The Global Alliance for Genomics and Health (GA4GH) Regulatory and Ethics Work Stream (REWS)

Global Alliance for Genomics & Health
Collaborate. Innovate. Accelerate.

Maili Raven-Adams[1], Lindsay Smith[2], Beatrice Kaiser[3], Yann Joly[3] and Dianne Nicol[4]

[1]Wellcome Sanger Institute, United Kingdom; [2]Ontario Institute for Cancer Research (OICR), Canada; [3]Centre of Genomics and Policy, McGill University, Canada; [4]Centre for Law and Genetics, University of Tasmania, Australia

REWS Goals

The **GA4GH Regulatory and Ethics Work Stream (REWS)** seeks to engage with Article 27 of the Universal Declaration of Human Rights (1948) - activating the right to science (its benefits and advancement) and the right to recognition for scientific production - by:

- Developing policies and tools to harmonise and address regulatory and ethical hurdles to genomic research and international data sharing
- Guiding GA4GH Technical Work Streams and Driver Projects in addressing the ethical, legal, and social implications of genomic and health data sharing

Universal Declaration of Human Rights (1948)

27(1) "The Right to Science"

"Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and **to share in scientific advancement and its benefits.**"

27(2) "The Right to Recognition"

"Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author."

REWS Projects

Diversity in Datasets: Investigating the meaning of 'diversity' and developing a policy that addresses how to promote diversity in datasets within genomic research - from an international perspective.

Genetic Discrimination (GD): Exploring the meaning and implications of GD, in collaboration with the Genetic Discrimination Observatory, through the collaborative development of policy-focussed outputs.

Ethical Provenance Toolkit: Linking key policy, ethical, procedural and technical tools that facilitate the biomedical data lifecycle by creating new tools that promote transparency and consistency in ethically sound genomic research.

Data Access Committee Review Standards: Harmonising data access committee standards and considering the role of automated decision support tools to create an online, evidence-based toolkit.

Clinical Data Sharing and Consent: Identifying best practices for consent standards for sharing clinical data to support variant interpretation. This includes what types of data can be shared and where explicit consent is or is not required.

Public Attitudes for Genomic Policy: Developing blogs to disseminate the findings from the Your DNA, Your Say study and other public attitudes studies in order to inform GA4GH and external actors on these views and how to address them in research policy.

GDPR Forum: Discussing and disseminating information regarding European data protection law and its impact on international genomic and health-related data sharing through a series of blogs.

Newborn Sequencing (*coming soon*): Exploring the ethical and regulatory landscape relating to newborn whole genome sequencing and create a useful tool for the international community.

Learn more and get involved!

If you are interested in joining any of these working groups please contact **rews-coordinator@ga4gh.org**

Visit the REWS Toolkit

View the REWS Roadmap

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NIHR National Institute for Health and Care Research
wellcome
NIH National Institutes of Health
UKRI Medical Research Council