

FACT SHEET: A GLOBAL ALLIANCE TO ENABLE RESPONSIBLE SHARING OF GENOMIC AND CLINICAL DATA

THE GLOBAL ALLIANCE

Nearly 70 leading health care, research, and disease advocacy organizations that together involve colleagues in more than 40 countries have taken the first steps to form an international alliance dedicated to enabling secure sharing of genomic and clinical data. The cost of genome sequencing has fallen one-million fold, and more and more people are choosing to make their genetic and clinical data available for research, clinical, and personal use. However, interpreting these data requires an evidence base for biomedicine that is larger than any one party alone can develop, and that adheres to the highest standards of ethics and privacy. These organizations recognize that the public interest will be best served if we work together to develop and promulgate standards (both technical and regulatory) that make it possible to share and interpret this wealth of information in a manner that is both effective and responsible.

BACKGROUND

Technological advances have led to large-scale collection of data on genome sequencing and clinical outcomes, with great promise for medicine. In late January 2013, 50 colleagues from eight countries met to discuss the current challenges and opportunities in genomic research and medicine, and how these groups could work together to foster medical progress. They concluded that the greatest need was a common framework of international standards designed to enable and oversee how genomic and clinical data are shared in an effective, responsible, and interpretable manner. They envisioned a trusted and authoritative international partnership, intended to include leading healthcare providers, research institutions, disease advocacy groups, life science and information technology companies, and others, to facilitate this.

This alliance is now in the beginning stages of formation. Following the circulation of a White Paper, nearly 70 organizations from Africa, Asia, Australia, Europe, and North and South America, have joined together to form a non-profit global alliance that will work to develop this common framework, enabling learning from data while protecting participant autonomy and privacy.

THE COMMITMENT

Each organization has signed a non-binding Letter of Intent, pledging to work together to create a not-for-profit, inclusive, public-private, international, non-governmental organization (modeled on the World Wide Web Consortium, W3C) that will develop this common framework. They have committed to furthering innovation by supporting the creation of open technology standards to support the development of interoperable information technology platforms that will embody these principles and accelerate progress in biomedicine. The aim is that ultimately data will be stored in platforms built using the interoperable standards. Whether participants and organizations put all or some data into these or other platforms will be their own decision, but the common vision for the platforms is not that they will be a shared repository for data; rather, the platforms will enable sharing and learning regardless of where data are stored.

In signing the Letter of Intent, the organizations have committed to the global alliance having the following core principles:

- Respect – for the data sharing and privacy preferences of participants
- Transparency – of governance and operations
- Accountability – to best practices in technology, ethics, and public outreach
- Inclusivity – partnering and building trust among stakeholders
- Collaboration – sharing data and information to advance human health
- Innovation – developing an ecosystem that accelerates progress
- Agility – acting swiftly to benefit those suffering with disease

Member organizations recognize that when discussions occur about sharing large amounts of data, important questions about ethics and privacy naturally arise. Accordingly, members have committed to work together to establish a framework so that participants will have the right to share genomic and clinical information to advance human health as broadly or narrowly as they are comfortable with, including not at all.

A list of organizations that have signed the Letter of Intent is attached below.

NEXT STEPS

Thus far, the Letter of Intent has been signed by healthcare providers, disease advocacy organizations, research funders, and biomedical research institutions—all dedicated to improving human health. Now, they are inviting other organizations – for-profit as well as not-for-profit – to join in forming the alliance, building on many ongoing efforts around the world to address these opportunities and challenges. There is much work ahead, but they are confident that, working together as partners, they will respond to important challenges and enable future advances that would be impossible working alone.

LIST OF PARTNERS

Signatories to the global alliance letter of intent

American Association for Cancer Research (US)
American Society of Clinical Oncology (US)
American Society of Human Genetics (US)
A-T Children's Project (US)
Beth Israel Deaconess Medical Center (US)
BGI-Shenzhen (China)
Boston Children's Hospital (US)
Brigham and Women's Hospital (US)
Broad Institute of MIT and Harvard (US)
California Institute of Technology (US)
Canadian Cancer Society (Canada)
Cancer Research UK (UK)
Center for Genomic Regulation (Spain)

Centro Nacional de Analisis Genomico (Spain)
Centre for the Advancement of Sustainable Medical Innovation (UK)
Chinese Academy of Sciences (China)
Dana-Farber Cancer Institute (US)
European Molecular Biology Laboratory (Germany)
EMBL- European Bioinformatics Institute (UK)
European Society of Human Genetics (Austria)
Genetic Alliance (US)
Genetic Alliance UK (UK)
Genome Canada (Canada)
Global Genes | RARE Project (US)
H3ABioNet Consortium (South Africa)
Hospital for Sick Children (Canada)
Howard Hughes Medical Institute (US)
Human Variome Project International (Australia)
Huntington Society of Canada (Canada)
Institut National du Cancer (France)
International Cancer Genome Consortium (Canada)
International Rare Diseases Research Consortium (France)
Johns Hopkins University School of Medicine (US)
Knight Cancer Institute, Oregon Health & Science University (US)
Lund University (Sweden)
Massachusetts General Hospital (US)
Massachusetts Eye and Ear Infirmary (US)
McGill University/Université McGill (Canada)
McLaughlin Centre, Faculty of Medicine, University of Toronto (Canada)
Memorial Sloan-Kettering Cancer Center (US)
National Cancer Center (Japan)
National Cancer Institute (US)
National Human Genome Research Institute (US)
National Institute for Health and Welfare (Finland)
National Institute for Health Research (UK)
National Institutes of Health (US)
New York Genome Center (US)
Ontario Institute for Cancer Research (Canada)
Partners HealthCare (US)
P3G – Public Population Project in Genomics and Society (Canada)
PHG Foundation (UK)
Sage Bionetworks (US)
Samuel Lunenfeld Research Institute, Mount Sinai Hospital (Canada)
Simons Foundation (US)
St. Jude Children's Research Hospital (US)
Sunnybrook Health Sciences Centre (Canada)
The University of Cape Town (South Africa)
University Health Network (Canada)
University of California Health System (US)

University of California, San Francisco (US)
University of California, Santa Cruz (US)
University of Chicago (US)
University of Michigan (US)
University of Oxford (UK)
University of Texas M.D. Anderson Cancer Center (US)
University of Toronto (Canada)
University of Waterloo (Canada)
Wellcome Trust Sanger Institute (UK)
The Wellcome Trust (UK)