

Global Alliance for Genomics and Health

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Research Areas



Tool Development

Standard



Data-Sharing Enabler

At a Glance

- Status: **Active Consortium**
- Year Launched: **2013**
- Initiating Organization: **70 Participating Organizations**
- Location: **International**

Abstract

The Global Alliance for Genomics & Health (Global Alliance) is an international coalition, dedicated to improving human health by maximizing the potential of genomic medicine through effective and responsible data sharing. The promise of genomic data to revolutionize biology and medicine depends critically on our ability to make comparisons across millions of human genome sequences, but this requires coordination across organizations, methods, diseases, and even countries. Global Alliance members work together to create interoperable approaches and to catalyze initiatives that will help unlock the great potential of genomic data.

Mission

The Global Alliance mission is to accelerate progress in human health by helping to establish a common framework of harmonized approaches to enable effective and responsible sharing of genomic and clinical data, and by catalyzing data-sharing projects that drive and demonstrate the value of data sharing.

To achieve this mission, the alliance will work collaboratively with its membership to:

- **Convene:** Bring together stakeholders from different sectors and localities to share information, establish best practices, and enable interoperability across the broadest possible group
- **Catalyze Sharing of Data:** Play an active role in catalyzing sharing of data among members to advance science as well as the positive impact of genomic information on human health
- **Create Harmonized Approaches:** Identify existing standards and application programming interfaces (APIs) by consulting experts and studying best practices and, where needed, develop new standards and other interoperable tools and methods. These approaches (whether existing or new) will be broadly disseminated and will result in a common framework for representing data, for security and privacy, for ethics and regulation, and for interface with the clinical environment.
- **Act as a Clearinghouse:** Share best practices, cross-pollinate ideas and learning, and communicate with diverse communities. Although the alliance encourages participation by the entire biomedical research community, even those who do not join will be given access to the shared approaches to ethics and technical models for data sharing.
- **Foster a Culture of Innovation and Discovery:** Lower the barriers to parties working together and sharing data, enhancing innovation, and enabling discovery
- **Commit to Responsible Data Sharing:** Work together to promote the highest standards for ethics and ensure that participants have the choice to responsibly and securely share their genomic and clinical data to advance human health

Consortium History

The Global Alliance's origin occurred in January 2013, when more than 50 colleagues from eight countries met to discuss current challenges and opportunities in genomic research and medicine and how their groups could work together to accelerate medical progress. A clear consensus emerged: that the greatest need is a common framework of harmonized approaches that will allow oversight of international standards designed to enable sharing of genomic and clinical data in an effective, responsible, and interpretable manner. In June 2013, 70 organizations came together by signing a Letter of Intent, publicly announcing their intentions to form a global alliance.

Structure & Governance

The Global Alliance is a collaborative, global partnership led by a Steering Committee and an executive team.

The role of the Steering Committee is to make high-level decisions about the direction, values, and working products from the Global Alliance. Steering Committee members are determined through a nomination process and, collectively, reflect the diversity of perspectives, backgrounds, and geography of the Global Alliance generally. The Steering Committee appoints a committee chair and an executive director.

Global Alliance members compose a plenary body and collaborate to advance its mission. These members participate in Working Groups and other committees.

The Steering Committee and Working Groups are supported by professional staff, located at Host Institutions.

Financing

The Global Alliance is a nonprofit organization dedicated to the public good. It is supported by a variety of means consistent with nonprofit funding, including philanthropic support, grants from research and government agencies, and other funding.

Patent Engagement

Participant-centric consent is a core value of the Global Alliance, which respects individuals' autonomy, privacy, and security choices. In addition to technical experts, the Alliance members include ethicists and disease advocates, all of whom share a core commitment to the idea that each individual should decide whether and how widely to share his or her own data.

Data Sharing

The Global Alliance seeks active participation of diverse stakeholders with various perspectives, including funding institutions, patient advocacy groups, technology companies, and others who do not themselves generate or analyze data. Although all members of the alliance are committed to advancing the goal of effective and responsible data sharing, some members may not themselves have data to share. At this time, each member organization decides for itself whether and how to apply these approaches in order to share data to advance human health.

Impact/Accomplishment

Each Working Group aims to deliver tangible, innovative, and actionable work products that improve and impact the field of genomic medicine and advance human health. This work serves to facilitate the use of interoperable technical standards for managing and sharing genomic and clinical data, to develop guidelines and harmonize procedures for privacy and ethics, and to encourage responsible and voluntary sharing of data.

All work products can be found on the Global Alliance website.

Links/Social Media Feed

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Sponsors & Partners

A full list of members can be found at <http://genomicsandhealth.org/members>.

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