A Data Governance Framework for an African Health Information Exchange

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• An African **Health Information Exchange**
• Developed and hosted at the Western Cape Department of Health
~ 6 million individuals

Routine electronic administrative records
• Individual patients
• Multiple data sources
• Uploaded every night

Linking of data to a Patient Master Index
• Facilitated by Province unique health ID
Disease monitoring systems (eg HIV / TB)
Laboratory and pharmacy data
Hospital and primary care registration systems
Population register
Many other systems

Health information exchange
or
Data Centre
or
Whatever you want to call it

Clinical viewing
Care cascades and operational reports
Alerting engine (eg. NMC’s)
Management reporting
Epi analyses
Business intelligence
Research support and stewardship

Unique identifier
Linkage and deduplication

Health Systems Strengthening
Patient care

Academic
Data Governance

1. Participant Protection - Ethics
2. Legislation
3. Procedural and Structural Data Access Controls
4. Sustainability
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Participant Protection - Ethics

- Confidentiality
- Beneficence
- Potential harms
- Vulnerable populations

Poor health, low SES, access to health care

DoH Research approval
HRECS and Ethics approval
Informed consent with review of provided patient information
Anonymisation/aggregation/data perturbation

De-identification is not equivalent to anonymisation
Data Governance

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4. Sustainability
Legislation and legal compliance

**POPI** Protection of Personal Information act

Health data are **Special Personal Information**
Responsible Party: Department of Health
Primary purpose of data collection: Provision of health care

Secondary data use/data repurposing/data sharing not allowed (unless with informed consent)

**HEALTH CARE ACT** Patient confidentiality

**PAIA** Promotion of access to information act

Record keeping of how individuals’ data are used
- records of all data access
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Data Access Control - Procedural

- Systematic processing of data requests.
- Precedence given to OPERATIONAL data requests from within DoH, to enhance health service delivery.
- Detailed SOPs governing data access, use and management.
- Logging of all identifiers used in all studies
- Logging all queries of the database
Data Access Control - Structural

• Database- and field- specific access restrictions
• Firewalls, passwords
• Data transfer protocols
  – Use purposed platforms e.g. LIFT server, Filesender
  – No emailing of sensitive information
  – Password protection
  – Encryption (e.g. bitlocker, 7zip)
  – Separate file sends for clinical and identifying data
• Separation of demographic and clinical databases and datasets
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Sustainability

Documentation of:
• Database structure
• Data processing protocols
• SOPs (Data access process, data handling, etc)

Key tenets:
• Knowledgebase not reliant on individuals
• Deployment-ready for implementation elsewhere
• Backups and disaster recovery protocols in place
Thank you

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