Experience Sharing Session on Data Governance by Privacy-Friendly Awardees 2025

Hong Kong Genome Institute

2 December 2025

Speaker:
Don Tai
Senior Manager (Infrastructure and Information Security)

Hong Kong Genome Institute
香港基因組中心

Agenda

- Hong Kong Genome Institute
- Hong Kong Genome Project
- Overview of HKGI's Data Framework
  - People
  - Process
  - Technology
- Conclusion

Hong Kong Genome Institute
香港基因組中心

Hong Kong Genome Institute (HKGI)

Who we are

- Established and wholly owned by the Hong Kong SAR Government.
- Commenced full operations in 2021 at Hong Kong Science Park.
- Implements the Hong Kong Genome Project and drives the development of genomic medicine in partnership with public hospitals, universities, and professional bodies.

Hong Kong Genome Institute 香港基因組中心

Vision

To avail genomic medicine to all for better health and well-being.

Strategic Foci

Integrate Genomic Medicine into Clinical Care

Advance Research in Genomic Science

Nurture Talents in Genomic Medicine

Enhance Public Genomic Literacy and Engagement

Hong Kong Genome Project (HKGP)

What it is

- Hong Kong's first large-scale whole-genome sequencing initiative.
- Launched in 2021 and implemented by the Hong Kong Genome Institute.
- Focuses on patients and research cohorts where genomics can bring the greatest clinical benefit.

