





ЦАХИМ ЭРҮҮЛ МЭНД



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### **Health Data Management and Governance**

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# **Definitions and Key Terms**

**Data Management** is the process of validating, organizing, protecting, maintaining, and processing data to ensure its accessibility, reliability, and quality for its users.

**Health data management** comprises all activities relating to managing health data as a valuable resource. It encompasses data gathered in the different areas of health care, for example at the level of health care providers (physicians, hospitals, pharmacies and other health care facilities) and at the level of health care payers (health insurances, social insurances).

**Data governance** is a set of practices for making decisions about data and for managing data throughout its lifecycle to optimize the organization's capability to use data to generate information that informs policy, strategy, and operational management. Data governance enables organizations to effectively manage, protect, maintain, and use data to generate information that improves health care quality, health outcomes, and health system performance.

Source:

National Institutes of Health (NIH), USA

Böcking, W., Trojanus, D. (2008). Health Data Management . In: Kirch, W. (eds) Encyclopedia of Public Health. Springer, Dordrecht.

https://doi.org/10.1007/978-1-4020-5614-7\_1398

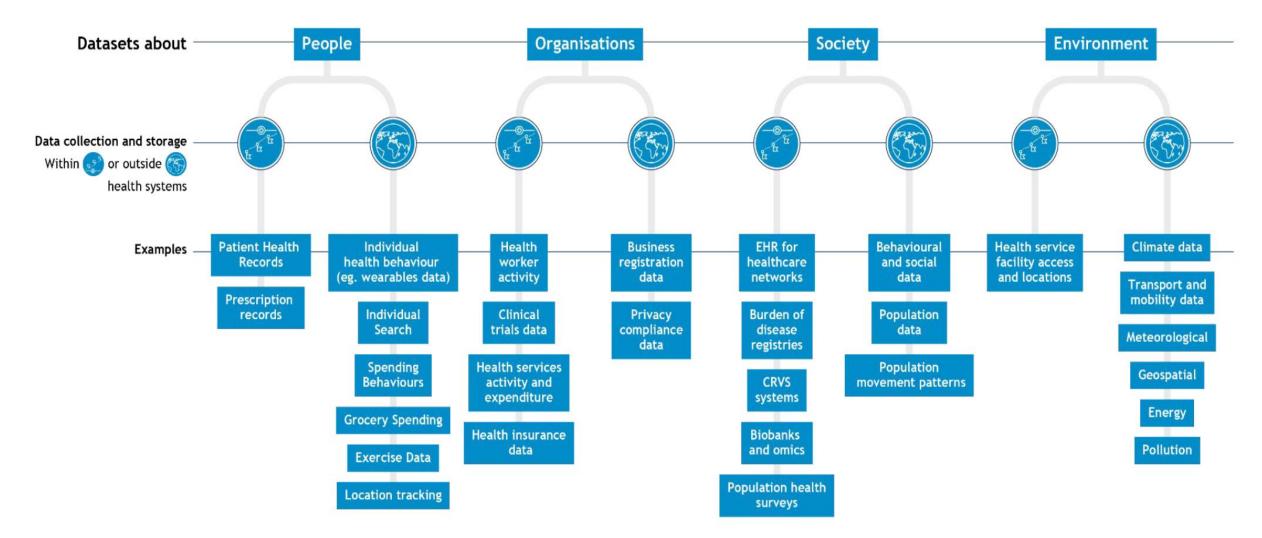
Pan American Health Organization (PAH0), 2022

## **Classification of Data Types in healthcare**

| Data Type                            | Definition  | Examples   | Possible Applications   |
|--------------------------------------|---|--|---|
| Demographic                          | Attributes of the population under study  | Age, race, sex, education, occupation, income, etc.  | Population stratification, bias prevention, etc.  |
| Medical                              | Data collected through<br>the course of medical<br>treatment at healthcare<br>units                         | Vital parameters,<br>medication, medical<br>tests, imaging, electronic<br>health records, etc.   | Medical diagnosis, treatment, continuity of care, etc.  |
| Consumer<br>Generated<br>Health Data | Information on the<br>health and behaviour<br>of individuals collected<br>through personal smart<br>devices | Smart personal devices<br>data such as sleep<br>patterns, heart rate,<br>physical activity, etc. | Health self-management,<br>behaviour and social habits<br>assessment, etc.                              |
| Financial                            | Information related<br>to the financing of<br>healthcare  | Claims and<br>reimbursements, out-of-<br>pocket costs, hospital<br>financial statements, etc.    | Cost-effective analyses, health<br>technology assessments,<br>health economic models, etc.              |
| Environmental                        | Information gathered<br>from the context in<br>which people live  | Air, food and water<br>quality; safety;<br>infrastructure etc.                                   | Impact of social determinants of health, etc.   |
| Research                             | Data collected through<br>healthcare research<br>and clinical trials  | Genomics, observational studies, etc.  | Pharmacogenomics,<br>clinical trials improvement,<br>advancements and innovation<br>in healthcare, etc. |

Source: National University of Singapore School of Public Health. (2022, May). White Paper on Responsible Data Sharing in Health and Healthcare.

