

The Provincial Health Data Centre (PHDC)

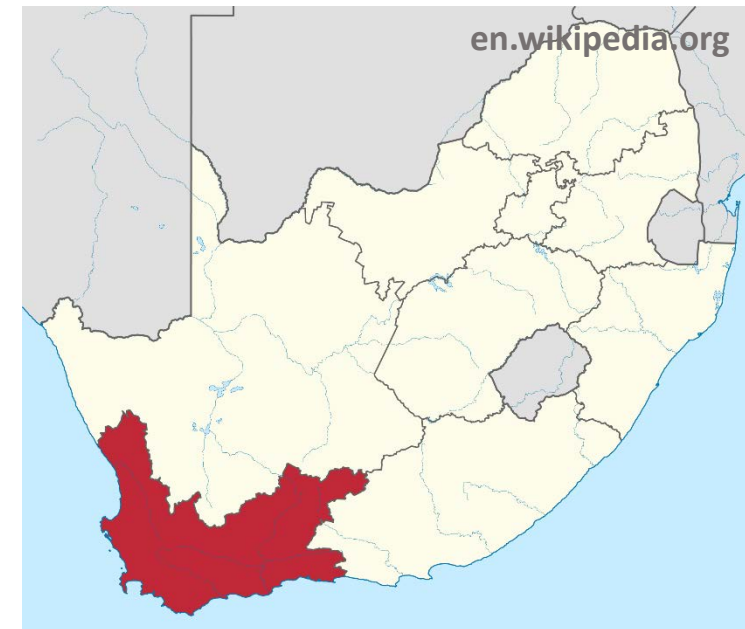
- An African **Health Information Exchange**
- Developed and hosted at the Western Cape Department of Health
- ~ 6 million individuals

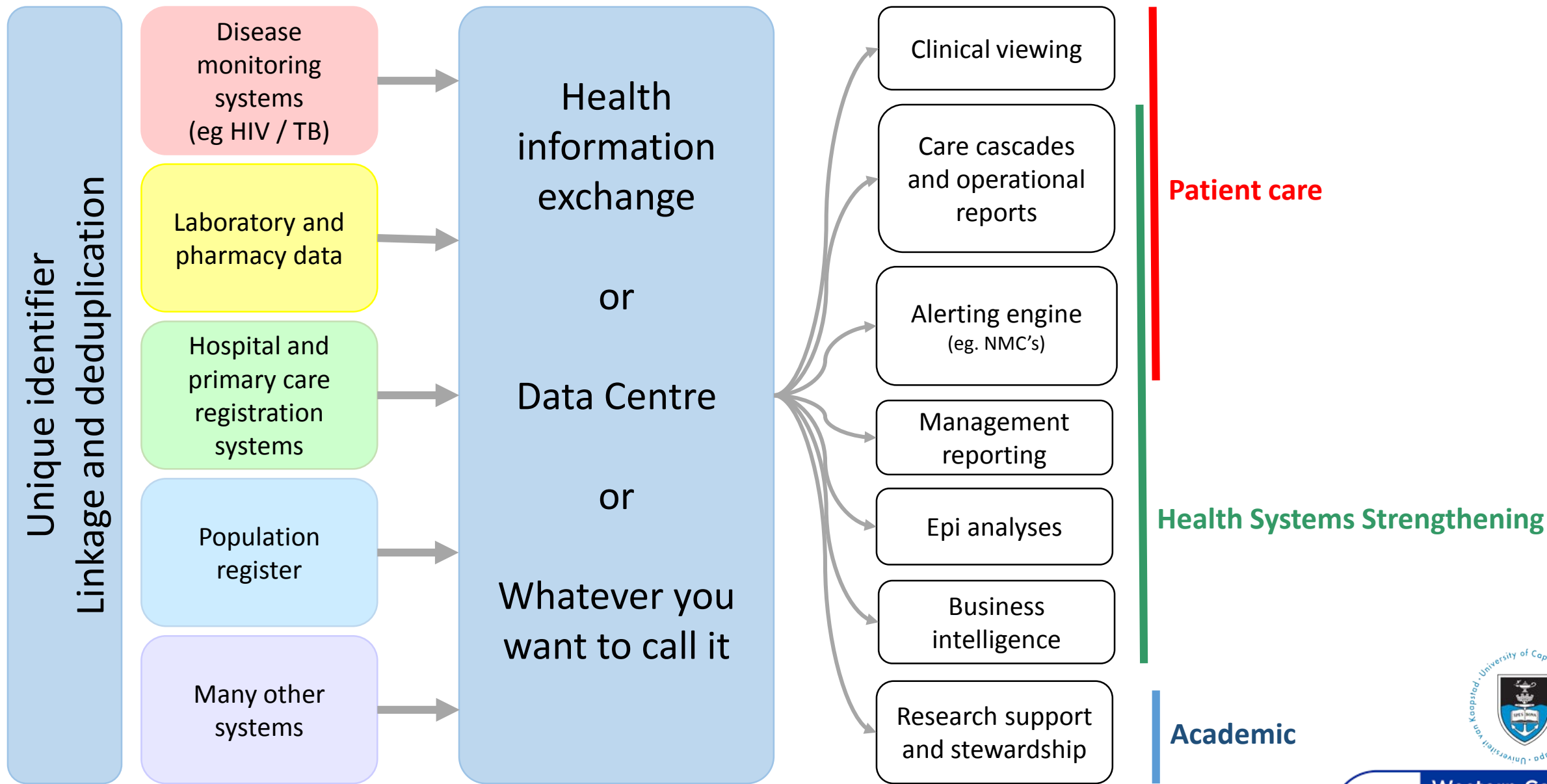
Routine electronic administrative records

- Individual patients
- Multiple data sources
- Uploaded every night

Linking of data to a Patient Master Index

- Facilitated by Province unique health ID





Data Governance

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



Data Governance

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



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

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



Data Governance

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



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



Data Governance

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



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



FUNDING:

Wellcome CIDRI-AFRICA grant (203135/Z/16/Z)

PHDC:



The National Institute of Child Health and Development (NIH, USA): B-Positive
R01HD080465

Andrew Boule

Alexa Heekes

Mariette Smith

Themba Mutemaringa

Nesbert Zinyakatira

Florence Phelanyane

Njabulo Dube

Cara Peinaar

HIA Directorate



The Bill and Melinda Gates foundation: The African Health Information Exchange:
OPP1164272



National Human Genome Research Institute (NHGRI), National Institutes Of Health (OD)
H3ABioNet award, number U24HG00694