Over 50,000
participants recruited

Over 9,000 TB
genomic data processed

Pilot Phase: Start from Jul 2021 and completed

Main Phase: Since Jul 2022 and ongoing

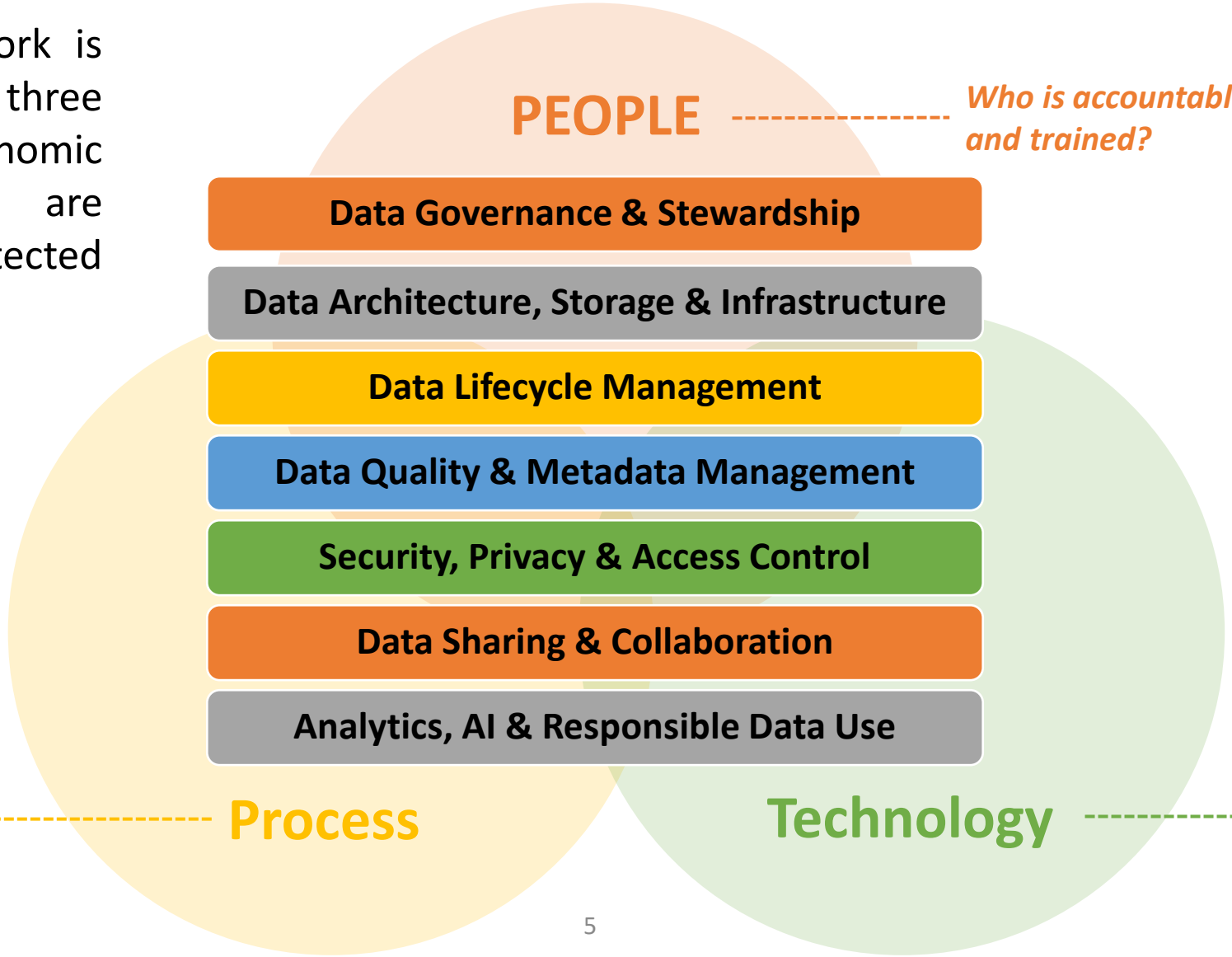
Who we serve

1. Undiagnosed diseases
2. Hereditary cancers
3. Genomic & precision health cases

Hong Kong Genome Institute
香港基因組中心

HKGI Data Framework – Enabled by P-P-T

HKGI's Data Framework is underpinned by the three pillars to ensure genomic and clinical data are governed and protected end-to-end.



People – Governance & Oversight on Data Protection

Board-level Committees on Data Governance

Board Committee

Data Advisory Committee (DAC)

- Advise the Board on governance of genomic, clinical and related data.
- Steer the overall architecture for storing and accessing Hong Kong Genome Project data.
- Review and endorse key data access and transfer protocols.

Information Security Governance Committee (ISGC)

- Advise on information security strategy, planning, policies and standards.
- Provide oversight, guidance and recommendations for major security initiatives.

Information Security Management Committee

- Makes day-to-day information security management decisions.
- Develops and reviews security policies, procedures and security plans.

Information Security Working Group

- Implements information security controls.
- Reports and handles security incidents; completes assigned tasks.

People – Building a Privacy & Security-Conscious Workforce

Mindset & Accountability

HKGI recognises that people play a decisive role in safeguarding sensitive data.

- Staff at all levels are responsible for upholding data protection standards and ensuring compliance with privacy obligations.
- We cultivate a culture of accountability, professionalism, and continuous awareness.

Awareness for All

- Onboarding security training for all new joiners
- Annual security awareness training
- Mandatory staff security assessment
- Regular security tips/reminder

Resilience Drills

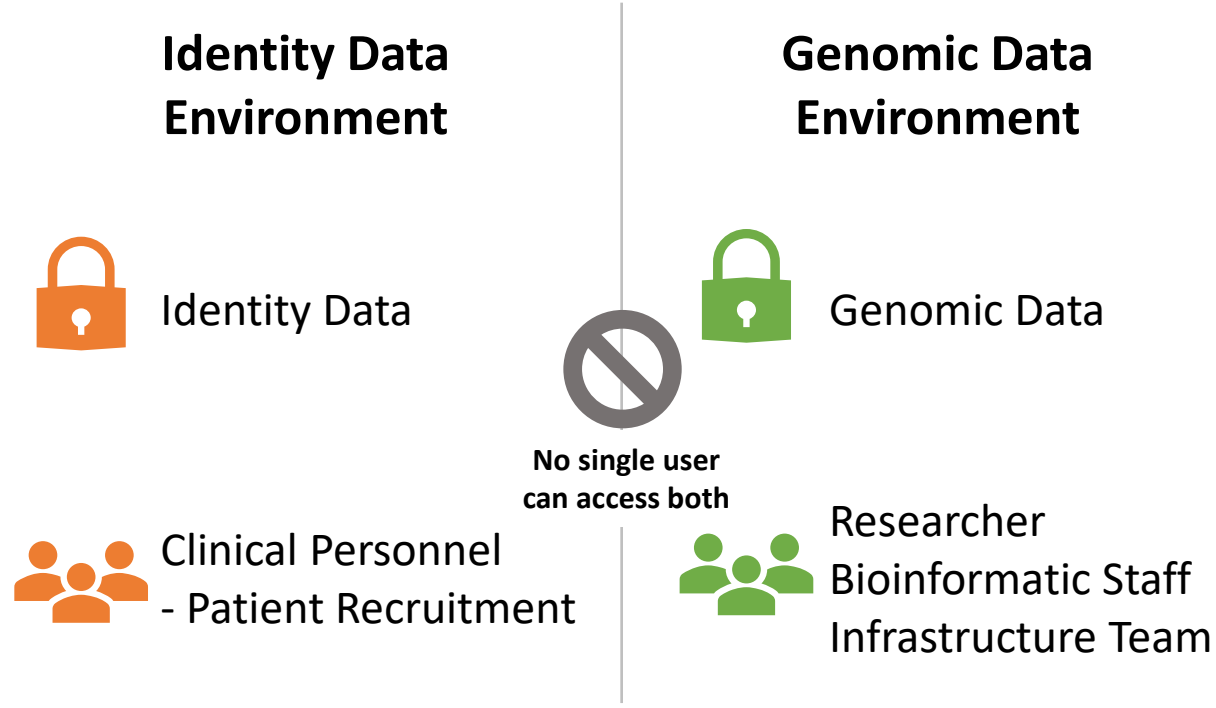
- Phishing Email Drill
- Incident Response Drill
- Disaster Recovery Drill

