International Workshop

Data Visitation in Genomics

Ethics, Sovereignty, and Scientific Integration

co-organized by
CODATA International Data Policy Committee (IDPC)
China National GeneBank (CNGB)
BGI
Human Genome Project II (HGPII), ELSI Working Group

in collaboration with
Global Open Science Cloud (GOSC), Computer Network Information Center (CNIC),
Chinese Academy of Sciences
African Academy of Science (AAS)
Algerian Academy of Sciences and Technologies (AAST)
Institute of Philosophy of NAS (National Academy of Science) of Belarus
African Open Science Platform (AOSP)
India CODATA National Committee
#SemanticClimate
Leiden Institute for FAIR and Equitable Science (LIFES)
Lifetime Omics
Data Visitation for the Research Data Alliance (DV4RDA), EOSC-Future/RDA AIDV-WG
The Pistoia Alliance
ELIXIR Ireland
CoARA's Ethics and Research Integrity Policy for Responsible Research Assessment in Data and Artificial Intelligence (ERIP) Working Group
Bioinformatics and Artificial Intelligence for Infectious Diseases Drug Discovery (BIND) Platform
Data Science Without Borders (DSWB), African Population and Health Research Center (APHRC)

Program

Thursday 31 July 2025
8:00 to 10:00 am UTC
4:00 to 6:00 am EDT (New York) / 10:00 to 12:00 noon CEST (Brussels/Paris)
16:00 to 18:00 CST (Beijing/Shenzhen) / 18:00 to 20:00 AEST (Sidney)
Fully Virtual
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Workshop description

This international policy workshop convenes key stakeholders to define and advance the governance frameworks necessary to support data visitation in genomics. Data visitation, where data remains securely at its source and analytic tools are sent to the data, offers a powerful model for enabling cross-border genomic research while safeguarding privacy, security, and sovereignty. It avoids centralization and unnecessary data movement, making it ideal for sensitive, distributed datasets across organizations and jurisdictions.

The workshop explores how data policies can operationalize data visitation as a scalable, rights-based, and ethically robust approach to accessing genomic data. Participants will assess how policy instruments such as machine-readable consent, legal access protocols, and technical standards can be designed to promote trusted data reuse in federated systems. The discussion will be grounded in existing international frameworks, notably the UNESCO Recommendation on Open Science (2021) and the UNESCO Open Science Toolkit contributions on Data Policies for Times of Crisis Facilitated by Open Science (2025), which advocate for equitable, resilient, and interoperable models for data governance.

The agenda includes focused sessions intended to provide pathways to implementing data visitation based on data policies that support data sharing, data sovereignty, and data security:

- Defining data visitation and its policy requirements;
- Embedding sovereignty, equity, and rights in access frameworks;
- Building institutional and legal readiness for secure data visitation environments;
- Deriving policy lessons from pilot projects under the Human Genome Project II (HGP2); and
- Aligning national, regional, and global platforms for policy coherence and sustainability.

A central outcome of the workshop will be the initiation of a White Paper on The workshop will contribute directly to the drafting of a White Paper on ‘Data policies for genomic data visitation’, which will offer policy recommendations to support secure, ethical, and equitable access to genomic data through data visitation,’ coordinated by CODATA, CNGB, BGI, HGP2-ELSI, and other international partners. This White Paper will aim to establish shared principles and policy models for ethical, secure, and scalable data visitation across global genomics ecosystems.

By anchoring the discussion in current pilots and international standards, the workshop will contribute to shaping a coordinated data policy agenda that empowers open science, protects data sovereignty, and supports global collaboration in genomics.