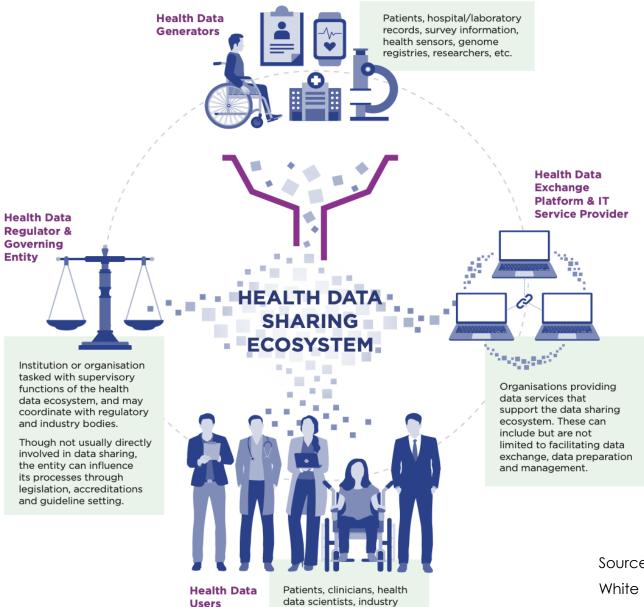
### **Datasets in Healthcare**



Source: ODI's 'Pre-read: The health data landscape' for the WHO Health Data Governance Summit ( https://cdn.who.int/media/docs/default-source/world-health-

data-platform/events/health-data-governance-summit/preread-1-who-data-governance-summit/health-data-landscape.pdf?sfvrsn=1fa04413\_8)

### **Roles in a Health Data Sharing Ecosystem**



experts, policy makers, etc.

Source: National University of Singapore School of Public Health. (2022, May). White Paper on Responsible Data Sharing in Health and Healthcare.

### **Benefits of Health Data Use for Stakeholder Types**

#### For citizens the benefits include:

- · Personalised healthcare provision, even across country borders.
- Better access to care for citizens that live in rural areas or who are not able to visit healthcare facilities as needed.
- Improved patient empowerment to manage their own conditions.
- Predictive techniques foreseeing certain health events can ensure a timelier intervention and improved patient outcomes.
- Enhanced insights in rare diseases, which can improve clinical benefits.
- Access to state-of-the-art devices and the development of innovative technologies.

What are the benefits of the use of health data for all stakeholders?



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#### For healthcare professionals, the benefits include:

- Increased accuracy of healthcare provision, through increased evidence-based decision-making.
  Reduction in the risk of adverse events.
- Enhanced knowledge dissemination, helping healthcare professionals to stay current with latest clinical practices.

#### For the health system, benefits included:

Increased efficiency of the healthcare provision, for instance by relieving burden on healthcare professionals.
Enhanced capabilities to identify risk factors for a disease at the population level.

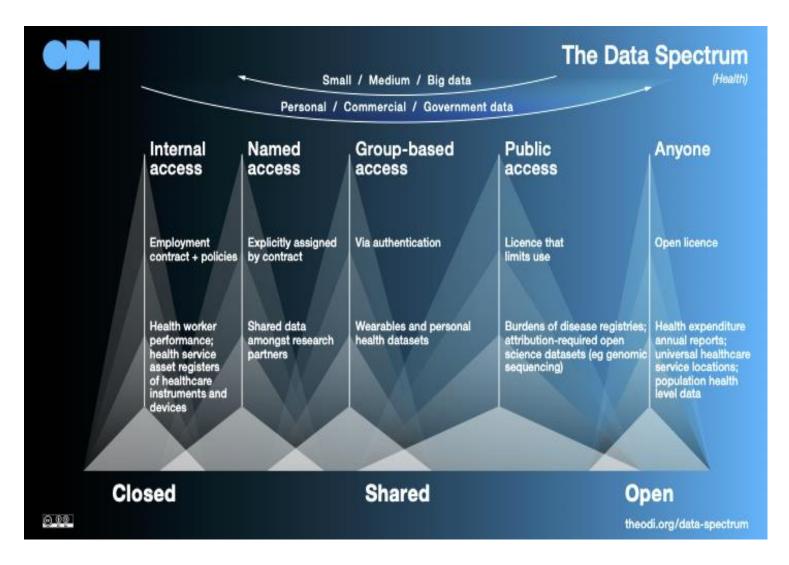
Support in infectious disease surveillance and prevention possibilities.