Reinforced by Governance

- Regular internal and external audits

People – Segregation of Duties

- Clear segregation of duties ensures no single individual can access both identity information and genomic data.
- Clinical personnel, researchers, bioinformatics staff, and IT operate within separate environments.
- Accountability is reinforced through regular entitlement reviews and access recertification.



Hong Kong Genome Institute
香港基因組中心

Process – Data Classification

Genomic Data

Sequencing data, variant information, genome interpretations and derived analytics.

Clinical Data

Diagnoses, clinical notes, laboratory results, medical images and treatment records.

Personal Data (PII)

Patient and staff identifiers such as name, HKID, contact details and other identifying information.

Commercial / Financial Data

Billing and payment records, vendor and contract information, procurement and other commercial documents.

Hong Kong Genome Institute
香港基因組中心

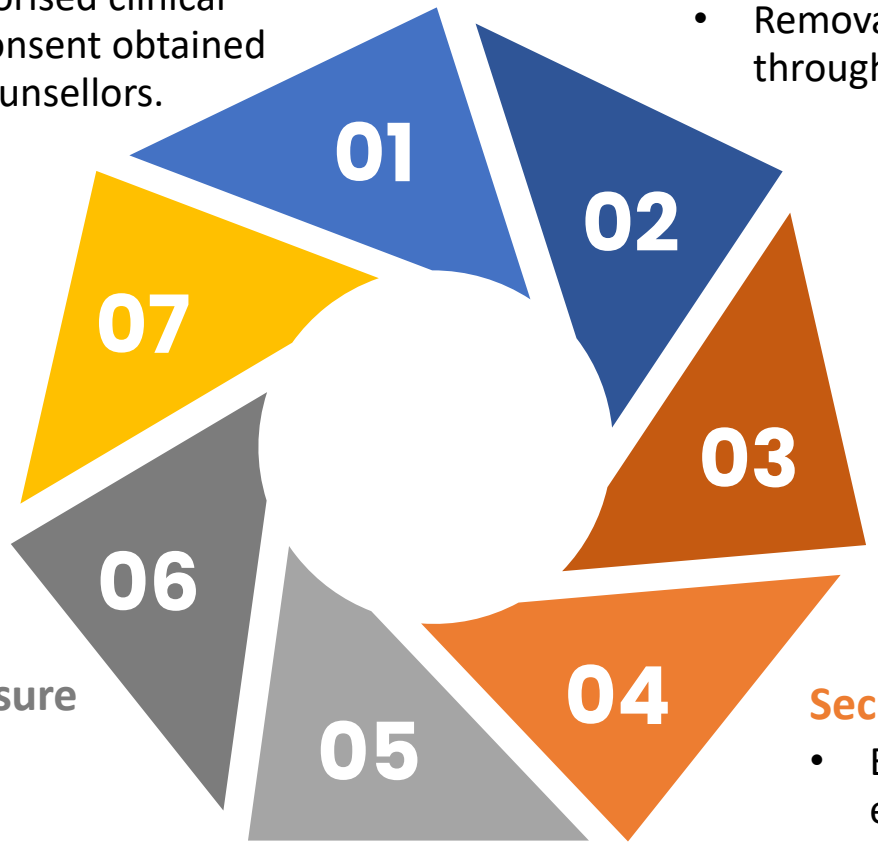
Process – End-to-End Data Lifecycle Governance

Patient Registration

- Patient registration by authorised clinical staff, with explicit patient consent obtained and explained by genetic counsellors.

