
Genome Data Governance for Health Systems Course: Consent, Sharing and Algorithm Assurance

23 – 27 August 2027
Madrid





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Programme Summary

Genome data governance for health systems is the subject of this one-week training course for health programme, laboratory and data governance leaders, ending in a governance plan for one genomic programme. Health systems now collect genomic data at scale and apply algorithms to it, often before consent, sharing and validation rules are settled. The programme moves from use cases to consent, sharing, algorithm assurance and equity, using cases from hospital genetics services, population studies and public health laboratories. Mars Training Centre UK delivers this programme on genome data governance for health systems to mixed-organisation cohorts.

The Business Case

Genomic data identifies people and their relatives for life, and algorithms trained on it can fail groups that are poorly represented. A system that expands without agreed rules risks loss of public trust, blocked data sharing and clinical tools that cannot be defended. A common method lets leaders decide who may use which data, on what consent, and how an algorithm earns its place in care.

- Participant Trust: Improves as consent and feedback arrangements are clear and kept.
- Data Reuse: Improves as sharing rules and access decisions are set before requests arrive.
- Clinical Safety: Improves as algorithms are validated on the populations they will serve.

Principles and Evidence Base

- WHO Guidance for Human Genome Data Collection, Access, Use and Sharing: Sets principles for consent, privacy, equity and transparent governance, applied in Sessions 1, 2 and 3.
- Informed Consent Principles: Define what participants must be told and may control, applied in Session 2.
- Algorithm Validation Principles: Require testing on representative groups before and after deployment, applied in Session 4.

Intended Participants

- Health programme directors who plan and fund genomic services.
- Laboratory and hospital directors who hold sequence data and clinical records.
- Genomic medicine service leads who introduce algorithms into diagnosis and risk assessment.
- Research and data governance leads who approve access and sharing.
- Ministry officials who set direction for population genomic programmes.

Typical settings include hospital networks, public health laboratories, research institutes and health ministries.



Learning Outcomes

1. Participants will be able to prioritise genomic use cases by health value, data need and risk.
2. Participants will be able to construct a consent model that states uses, sharing and feedback of results.
3. Participants will be able to evaluate a data access request against agreed sharing rules.
4. Participants will be able to diagnose validation and ancestry bias gaps in an algorithm used with genomic data.
5. Participants will be able to design oversight roles and review cycles for a genomic programme.
6. Participants will be able to justify a governance plan for one genomic programme.

Programme Structure

Day 1: Genome Data Governance for Health Systems and Use Cases

What is genomic data used for, and who is accountable for it?

- Genomic Use Case Inventory
- Data Flow and Custodian Map
- Health Value and Risk Matrix
- Principle Mapping to WHO Guidance
- Roles and Accountability Chart

Day 2: Consent and Participant Rights

What do participants agree to, and how is that kept?

- Consent Model Options
- Participant Information Template
- Result Feedback Policy
- Withdrawal Procedure
- Relative and Family Impact Note

Day 3: Access and Data Sharing

Who may use the data, under what conditions?

- Access Request Review Form
- Data Sharing Agreement Outline
- De-Identification Risk Test
- Security Control Checklist
- Benefit Sharing Statement



Day 4: Algorithm Assurance and Equity

Does an algorithm work for the people it will serve?

- Algorithm Validation Plan
- Ancestry Representation Check
- Performance Monitoring Indicators
- Clinical Use Boundary Statement
- Incident and Correction Procedure

Day 5: Governance Plan for One Genomic Programme

Do the earlier records form one plan that leaders can run?

- Applying the Session 1 Data Flow and Custodian Map
- Testing the Session 2 Consent Model Options
- Reviewing the Session 3 Access Request Review Form
- Checking the Session 4 Algorithm Validation Plan
- Completing the Genomic Programme Governance Plan

Methodology

The programme uses a structured exercise method built on a shared case of a large-scale genomic programme with a hospital partner and an algorithm supplier. Participants work through prepared consent forms, access requests and validation reports and then adapt each artefact to their own programme.

- Suggested activity: Revising a consent form so that sharing and feedback are stated plainly.
- Suggested activity: Ruling on three competing data access requests against agreed rules.
- Suggested activity: Reviewing a supplier's validation report for gaps in group representation.

Capstone Output

Each participant completes a governance plan for one genomic programme. It holds a data flow map, a consent model, an access and sharing procedure, an algorithm validation plan and an oversight calendar. The plan is used at work to brief a governing board, brief a supplier and set conditions for opening data to partners.



Frequently Asked Questions

Is genome data governance for health systems training suitable for leaders without a genetics background?

Yes. Genome data governance for health systems is taught through cases and templates. It assumes experience in health service, laboratory, research or data management but no training in genetics or programming.

Which guidance does genome data governance for health systems training rest on?

Genome data governance for health systems training rests on the WHO guidance for human genome data collection, access, use and sharing, together with informed consent and algorithm validation principles.

How is the plan from genome data governance for health systems training used at work?

You use the governance plan to brief a governing board and suppliers, set consent and access rules and decide when an algorithm may enter clinical use.

How does genome data governance for health systems differ from general health data protection training?

Genome data governance for health systems addresses lifelong identifiability, family impact, ancestry equity and algorithm validation, while general health data protection training covers routine patient records and standard processing duties.