### **Stakeholder Segments - Use Cases and Challenges**



Source: ODI's 'Pre-read: The health data landscape' for the WHO Health Data Governance Summit (<u>https://cdn.who.int/media/docs/default-source/world-health-</u>data-platform/events/health-data-governance-summit/preread-1-who-data-governance-summit health-data-landscape.pdf?sfvrsn=1fa04413 8)

### The Data Spectrum



Source: ODI (2019), "The Data Spectrum', <u>https://theodi.org/about-the-odi/the-data-spectrum/</u> Modified to address the health data landscape, U.S. Health and Human Services (2020)

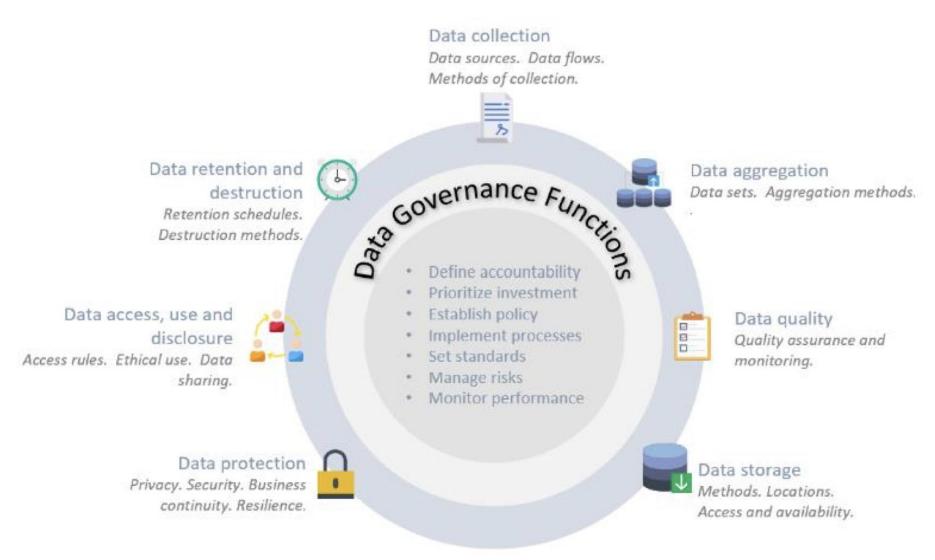
### **Data Governance Approaches - Three General Categories**



"Data governance builds trust, creates robust processes to enable data sharing and can ensure ethical, responsible, quality management of data across the data journey"

Source: ODI's 'Pre-read: Data Governance maturity and best practices' for the WHO Health Data Governance Summit (<u>https://cdn.who.int/media/docs/default-source/world-health-data-platform/events/health-data-governance-summit/preread-3-who-data-governance-summit\_data-governance-of-health-data-governance-summit\_data-governance-of-health-data-governance-summit\_data-governance-of-health-data-governance-summit/preread-3-who-data-governance-summit\_data-governance-of-health-data-governance-summit\_data-governance-summit\_data-governance-of-health-data-governance-summit\_governance-summit\_governance-summit\_governance-summit\_</u>

# What should data governance address?

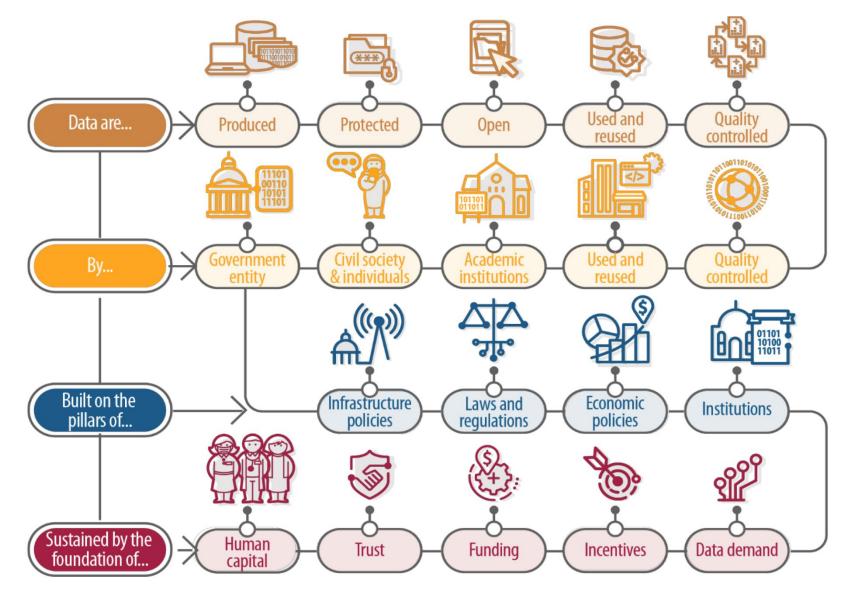


Source: Pan American Health Organization (PAH0), 2022. Data Governance in Public Health