De-Identification

- Removal of personal identifiers through de-identification process.



Data Archival & Disposal

- Secure archival of essential records and irreversible disposal of data and media when they are no longer required, according to documented procedures.

Data Asset Protection

- Secure sequencing and data generation.

Minimal Information Disclosure

- Release of Clinical Reports with Only Essential Information.

Secure & Controlled Data Storage

- Encrypted storage under controlled environments.

Managed Access

- Approved Research Access within Secure Platforms.

Hong Kong Genome Institute
香港基因組中心

*** Each step is governed by documented procedures and audit controls.**

Process – De-identification & Anonymisation Workflow

Earliest-stage removal of identifiers

Separate systems for identity & genomic data

Aligned with PCPD, DPO and International best practices (e.g., GDPR)

Hong Kong Genome Institute
香港基因組中心

Process – Synergistic Research Environment (SRE) Governance

- The Synergistic Research Environment (SRE) is accessible only to approved projects and vetted researchers.
- All requests undergo formal review and approval.
- Only de-identified datasets are made available.
- All activities within SRE are logged and auditable.
- Only approved research outputs—not data—may be exported.

Hong Kong Genome Institute
香港基因組中心

Process – Continuous Compliance & Assurance

Regular Security Audit

- Conducting regular, institute-wide security assessments and audits across all HKGI systems and operations is not just a compliance exercise – it is a crucial "health check" on HKGI's overall security posture

Vulnerability Assessments

- Proactive security checks to find and fix system weaknesses before attackers can exploit them

Privacy Impact Assessments

- A formal, institute-wide process is in place to identify and mitigate privacy risks for any new HKGI project or system that involves personal or other sensitive data before it is launched

Policy & Procedure Review

- Continuously updating the rules and guidelines to keep pace with new threats and business changes.

Hong Kong Genome Institute
香港基因組中心

Technology: Strong Access & Authentication Controls

IDENTITY

Unique HKGI ID for every user (no shared account)

AUTHENTICATION

VPN + MFA for all remote and system access

AUTHORISATION

RBAC and least-privilege enforced across systems

USER MONITORING

Continuous monitoring and security logging

Layered security controls protect HKGI systems and sensitive genomic data from unauthorised access.

Technology: Encryption & Infrastructure Security

Encryption in transit & at rest

Secure and isolated storage

3-2-1 Backup Strategy

Perimeter & endpoint protections (Firewall, WAF, IDS, EDR)

Hong Kong Genome Institute
香港基因組中心

Technology: Synergistic Research Environment (SRE)

- Increase support for collaborative data sharing and synthesis efforts, HKGI established SRE as a collaborative platform for scientific research

Closed & Isolated Network.

Full logging of user activity.

No screen capture and raw data downloads allowed, Only approved aggregated results can be exported.

Data is protected under HKGI's infrastructure at all times.

No Internet Connectivity.

Support for approved analytical tools.

Preparing for Future Threats

Incident Response Drill

- Examine HKGI's capability to detect, respond to, and contain cyber incidents, ensuring response procedures and team readiness are effective.

Disaster Recovery Drills

- Assess the effectiveness of recovery procedures to quickly restore essential systems following a disruptive event, maintaining operational continuity.

Trustworthy AI & Data Analytics

- Embrace AI to generate insights from genomic and clinical data, while developing HKGI's AI Governance framework to ensure responsible, risk-aware use of AI. AI workloads are run in isolated, controlled environments to safeguard sensitive data and prevent leakage.

3-2-1-1-0 Data Resilience Strategy

- Implementing the 3-2-1-1-0 rule to safeguard critical data: multiple copies on different media, an offsite and immutable backup, and regular recovery testing to ensure zero-error restores.

