HEALTH DATA GOVERNANCE SUMMIT

GOVERNING DATA FOR BETTER HEALTH

Health Data Governance Summit

Pre-read: Data Governance maturity and best practices

30 June 2021

Data governance processes are essential to build trust and enable value creation from health data

The ODI has been working with WHO for the past month, holding discussions with 23 stakeholders and analysing 56 documents.

"A Global Data Convention will need a supporting a global institution to bring together the many data communities and ecosystems, that comprise not only of national governments, private sector and civil society but also including those who represent artificial intelligence, digital and IT services. This is a critical point. Modern data ecosystems are not controlled by states alone, so any convention, commons, or Bretton Woods-type agreement will require a multitude of stakeholders and signatories. This institution(s) ***would maintain and update data standards, oversee accountability frameworks, and support mechanisms to facilitate the exchange and responsible use of data****."*

Steve MacFeely, Angela Me, Haishan Fu, Stefan Schweinfest

There is a newly energised global movement driving discussions towards the sharing of data and creating data governance processes that can build trust amongst stakeholders

Global collaboration towards Sustainable Development Goals is a key driver for encouraging shared data to achieve goals, including to reduce global inequalities and leave no one behind.

A number of global agreements are now in place encouraging free-flow of data with trust, including:

- UN Secretary-General's Roadmap for Digital Cooperation
- 2030 Agenda for Sustainable Development
- Carbis Bay G7 Summit Communique.

These policies set broad agreements that a trustworthy free-flow of data is essential for the benefit of individuals, societies, and economies.

UN Secretary General's Roadmap on Digital Cooperation

G7 Summit Communique

"Openness, reciprocity and cooperation are shared G7 values. We commit to work together to uphold and protect the principles that underpin effective international collaboration that is as open as possible and as secure as necessary…. Data can play a transformative role in supporting effective early warning and rapid response to health crises. We therefore need to improve the quality and 7 coverage of international, regional and national pathogen surveillance to enable us to gather, share and analyse data to identify new variants in our fight against the current pandemic, and to detect and monitor future pathogens with pandemic potential. We support the establishment of the international pathogen surveillance network - a global pandemic radar - and welcome the WHO's commitment to work with experts and countries to help achieve this, based on a common framework, including standards and rules for sharing data, that builds on existing detection systems such as the influenza and polio programmes but with greater capacity for genomic sequencing and broader in coverage."

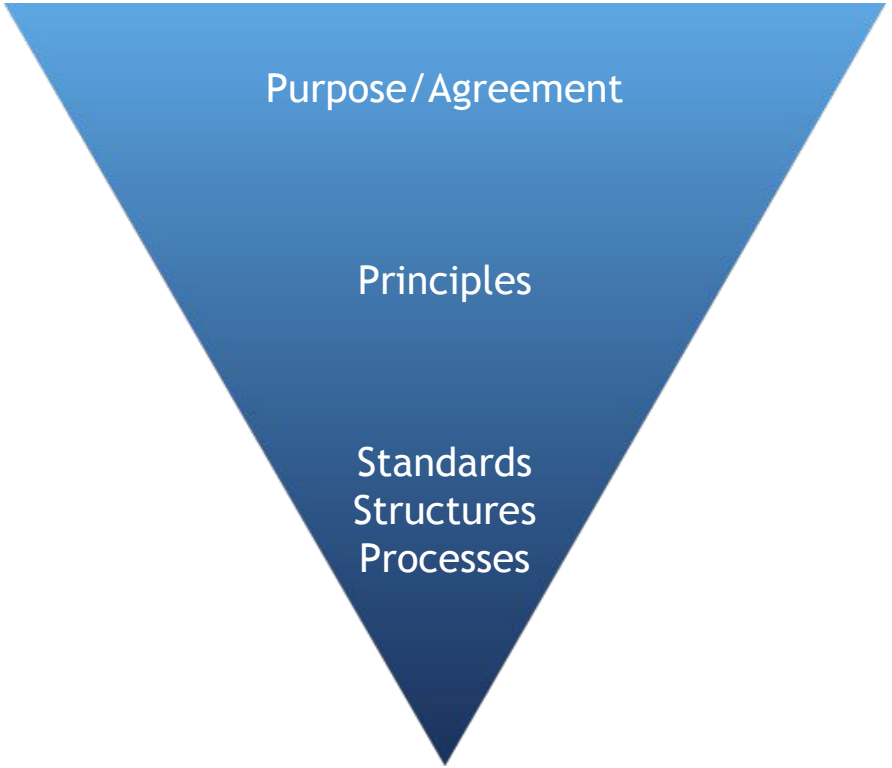
G7 Communique, Our Shared Agenda for Global Action to Build Back Better,
https://www.consilium.europa.eu/media/50361/carbis-bay-g7-summit-communique.pdf

With policy agreements and data governance principles in place, the next level of work requires a focus on data governance processes and best practices.

There will not be a global one-size-fits all approach to data governance. What is needed is a collection of best practices and guiding approaches so that organisations, countries and regions can select promising practices that align with global principles but that are suited to the local context and reflect community values and norms.

