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Гүйцэтгэх захирал

Health Data Management and Governance

State Productivity Recovery

Digital Health Convergence Workshop

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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.

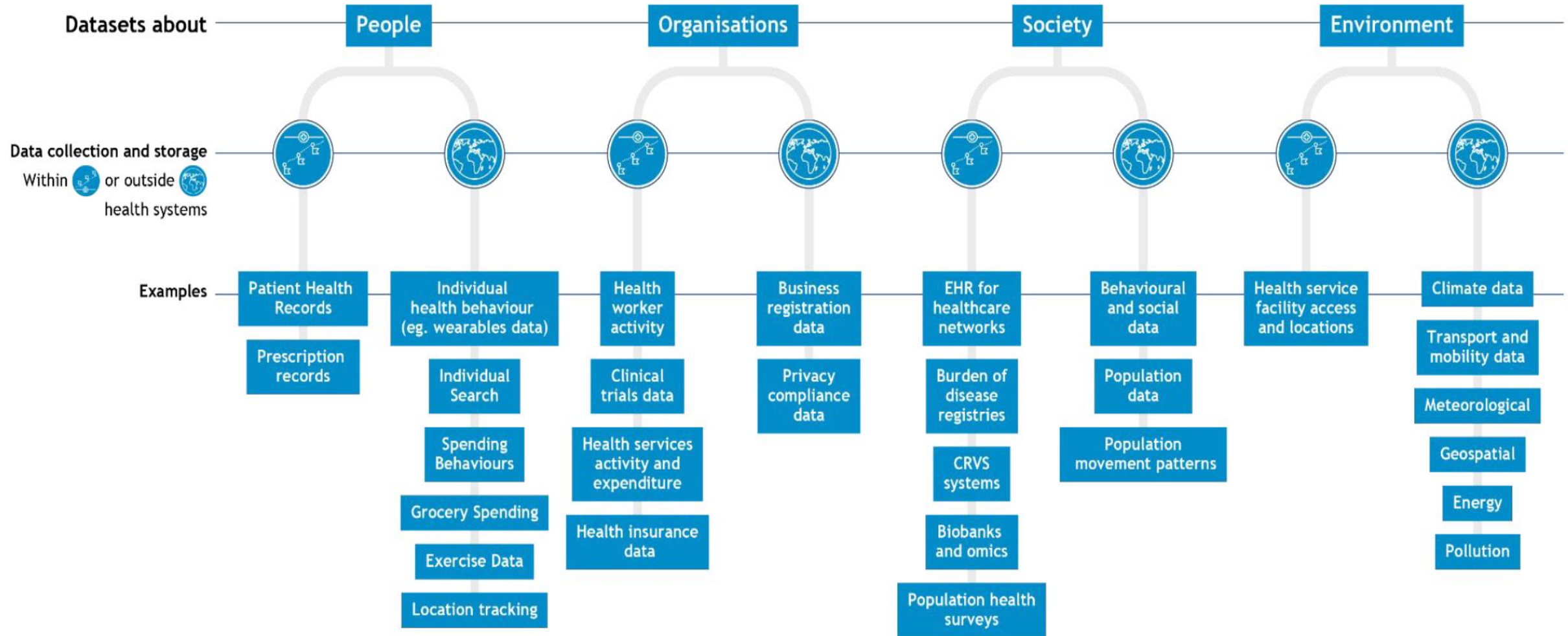
https://doi.org/10.1007/978-1-4020-5614-7_1398