Agenda

Time	Session title	Focus & policy-oriented questions
10:00-10:10	Opening ceremony	Welcome and introduction to the workshop.
10:10-10:25	Why data visitation and how to frame this within data visitation policies	Defining data visitation: Data Visitation is a model of data access and analysis where data remains at its source, and computational tools or algorithms are sent to the data for processing through a digitally secure environment. This approach enables researchers to work across distributed, disparate datasets while preserving data privacy, security, and sovereignty. By avoiding unnecessary data transfer or centralization, Data Visitation supports interoperability, scalability, and compliance with legal and ethical constraints, particularly when dealing with sensitive or restricted data in diverse jurisdictions or systems. It ensures efficient and secure research processes while maintaining data integrity and governance. 1. Why data visitation is needed for genomic research and healthcare? 2. What features must genomic data policies include to operationalize data visitation (e.g. legal clarity, access rules, ethical guardrails)? 3. How can we use the UNESCO Recommendation on Open Science and the UNESCO Open Science Toolkit contributions on Data Policies for times of Crisis as foundational frameworks for data visitation?
10:25-10:40	Governing data visitation through sovereignty and rights-based policies	What policy mechanisms are needed to uphold community and national sovereignty while enabling responsible data visitation?

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		How can policies account for indigenous governance of genomic data in federated and decentralized systems? How do data policies inform resilient, rights-based genomic data access models?
10:40-10:55	Building policy frameworks for secure data visitation	1. What are the essential components of a policy framework that supports secure, reliable, and privacy-preserving data visitation? 2. How can machine-readable consent and data visitation access standards be institutionalized in national and institutional policies? 3. What technical and governance standards must be embedded into data policies to support ethical AI use in data visitation environments?
10:55-11:10	Policy insights from data visitation pilot projects	1. What policy gaps can be identified in the need to enable and promote data visitation? 2. How can data visitation pilot experiences might help define scalable policies for diverse legal and cultural settings? 3. What role should policies play in harmonizing ethical review, data access, and consent in genomic environments?
11:10-11:25	Aligning global platforms through policy for data visitation	1. How can international and regional platforms (e.g. CODATA, WHO, UNESCO, EOSC, GOSC, AOSP) coordinate their policies to enable seamless data visitation? 2. What are the risks of policy misalignment or fragmentation in global genomics data exchange? 3. How can open science policy frameworks ensure inclusivity, interoperability, and trust in genomic data visitation?
11:25-11:55	Roundtable: Toward a White Paper on data policies for genomic data visitation	1. What common data policy principles (e.g. sovereignty, consent, equity, interoperability) should structure the White Paper? 2. How can the White Paper balance global guidance with flexibility for national and institutional adaptation? 3. What governance body or coordination mechanism should oversee the endorsement, dissemination, and implementation of the White Paper?

Time	Session title	Focus & policy-oriented questions
11:55-12:00	Summary reflections and next steps	Preparations for further developments of the working group and the White Paper.
12:00	Workshop closes	

Workshop Format

This workshop is open to a wide range of stakeholders engaged in genomics, data governance, and policy development, including participants from government bodies, research institutions, ethics committees, academic communities, health systems, civil society, indigenous groups, and technical experts in data infrastructure, AI, and law.

The workshop will follow a moderated, interactive format structured around key policy domains that support the implementation of data visitation in genomics. Each session corresponds to a focused policy question or set of questions, designed to facilitate structured input and reflective dialogue from both panelists and participants. The goal is to surface actionable insights that inform the development of practical, rights-based data policy frameworks.

Sessions will address how data policies can support the following objectives for implementing data visitation into genomic research and healthcare environments:

- Define and enable data visitation as a secure model for distributed analysis;
- Uphold sovereignty and embed equity, consent, and community rights;
- Support privacy-preserving and access disparate infrastructures;
- Translate pilot experiences into scalable governance mechanisms;
- Align global and local policy environments for coherence and resilience.

All participants are encouraged to contribute actively to the preparation of the White Paper and the workshop and the discussions while sharing relevant experiences or challenges and helping to articulate principles and proposals that can shape a shared vision. The workshop will contribute directly to the drafting of a White Paper on ‘Data policies for genomic data visitation’, which will offer policy recommendations to support secure, ethical, and equitable access to genomic data through data visitation.

This format is proposed to promote open exchange, consensus-building, and collaborative policymaking at the intersection of science, ethics, and data governance.