WHO and other bodies like the UN and OECD have often played a global role in harmonising understanding around best practices by sharing what works and encouraging adoption of common tools.

At the global purpose level, there are also a range of guiding agreements such as the Human Rights Framework that should underpin any considerations of how to introduce health data governance processes.



From these broad agreements, core principles are emerging to guide discussions. These are then developed further through frameworks.

Frameworks allow different cultural values to be expressed through collaborative work.

Informant interviews noted that data governance models are often built on a GDPR-based, Global North-defined set of values that recognise individual rights. These are also reflected in the FAIR Framework for open science, which are widely referenced when establishing norms for data governance policies globally.

There are other cultural norms and value sets that can be considered when defining global data governance principles. First Nations and Indigenous Peoples have proposed the CARE principles to better reflect their community values and principles, and to begin addressing the disparities in decision-making and impact of value extraction that occurs when data from local communities is used in a global setting.

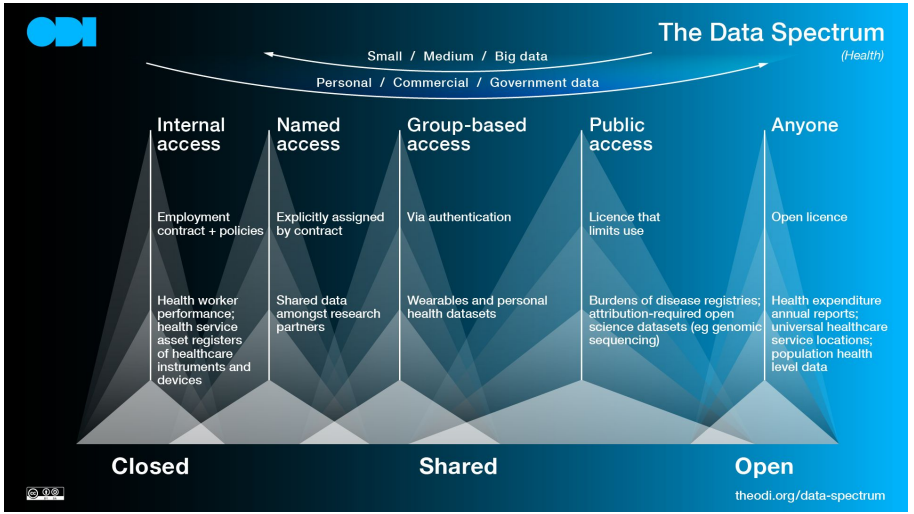
Practice 'CARE' in data collection	Engage 'CARE' in data stewardship	Implement 'CARE' in data community	Use 'FAIR' with 'CARE' in data applications
Define cultural metadata Record provenance in metadata	Use appropriate governance models Make data 'FAIR'	Indigenous ethics inform access Use tools for transparency, integrity and provenance	Fairness, Accountability, Transparency Assess equity

Sources: Nature (2021), 'Operationalizing the CARE and FAIR Principles for Indigenous data futures' https://www.nature.com/articles/s41597-021-00892-0, Global Indigenous Data Alliance, CARE Principles of Indigenous Data Governance, https://www.gida-global.org/care

The ODI Data Spectrum can be used by data stewards to determine the level of risk and robustness of data sharing agreements required to make data available

Based on the degree of risk and the openness of the health dataset, access permissions can be determined so that health data at lower risk can be more easily facilitated to be shared, while sensitive data can be protected through stricter data sharing arrangements.

Technology can also be used as an enabler to manage data sharing. A security model known as 'zero trust', for example, builds in access and permission controls in a way that assumes data users should not have access. Zero trust technology implementations then check for identity verification and access permission levels before every instance of granting access. These technologies can be applied to everything to the left of open licences in the data spectrum.



Sources: 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), 'Zero Trust in Healthcare', https://www.hhs.gov/sites/default/files/zero-trust.pdf

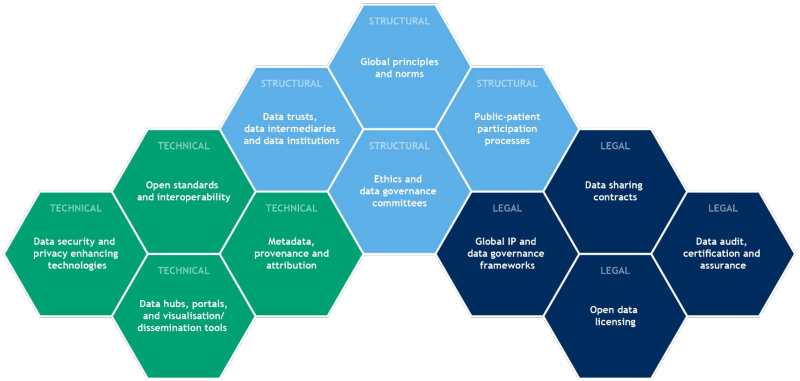
Data governance builds trust, creates robust processes to enable data sharing and can ensure ethical, responsible, quality management of data across the data journey

The health sector is already advanced in applying good data governance approaches, which fall under three general categories:

Structural data governance practices,including global principles and norms around data practices, ensuring accountability through ethics and data governance committees, creating new organisations to steward data and encouraging participation by all stakeholders including patients and the wider community

Legal data governance practices, including global IP and data governance frameworks, creating data sharing contracts, adopting standard open data licences, and requiring certification and assurance processes.