Pan American Health Organization (PAHO), 2022

Classification of Data Types in healthcare

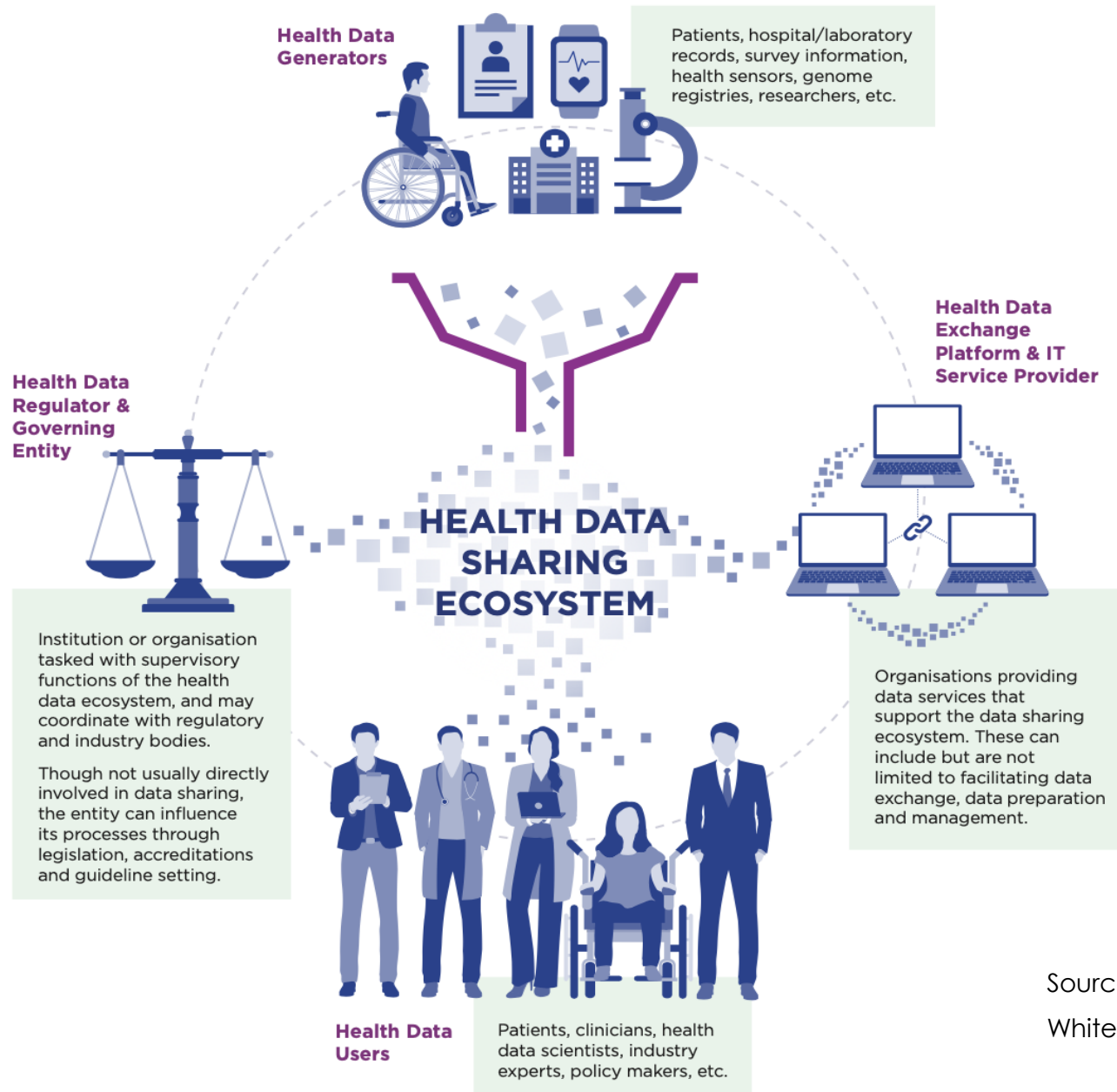
Data Type	Definition	Examples	Possible Applications
Demographic	Attributes of the population under study	Age, race, sex, education, occupation, income, etc.	Population stratification, bias prevention, etc.
Medical	Data collected through the course of medical treatment at healthcare units	Vital parameters,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

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



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

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



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.



For healthcare professionals, the benefits include:

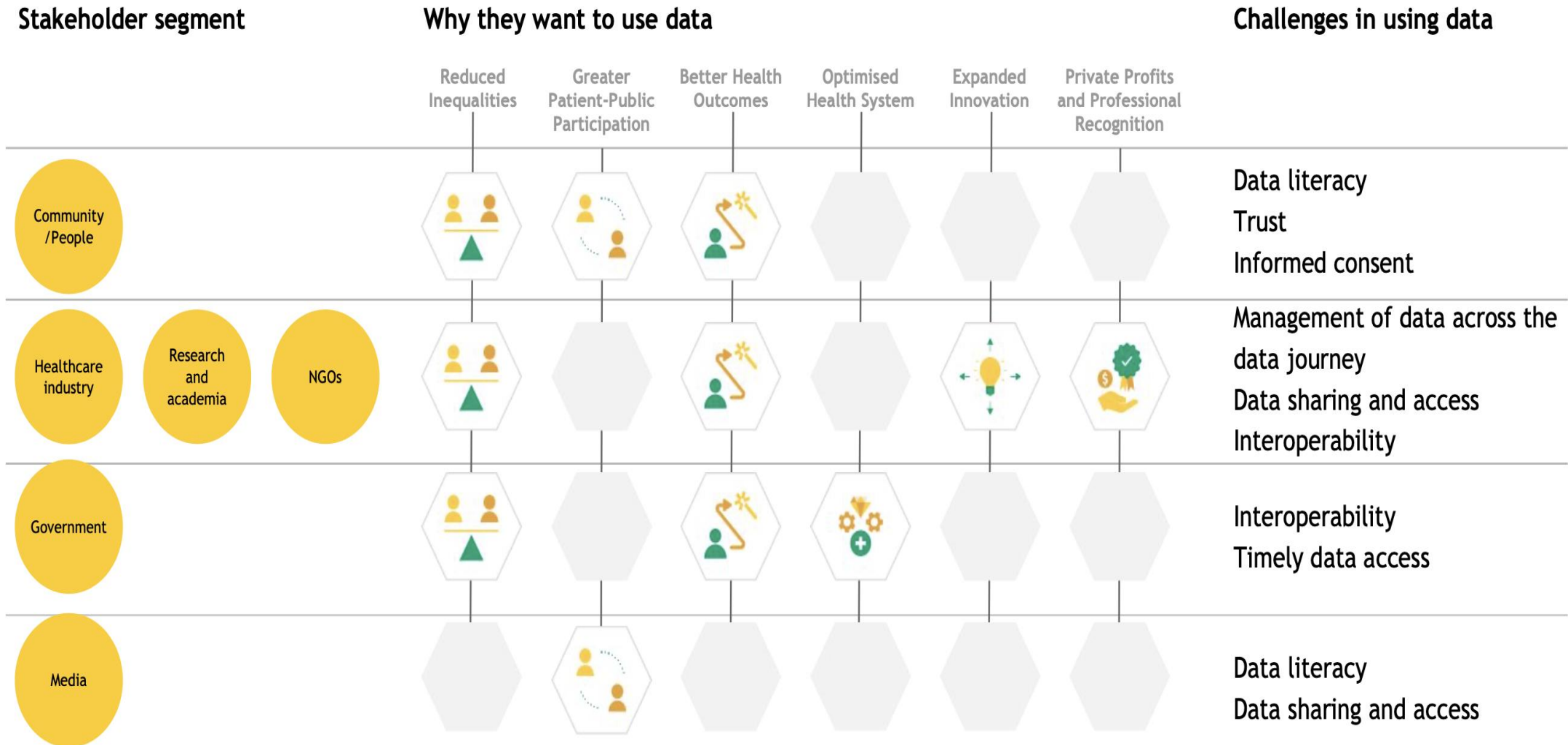
- Increased accuracy of healthcare provision, through increased evidence-based decision-making.
- Reduction in the risk of adverse events.
- Enhanced knowledge dissemination, helping healthcare professionals to stay current with latest clinical practices.



For the health system, benefits included:

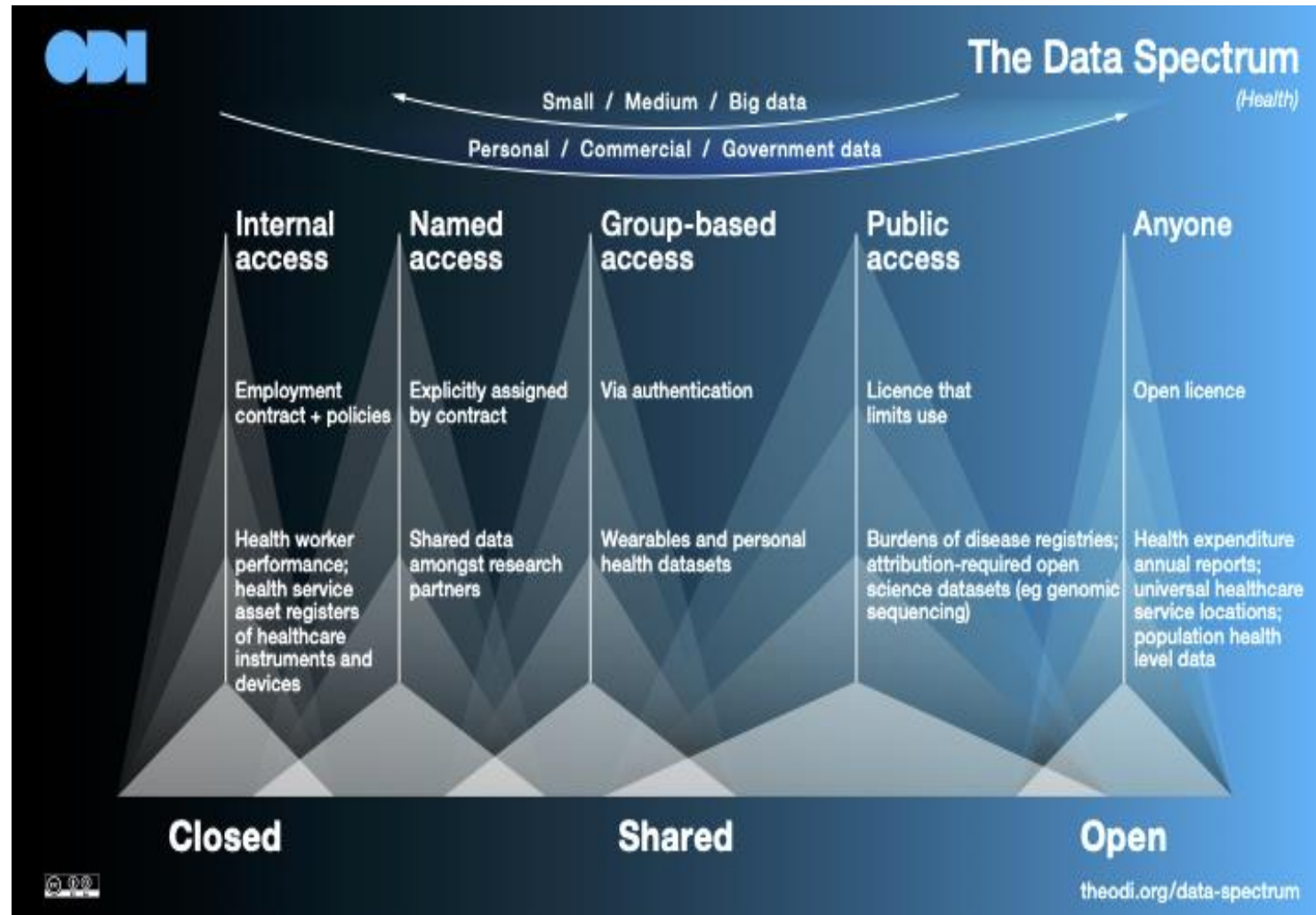
- Increased efficiency of the healthcare provision, for instance by relieving burden on healthcare professionals.
- Enhanced capabilities to identify risk factors for a disease at the population level.
- Support in infectious disease surveillance and prevention possibilities.

Stakeholder Segments - Use Cases and Challenges



Source: ODI's 'Pre-read: The health data landscape' for the WHO Health Data Governance Summit (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)

