Global Alliance for Genomics and Health (ELSI): Quick tour

This quick tour provides a brief introduction to The Global Alliance for Genomics and Health (Global Alliance), which was formed to help accelerate the potential of genomic medicine to advance human health. This Quick tour focuses on the Ethical, Legal and Social Implications (ELSI) of data sharing that have been addressed by the Global Alliance.

An undergraduate degree in the life sciences would be an advantage.

Learning objectives:

- Basic understanding of what the Global Alliance is and what resources are available.
- Know where to find out more about the Global Alliance.

What is the Global Alliance?
organisations in 40 countries. Its mission is to accelerate progress in human health by helping to establish a common framework of approaches to enable effective and responsible sharing of genomic and clinical data. The partnership also catalyses projects that drive and demonstrate the value of data sharing.

The Global Alliance is seeking to make it easier for researchers and clinicians to access data and combine data sets, whilst also considering the ethical, legal and societal implications of the work they are doing and ensuring that research participants’ privacy is protected.

The Alliance works collaboratively to:

- bring together stakeholders from different sectors around the world;
- promote data sharing through the harmonisation of standards and applications;
- to share ideas and knowledge gathered from the genomics community and beyond.

The goal is to promote the highest standards of data sharing in order to maximise the benefit of the data for human health - whilst ensuring that participants are protected.

* Image credit: Dominic Alves. [CC 2.0](2)

### Why do we need the Global Alliance?

The cost of genome sequencing has fallen one million-fold since the first human genome was sequenced (see image below from the National Human Genome Research Institute). As a result the use of sequencing has increased exponentially and is now routinely used in research and the clinic, resulting in the creation of vast amounts of genomic data. By combining these data it is possible to see complex genetic patterns that would not otherwise be visible in smaller data sets. This allows scientists and clinicians to understand complex genetic traits and diseases.
The amount of data needed to detect these patterns is often beyond the capability or capacity of a single individual or institution. This means that organisations must be willing to share their data with other researchers and these data must be in a usable format. Although the field of genomics is relatively young, researchers already spend disproportionate time collecting data, which is then held in isolated silos.

The Global Alliance seeks to encourage researchers to share their data in the interest of science and the public, and to develop technical and ethical standards to maximise sharing of data for global benefit in a manner that is effective and responsible.

What is ELSI?
The idea of formally examining the Ethical, Legal and Social Implications (ELSI) of genomics arose during (and was integral to) the Human Genome Project [4]. The National Human Genome Research Institute, part of the NIH, still funds an ELSI research programme [5].

The Human Genome Project ELSI programme consisted of four research priorities:

1. Genomic research and the issues that arise in the design and conduct of such research.
2. Genomic health care and how genomics may influence and change the delivery of health care.
3. Broader societal issues – how societal norms and belief systems will interact with genomics, which affects how people conceptualise and understand genomics and its relationship to health, disease and individuality.
4. Legal, regulatory and public policy issues

As genomics as a field has advanced so have the issues and implications of genomics. Early ELSI projects considered the impacts of genetic testing and provision of counselling for heritable cancers. But as genomics has become more established in society, issues have arisen around intellectual property rights, microbiome research, and the return of results to genomic research participants. For more information on ELSI, see our tutorial on Biomedical data: Ethical, legal and social implications [6].


Within the Working Group smaller task teams, whose work includes developing models to allow mutual recognition of different regional or national ethical review, creating policies for working with vulnerable groups such as children or those with dementia, and creating a series of standards from how to handle privacy breaches to standardised terminology around data sharing (see ELSI Toolbox [8]).

ELSI Toolbox

The Regulatory and Ethics Working Group provides various policies and tools that may help you to follow best practices in data sharing:

- **Accountability Policy** [9] - A guide to transparency and accountability in data sharing for different stakeholder groups. Includes guidance on handling of non-compliance with data sharing standards.
• **Consent Policy** [10] - A guide for the sharing of genomic and health-related data in a way that respects autonomous decision-making while promoting the common good of international data sharing.

• **Consent Tools** [11] - Guidance and tools for handling legacy data, addition of clauses to allow international data sharing, and a generic consent form template for international data sharing.

• **Data Sharing Lexicon** [12] - A glossary and dictionary of common terms used within data sharing. The purpose of this lexicon is to support international data sharing by promoting harmonised definitions across jurisdictions and research contexts.