### How is data governance implemented?

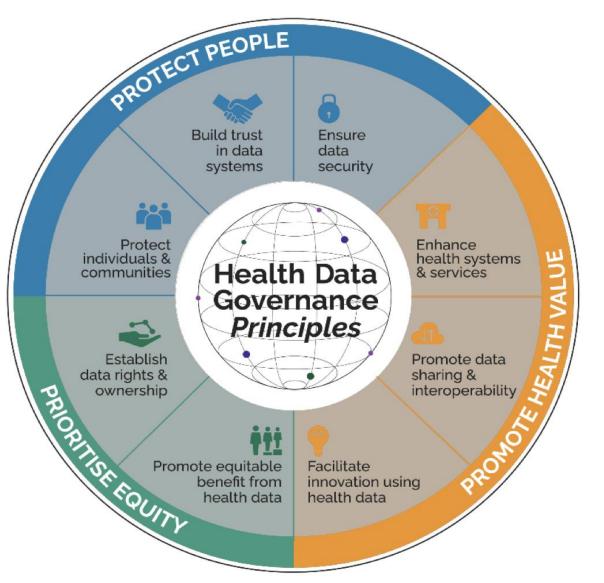
| People  | Processes   | Technology   |
|---|---|--|
| Decision-making Structure<br>Establish a data governance structure<br>which includes both executive decision-<br>making and technical bodies to define<br>priorities for investment, develop and<br>endorse policies and standards, and to<br>identify and manage risks.                                | Data Asset Management<br>Develop an inventory and classification of<br>data assets, and document data standards<br>(e.g. health data dictionary). Define and<br>document data flows. Define principles and<br>rules for data retention and destruction.   | Tools and Technology<br>Identify and implement the tools and<br>technologies (software and hardware)<br>required to effectively manage data<br>throughout its lifecycle, and to generate<br>information for decision-making.   |
| Roles and Responsibilities<br>Define operational functions and<br>responsibilities for the management of<br>data throughout its lifecycle. Clarify<br>decision rights. Identify and validate data<br>owners, data stewards, and data<br>consumers.  | Enabling Processes and SOPs<br>Establish and document processes and<br>standard operating procedures (SOPs) for<br>managing data throughout its lifecycle (e.g.<br>data collection, data quality, storage,<br>access, use, destruction, etc.).  | Quality, Availability and Security<br>Ensure information systems are<br>designed, implemented and maintained to<br>ensure quality, availability and security of<br>data.   |
| Communication and Transparency<br>Educate stakeholders on roles,<br>responsibilities, policies and processes for<br>data management. Ensure that decisions<br>related to data are documented and widely<br>communicated. Monitor and communicate<br>adherence to policies, processes, and<br>standards. | Standards and Policy Management<br>Establish collaborative processes for the<br>ongoing management and oversight of<br>standards (e.g. data dictionaries,<br>taxonomies and business rules) and<br>policies (e.g. data management principles,<br>privacy and security policies, guidelines for<br>secondary use of data, etc.). | Performance (20)<br>Ensure hardware, network infrastructure,<br>software and storage are monitored for<br>performance (e.g., availability, reliability,<br>usability, cost-effectiveness, etc.). Identify<br>remediation strategies for technology<br>performance improvement (e.g.<br>configuration, training, investment). |

### An Integrated National Health Data System (Ideal Scenario)



Source: World Bank. 2021. World Development Report 2021: Data for Better Lives. Washington, DC: World Bank. https://doi.org/10.1596/978-1-4648-1600-0

### The Health Data Governance Principles



- Bring a human rights and equity lens to the use of data within and across health systems.
- Are oriented towards supporting sustainable and resilient public health systems that can deliver **Universal Health Coverage (UHC)**.
- Aim to strengthen national and regional health data governance approaches, maximising the public value of health data whilst protecting individual rights.
- Align policymakers and other stakeholders around a **shared vision of equitable health data governance**, where all people and communities can share, use and benefit from health data.
- Recognise and build on existing norms, principles, treaties, conventions and guidelines, while further strengthening the health data governance ecosystem.
- Are a critical step towards a **global framework** for health data governance.



# Towards more effective and equitable Health Data Governance

PUBLIC CONSULTATION ON A DRAFT MODEL LAW: 7th April - 30th April 2024

Source: Transform Health Association. Draft Model Law on Health Data Governance (<u>https://healthdataprinciples.org/modellaw</u>)

Thank you

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