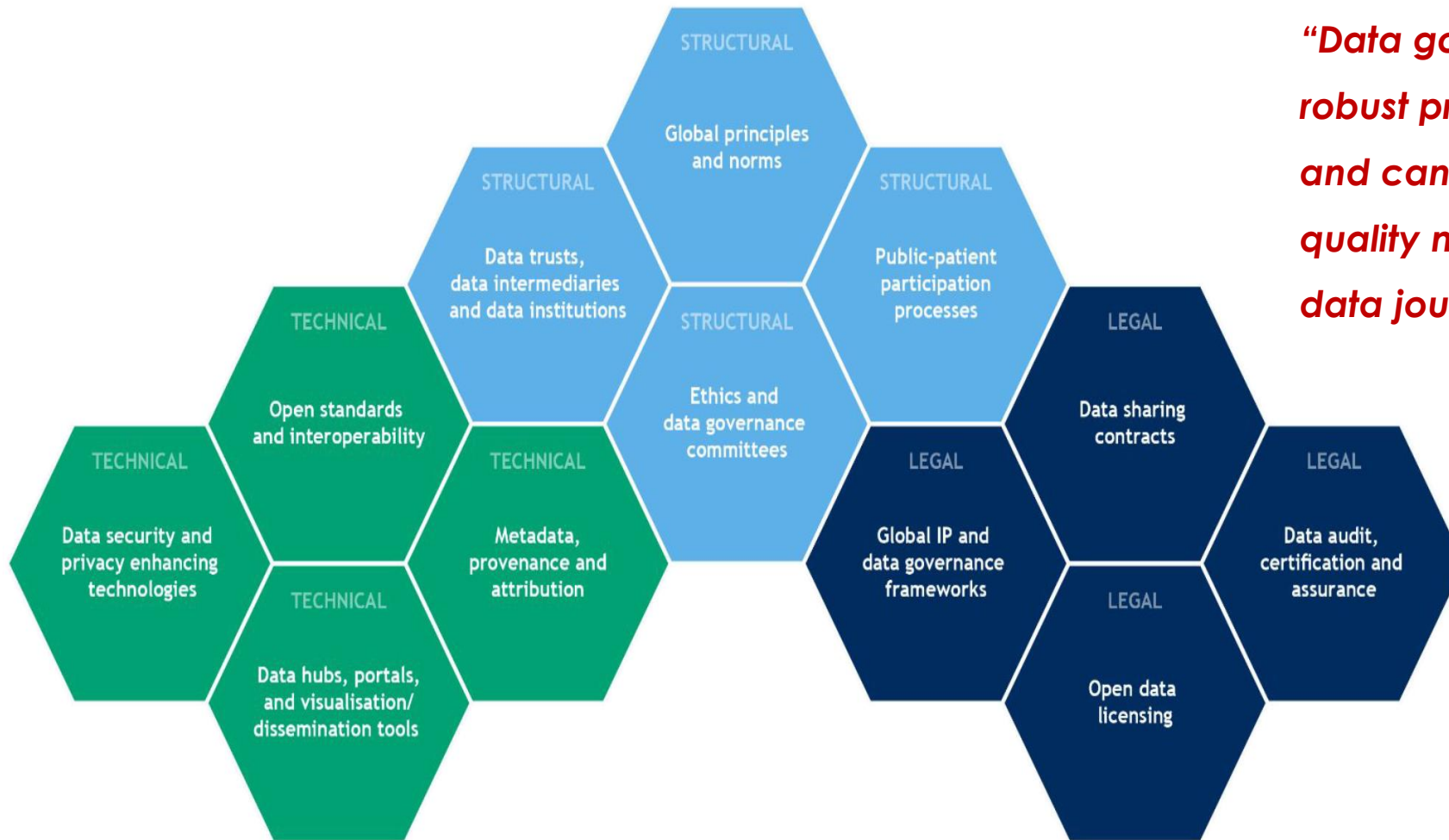
The Data Spectrum



Source: ODI (2019), 'The Data Spectrum', <https://theodi.org/about-the-odi/the-data-spectrum/>

Modified to address the health data landscape, U.S. Health and Human Services (2020)

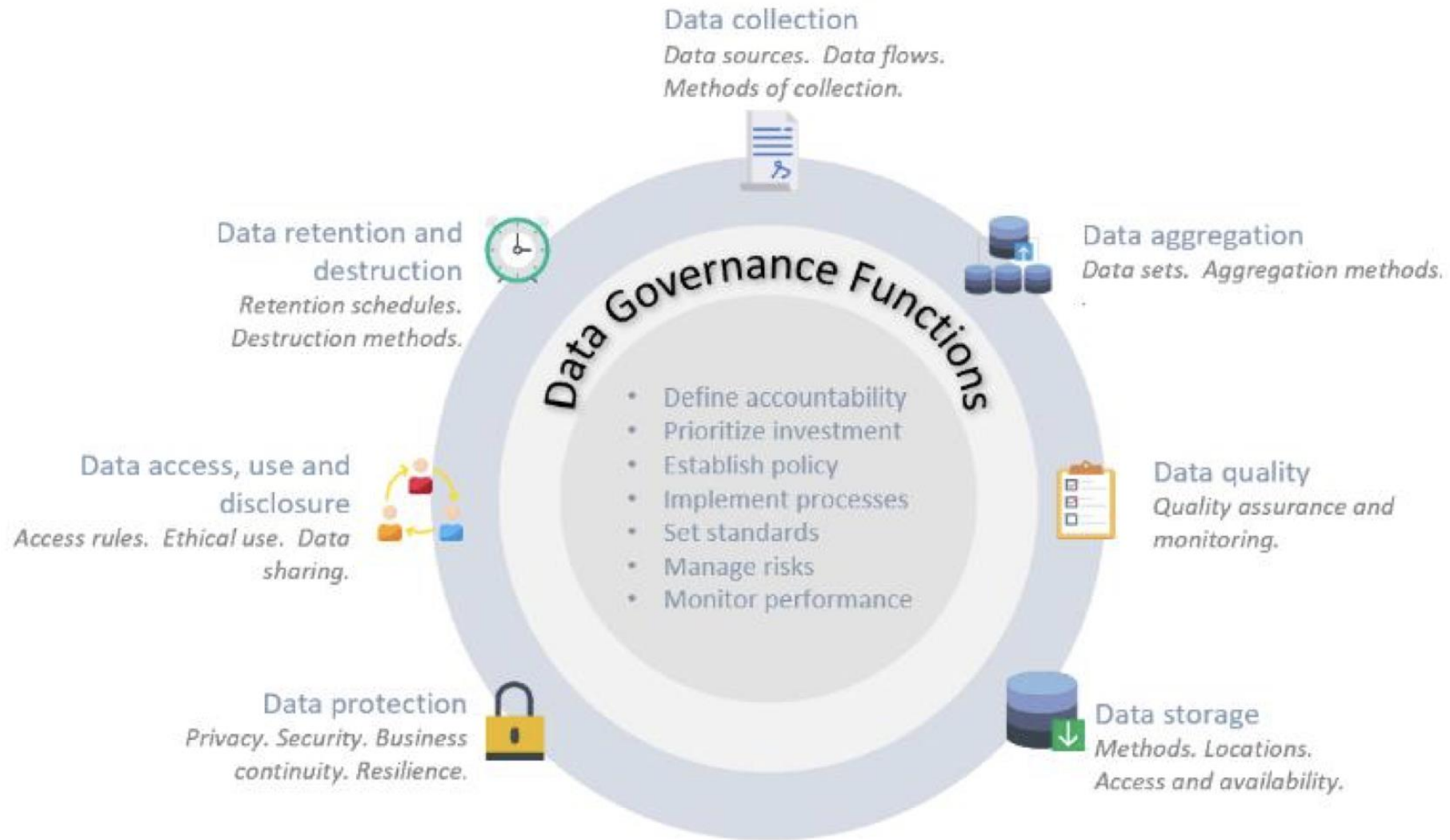
Data Governance Approaches - Three General Categories