• **Responsible Sharing of Genomic and Health-Related Data** [13] - This framework provides guidance on the benefits and limitations of sharing human genomic and health-related data, giving consideration to human rights including the benefits of science, the right of attribution and the right of scientific freedom. It aims to be both aspirational and practical, guiding the interpretation of international norms.

• **Policy Template** [14] - This Policy template provides guidance on writing policies for the Global Alliance, based on the founding **Principles and Core Elements** [15].

• **Privacy and Security Policy** [16] - A guide for managing privacy and security risks related to data sharing, and to ensure that data use respects individuals’ expectations and rights.

• **Security Infrastructure** [17] - A security infrastructure policy and technology recommended for stakeholders in the Global Alliance ecosystem.

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**Finding your way around the Global Alliance**

**Global Alliance homepage**

The Global Alliance has four active Working Groups:
1. Clinical
2. Data
3. Regulatory and Ethics (the focus of this quick tour)
4. Security

There are links to these Working Groups at the bottom of the homepage (Figure 1).

Figure 1 Global Alliance homepage, showing the various working groups.

**Regulatory and Ethics Working Group**

The work products and related projects of the Regulatory and Ethics Working Group can be found on this page, alongside names and contact details for the leadership.
Figure 2 Regulatory and Ethics Working Group resources.

**Project Pages**

Each project page has the latest version of the 'Work Products' (for example, policies and tools), available to download as a PDF (see Figure 2). The names and details of the members of the subgroup responsible for the work product are included at the bottom.

You can also browse links to related initiatives.
Accountability Policy

About This Work Product

Openness and accountability between stakeholders are needed to foster trust and collaboration. This policy is addressed to individual and organizational members of the GA4GH, as well as the broader community of stakeholders involved in data sharing. Section II outlines best practices for monitoring and responding to non-compliance with data sharing standards, and is primarily directed to stakeholders involved in oversight of research consortia, projects, or institutions: the clinical sector; or industry. Section III outlines best practices for transparent and accountable data sharing, addressed to specific stakeholder groups. The Policy builds on the GA4GH Framework for Responsible Sharing of Genomic and Health-Related Data, which sets forth a harmonized, human rights approach for responsible data sharing.

Downloads

- GA4GH Accountability Policy

Work Product Details

Working Group(s): Regulatory and Ethics
Work Product Type: Policy
Related Initiative(s): Accountability Policy
Related Work Product(s):
- Framework for Responsible Sharing of Genomic and Health-Related Data
- Privacy and Security Policy
- Consent Policy
- Security Infrastructure

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Topics:
- Compliance
- Data Sharing
- Accountability
- Oversight
- Monitoring
Joining the Global Alliance

The Global Alliance invites organisations and individuals to become members. Members have access to the latest updates from the Global Alliance, including tools and documentation. Members can also join working groups and subgroups, as well as comment on the latest initiatives.
If you wish to learn more about joining the Global Alliance, click on the green ‘Become a member’ button at the top of every page. Or you can click on the membership tab on the tool bar, where you will also find FAQs on membership. Applications are straightforward and should be responded to within 5 working days.
Get help and support on the Global Alliance

Support / find out more

More information about the work and mission of the Global Alliance and how to become a member can be found on their FAQs page [18].

For specific enquiries, you can theglobalalliance [at] genomicsandhealth.org (email the Global Alliance) or call 416-977-7599 (Toll-free: 1-866-678-6427).

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Become a Global Alliance Member

You can join the Global Alliance either as an individual or an organisation [19].

As a member, you may join Working Groups and contribute to Initiatives. You may also register to:

- Receive the latest Global Alliance updates
- Receive the latest Working Group updates through mailings and webinars
- Download documents and presentations
- Participate in regular meetings of Global Alliance Membership

Funding

The Global Alliance for Genomics and Health is a nonprofit organisation dedicated to the public good. The organisation is funded by a variety of means consistent with nonprofit funding, including philanthropic support, grants from research and government agencies, and other funding.

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Links
[1] https://www.ebi.ac.uk/training/online/trainers/sb46
[2] https://creativecommons.org/licenses/by/2.0/
[18] https://genomicsandhealth.org/about-the-global-alliance/frequently-asked-questions
[19] https://genomicsandhealth.org/members/become-ga4gh-member