episode-psychosis-based-on-nimh-funded-research.shtml)

Antipsychotics Use Goes Up Among Elderly (http://www.nimh.nih.gov//news/science-news/2015/antipsychotics-use-among-older-adults-increases-with-age.shtml)

Study Supports Coordinated Care for FEP (http://www.nimh.nih.gov//news/science-news/2015/team-based-treatment-is-better-for-first-episode-psychosis.shtml)

More (http://www.nimh.nih.gov//news/science-news/index.shtml)