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

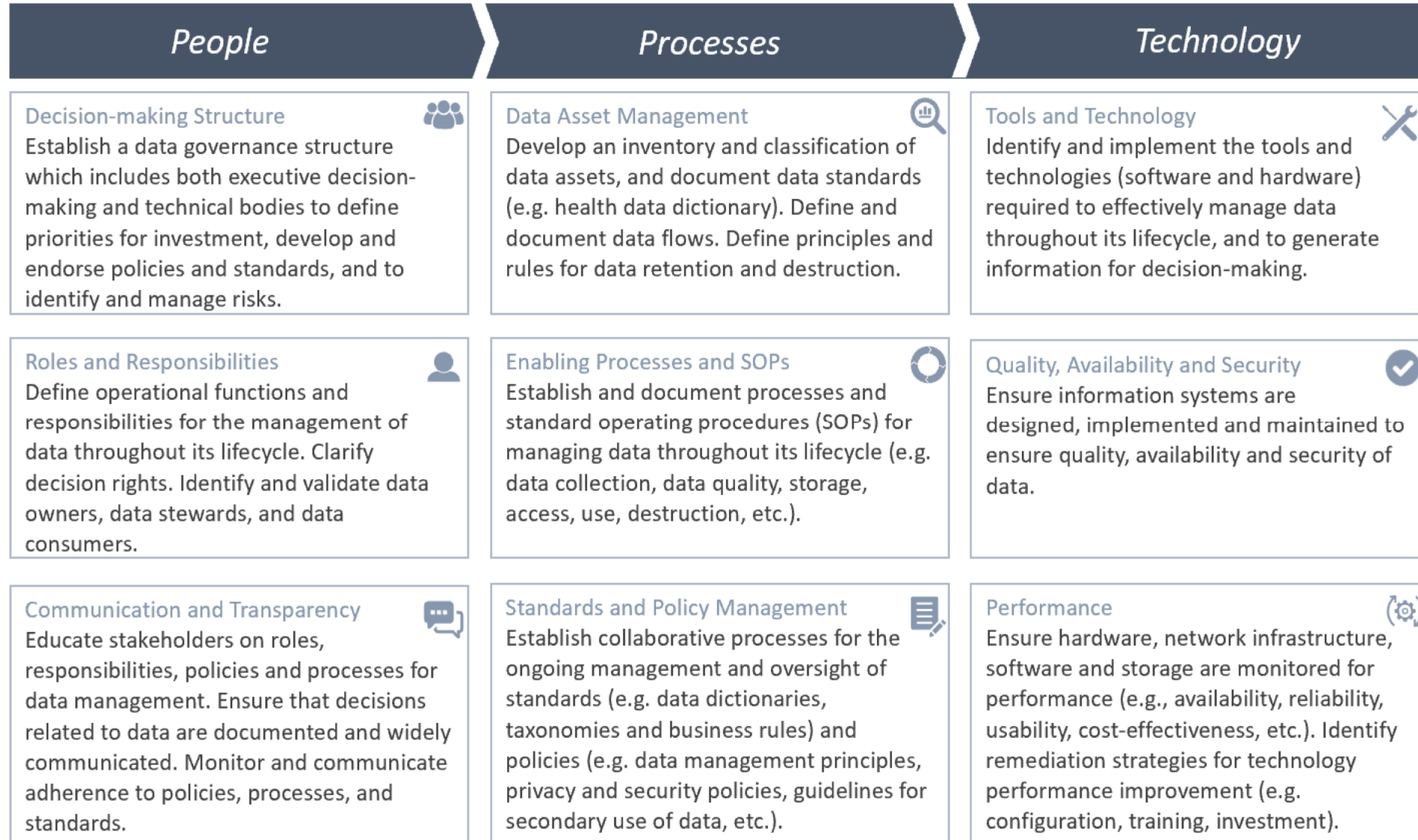
Source: ODI's 'Pre-read: Data Governance maturity and best practices' for the WHO Health Data Governance Summit (https://cdn.who.int/media/docs/default-source/world-health-data-platform/events/health-data-governance-summit/preread-3-who-data-governance-summit_data-governance-of-health-data.pdf?sfvrsn=ffbd4a33_10)