Behaviour-based Threat Detection

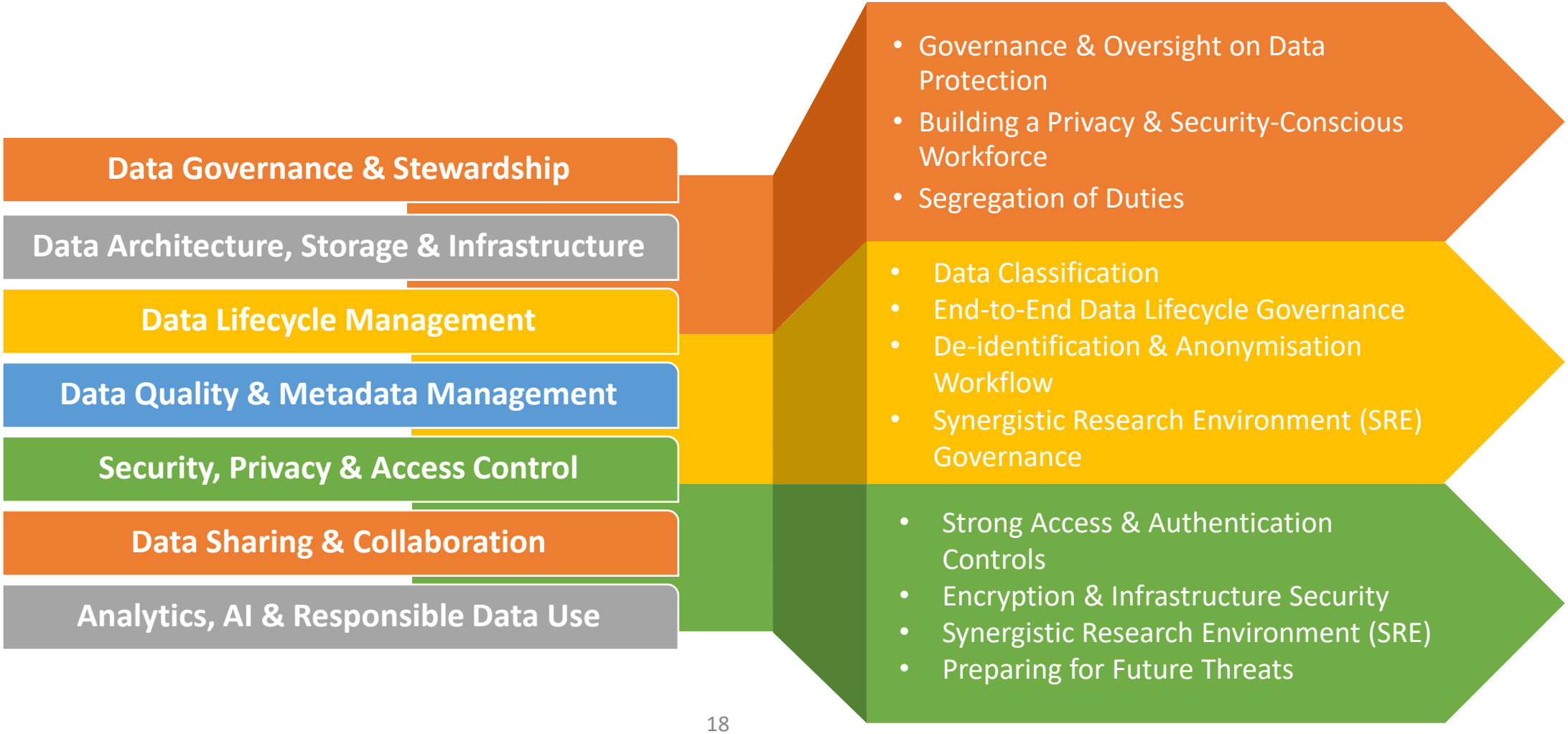
- Use analytics to detect unusual user or system behaviour that could signal a potential attack.

Security Operations Centre

- Core operations of a centralised unit responsible for continuously monitoring an organisation's security posture, analysing activity, and detecting potential security incidents in real-time.

Conclusion

HKGI safeguards genomic data through an integrated Data Management Framework.



Thank you

Hong Kong Genome Institute
香港基因組中心