

GA4GH presents vision, model for genomic and clinical data sharing

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In today's *Science*, the Global Alliance for Genomics and Health (GA4GH) calls for a federated data ecosystem for sharing genomic and clinical data. The authorship, which includes Richard Durbin, Julia Wilson, Stephen Keenan, and David Lloyd of the Wellcome Trust, as well as a diverse team of international leaders in academia, research, medicine, and industry, argues that a common framework of principles,



protocols, and interoperable technical systems are necessary to enable responsible and effective data sharing.

GA4GH was established in 2013 to bring the community together to build the tools and establish the standards necessary to achieve that goal. Today, it counts more than 400 organizations and more than 700 individuals in its membership, which spans more than 70 countries. "These stakeholders are working together across traditional boundaries to create the common framework that will allow us to make best use of the millions of genome sequences that currently sit in siloed databases around the globe," says Peter Goodhand, GA4GH Executive Director and a member of the author group.

"We are at a critical time for genomic data interpretation," said Richard Durbin of the Wellcome Trust Sanger Institute in the UK, and co-chair of the GA4GH Data Working Group. "We know from the international research that led human genome sequencing that the key to understanding individual genetic differences is to compare them to data from other people. But the scaling up of genomics for clinical use is being carried out by organisations that do not necessarily have the traditions or mechanisms in place to carry out the necessary sharing. We must establish trusted systems to enable safe mutual clinical benefit via effective data exchange."

To date, GA4GH has created a toolkit of diverse products, including the Genomics API, which allows disparate technology services to exchange genotypic and phenotypic data, as well as the Framework for Responsible Sharing of Genomic and Health Related Data, which outlines the basic principles and core elements for responsible data sharing. GA4GH has also catalyzed the development of three data sharing projects which aim to illustrate the value of sharing data in real world contexts. These consist of (i) an open-ended approach to sharing data across the Internet (the Beacon Project), (ii) an international



collaboration among breast cancer genetics experts (the BRCA Challenge), and (iii) a peer-to-peer network of clinicians (Matchmaker Exchange).

In addition to outlining successes, the paper notes a variety of remaining challenges to sharing data across national and institutional boundaries. For example, the membership is currently working on solutions to secure data access while maximizing the scope of information that can be shared, to create tools that are flexible enough to be readily implemented in different knowledge domains, and to establish sustainable funding models that support data curation, hosting, and computation.

"Private funders and national governments will need to be involved on some level to support these activities so that clinicians and scientists may access as much free, curated data as possible," says Mike Stratton, Director of the Wellcome Trust Sanger Institute, CEO of the Wellcome Genome Campus, and a member of the GA4GH Strategic Advisory Board. "The Sanger Institute has supported the Global Alliance since its inception as we are committed to helping researchers and clinicians access and freely share the genomic and related health data they need to transform human health."

More information: "A federated ecosystem for sharing genomic, clinical data" *Science*, <u>DOI: 10.1126/science.aaf6162</u>

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