What should data governance address?



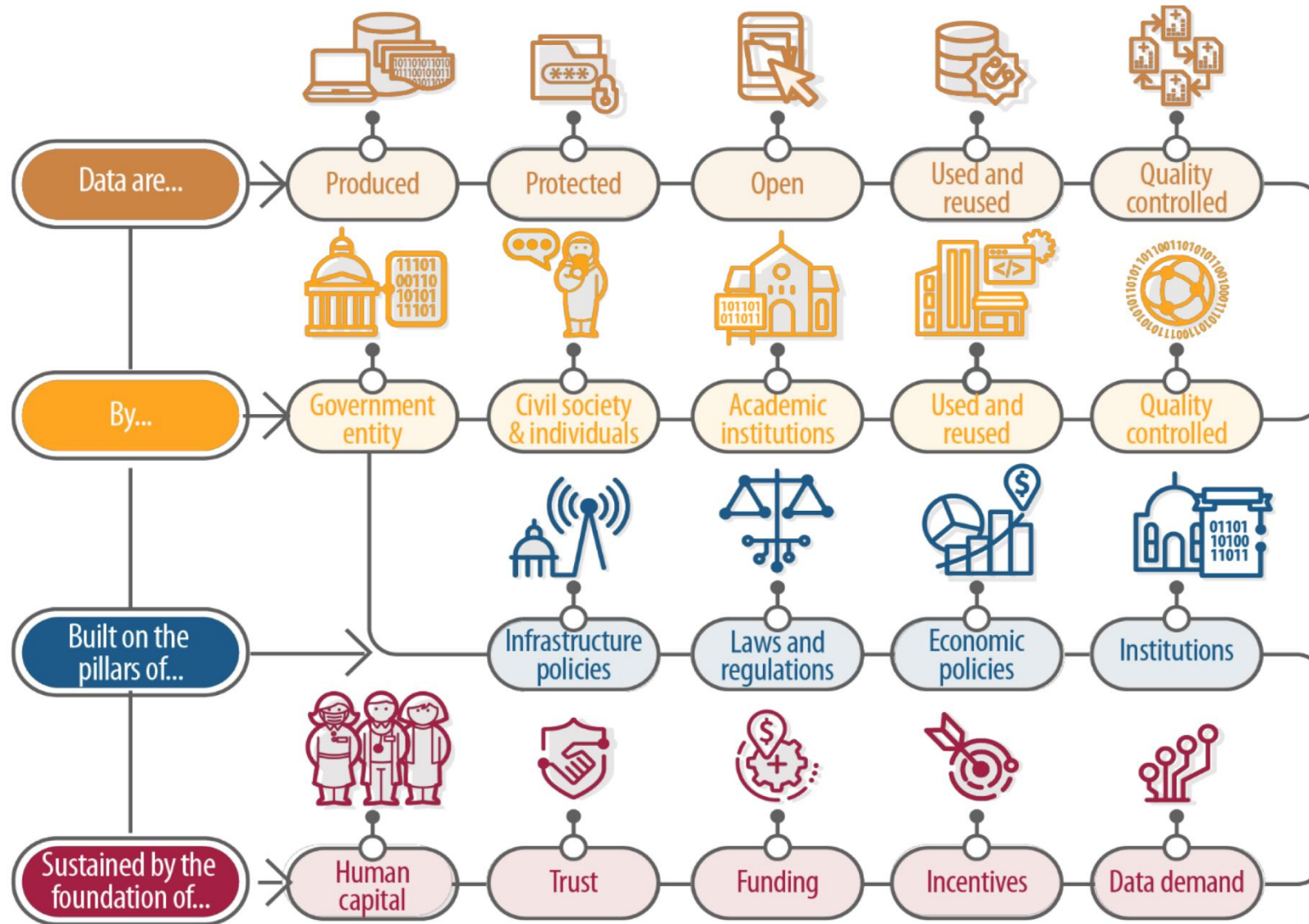
Source: Pan American Health Organization (PAHO), 2022. Data Governance in Public Health

How is data governance implemented?

