

Crowd-sourcing genetic data could help unravel the causes of disease

July 3 2013, by Rajaie Batniji

Earlier this month, researchers and advocates from 40 countries formed a global alliance to enable the secure sharing of genomic and clinical data, aiming to end the era in which only the people who collected your genetic data had access to it.

Efforts to collect and organize massive amounts of genetic data have up to now been led by the British government, Kaiser Permanente, the U.S. Department of Veterans Affairs and by [private companies](#). But with the new global alliance, it seems likely that genetic data collected by your doctor will one day be made widely available in the cloud, for researchers around the world to analyze. This has tremendous potential for science and medicine.

Putting genetic data online, however, also comes with serious, and not entirely known, risks. We know people can sometimes be identified even from anonymous genetic data, and that could lead to genes being used to deny employment or [insurance coverage](#). Perhaps most ominously, if mismanaged, DNA sequences could be used to create bio-weapons, frame crime suspects or discriminate against people in unforeseen ways. The sharing of genetic information will require a delicate and complex balance between broad access and tight privacy, a balance the Internet has never perfected.

Yet, crowd-sourcing genetic data and sharing it freely online could lead to incredible discoveries. It could help scientists unravel the complex [genetic causes](#) of disease and focus on early prevention. It could help

democratize research, allowing researchers equal access to data that can help answer questions that matter to them.

There are also untold changes that could come to personalized medicine and public health. With your DNA in the Internet cloud, you could open an app to give your doctor permission to run a program on your DNA sequence, which could then help her decide which [blood pressure medication](#) is best for you. With [gene sequencing](#), it will become far easier to trace a disease outbreak to its source (as was recently demonstrated in a tuberculosis outbreak), enabling public health officials to stop outbreaks earlier.

Achieving these advances in science, medicine and [public health](#) demand that we create the "Internet of Genes." Genomics has been remarkably absent from the information revolution. This is a surprise, because unlike a photo, which you can appreciate individually, extracting maximum value from your genome requires relating it to other peoples' genomes.

As the new global alliance has noted, the greatest challenge to our advancement of genomics and personalized medicine is our inability to bring together data from all over the world. With the exception of about 1,100 people who volunteered to make their whole gene sequences publicly available, complete genetic information is not accessible for wide use on the Internet. Instead, researchers, clinical laboratories, and pharmaceutical companies are sitting on petabytes of underutilized yet invaluable genetic data. Genetic studies remain small in size, despite the plummeting costs of sequencing. Data - paid for by taxpayers and insurance companies - sit mutely in laboratories around the world, used for a single study or clinical case and then discarded or archived.

The recently announced global alliance will begin to lay the foundation for breaking down these silos that render valuable data inert.

Pressure to keep this data in largely impenetrable silos comes from many places. There is the professor who wants to be the first to publish, the company that wants exclusive data for drug or algorithm development, the hospital worried about breaches in data privacy and governments that cannot legally release data on behalf of citizens. Individuals have legitimate concerns about being identified by their [genetic information](#) and making public their disease risks.

Building the Internet of Genes demands that we strike a delicate balance between broad access and tight privacy for genetic data. Our efforts with "open data" platforms have failed thus far to allow individuals to actually own their data.

We cannot replicate these errors in genomics without potentially devastating consequences. Individuals must be in control of their data at all times, and this will require fine-grained technologies for managing consent, and innovative platforms that ensure the security of genetic data wherever it sits. Personal [genetic data](#) are far more sensitive than pictures posted on Facebook and will require tools to ensure that data are adequately protected and that access is audited. But if the new global alliance to enable the secure sharing of genomic data succeeds, we will soon be using the Internet of Genes to get personalized healthcare, identify disease risks and democratize science.

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