

## The Global Alliance for Genomics & Health

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**T**HE GLOBAL ALLIANCE FOR GENOMICS & HEALTH (GA4GH) held its first partner meeting in March 2014 in London. Now numbering more than 176 organizations from 25 countries, the GA4GH is working to make it possible to share genomes responsibly. Harold Varmus, Director of the National Cancer Institute, began the meeting by asking a deceptively simple question, “Are we really ready to share data?”

Although this should have an obvious answer, there is no simple affirmative reply when the rubber hits the road. This effort is certainly resonant with, and has representation from, many of the other major efforts striving for ethical interoperability, including the Public Population Project in Genomics and Society (P3G), ELSI 2.0, Heredity and Health in Africa (H3 Africa), the Human Variome project, the 1000 Genomes project, the International Collaboration for Clinical Genomics (ICCG), the International Rare Disease Research Consortium, and the International Cancer Genome Consortium. It certainly has echoes in the Institute of Medicine’s Committee on Strategies for Responsible Sharing of Clinical Trial Data (Terry 2014) and the very practical project, PCORnet. The meeting engaged 180 people from 17 countries. We worked together to create a shared understanding of the Alliance’s purpose, prioritize important goals, determine how to measure progress, and engage the partners.

David Altshuler, a major force behind GA4GH and a director at the Broad Institute, described the world with which we are all quite familiar: If we want to eat a burrito for lunch in London, it is quite easy to find one, but it is difficult to find health information specific to our needs. GA4GH should facilitate a world where we can find what we need because a basis for sharing genomes and associated clinical information has been well established.

In the first meeting of the nascent Alliance, in New York in early 2013, 50 of us saw the Alliance as the “home” for a number of nodes that would execute actual sharing. Now, a year later, it is clear that there will instead be a federated effort, with the Alliance as a network akin to the World Wide Web Consortium. This concept is based on the theory of change that describes the pathway to a goal and requires that we gather a broad and diverse network of stakeholders, publically commit to advancing progress in data sharing, establish common framework to achieve this, and act as a

clearinghouse to share best practices and foster innovation. This is a balance of thinking and doing, of establishing guidelines and experimenting with implementation.

The effort itself is also a product, and it must also create a trusted, authoritative, and self-sustaining international network that serves the public interest, to ultimately facilitate better health. GA4GH must always be able to answer the question “So what?” and do so quickly and simply.

There are technical, regulatory, and ethical challenges inherent in sharing genomes. And so the practical work includes four working groups: Regulatory and Ethics, Data, Security, and Clinical.

Following a hallmark of agile software engineering as a model, these working groups are creating a working model using a process based on agency, consultation, and iteration to advance concepts to implementation rather quickly. These small working groups are very active (I can vouch for that—8 a.m. calls every week leading up to this meeting!). It is our task to write a charter, request comments, analyze the comments and make decisions about their impact, distribute initial work products in an open manner, get comments, and create a final work product. The steering committee signs off on process and content.

Because the individuals and organizations involved believe this will make a difference, they are committed to creating the infrastructure and governance to the achieve goals.

There are several generative tensions in the work. It is critical that the various working groups are focused on completing practical tasks and at the same time solving big challenges, resulting in a quest to balance engagement and action. There is also a tension between cooperation and competition. It is important to allow competition to provide incentives when it is generative but also to create incentives that foster cooperation. The significance of the diversity of genomes throughout the world is also critical to a truly global project.

When it was first mapped, the genome was much freer than many data sources in biomedical research. The cacophony of silo-building has been disturbing in the years since, and the GA4GH is gently, but hopefully, removing some of the walls so that data sharing can flourish. This is essential to human health and requires commitment and risk on the part of those who would most benefit from the silos. Many stakeholders have made the commitment and now are assessing the risks.

Let's boldly move forward in the name of those who need us the most.

#### References

- Global Alliance for Genomics & Health. Available at <http://genomicsandhealth.org/> Accessed April 20, 2014.
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