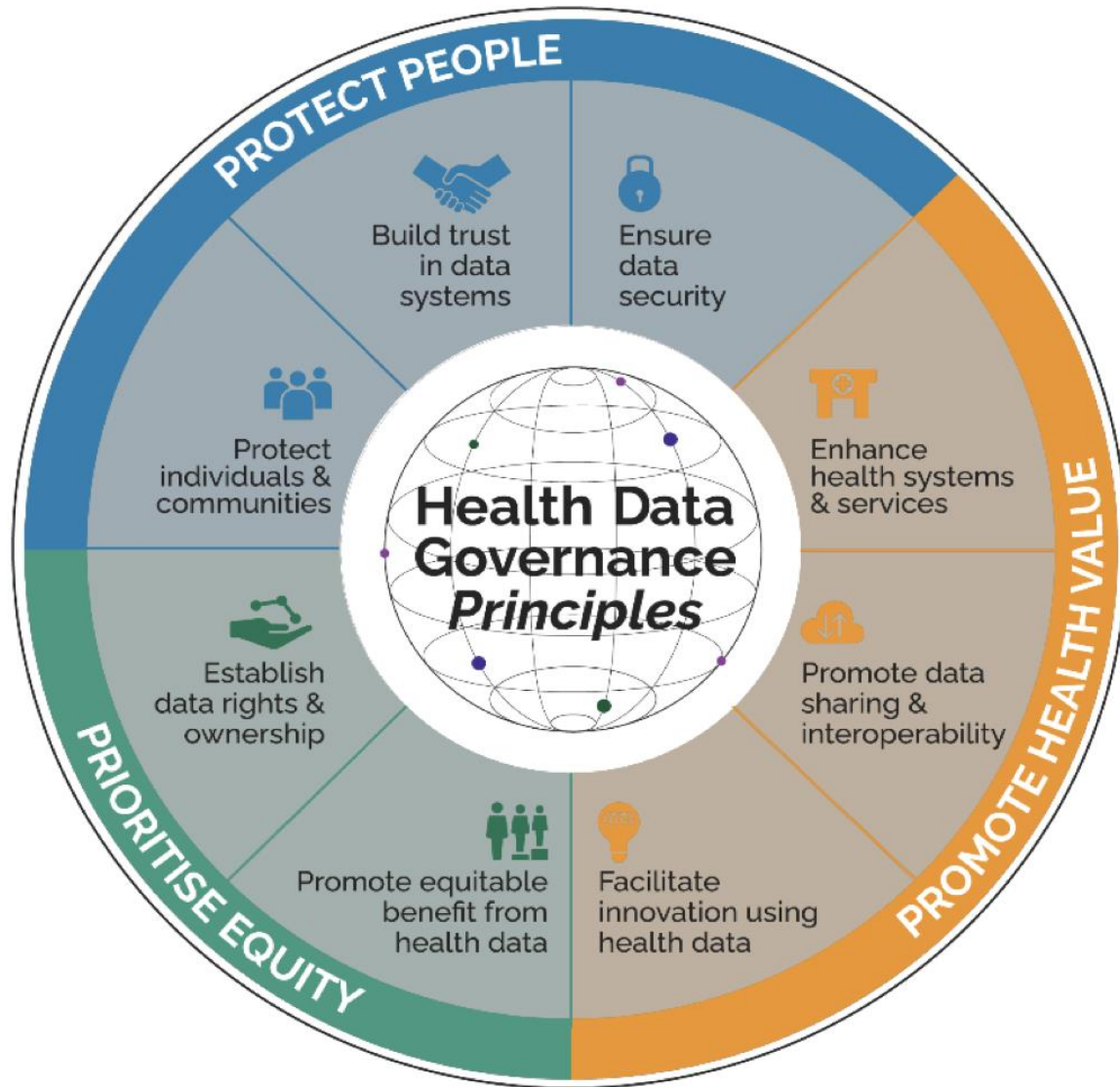


Source: Pan American Health Organization (PAHO), 2022. Data Governance in Public Health

An Integrated National Health Data System (Ideal Scenario)



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.



**Transform
Health**



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 (<https://healthdataprinciples.org/modellaw>)

Thank you

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