Technical data governance practices, including adopting open standards and interoperability, sharing good practices around providing metadata, provenance and attribution support appropriate reuse, creating data hubs, portals, and visualisation/dissemination tools and implementing data security and privacy enhancing technologies to make it easier to process and use data without revealing sensitive information.

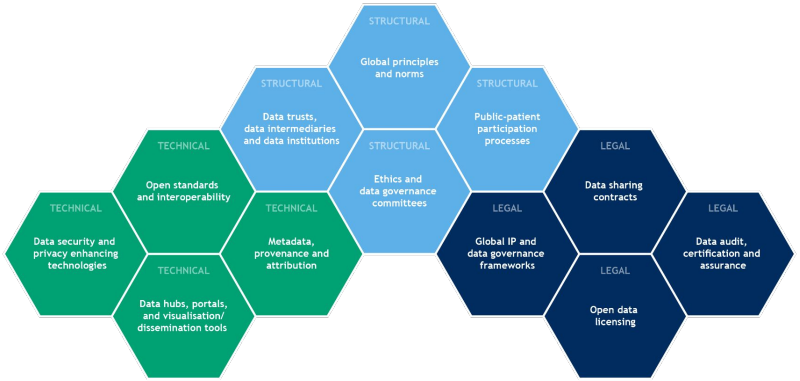


Global examples of data governance best practices

There are a number of global examples where shared data systems have been developed to create benefits for all stakeholders. The European Council for Nuclear Research, the World Wide Web Consortium and national models that open up weather data for access are all global examples where data governance processes have been put in place that enable researchers and other stakeholders to share data and work collaboratively to create new solutions.

In the health data landscape, building appropriate data governance processes will:

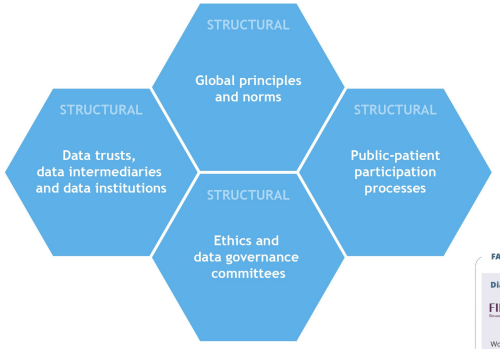
- Foster greater trust
- Enable data sharing while protecting individual privacy, and
- Create new partnerships that respect and value the positions of low-income countries, particularly in the Global South



Structural components establish oversight and guidance for data governance

Entities like PATH help countries to establish robust health data governance frameworks. They note that in-country leadership and support for prioritising data governance and developing legislative frameworks is essential (or foundational).

This leadership will need to foster trust through involving community participation, establishing entities to help guide and manage processes, and embedding ethical oversight and governance committees that will track and monitor progress towards building robust data governance systems.



Global partnership ACT Accelerator built on the existing governance mechanisms of partners to create a time-limited global collaboration designed to expedite the end of the acute phase of the Covid-19 pandemic. By rapidly leveraging existing global public health infrastructure and expertise it accelerated the development, production, and equitable access to Covid-19 tests, treatments, and vaccines.

Sources: WHO (2021) 'What is the Access to COVID-19 Tools (ACT) Accelerator, how is it structured and how does it work?', https://www.who.int/publications/m/item/what-is-the-access-to-covid-19-tools-(act)-accelerator-how-is-it-structured-and-how-does-it-work

Global principles and norms

Global principles and norms set the context in which data governance can occur.

At a global level, there are a number of guiding frameworks that set the overarching context for health data governance. However, several of these principles reinforce a Western/Global North concept of individual rights, which may not adequately reflect local cultural values in some regions.

The WHO has established five data principles to continually reaffirm trust in WHO's data governance:

- WHO will treat data as a public good
- WHO will uphold Member States' trust in data
- WHO shall support Member States' data and health information systems capacity
- WHO shall be a responsible data manager and steward
- WHO shall strive to fill public health data gaps

Chart of signatures and ratifications of Treaty 108

Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data

Status as of 21/06/2021

Title	Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data
Reference	ETS No.108
Opening of the treaty	Strasbourg, 28/01/1981 - Treaty open for signature by the member States and for accession by non-member States
Entry into Force	01/10/1985 - 5 Ratifications.

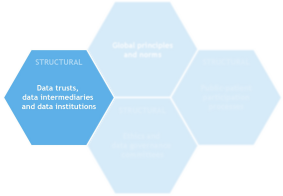
While the European Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data aligns with European data privacy principles focused on individual rights, it has signatories from Argentina, Burkina Faso, Cabo Verde, Mauritius, Mexico, Morocco, Senegal, Tunisia, and Uruguay.

Sources: https://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/108

Data trusts, data intermediaries and data institutions

Data institutions may be existing organisations or established specifically to hold and manage data for potential reuse.

Data institutions take on a number of organisational structures such as data trusts (where there is a fiduciary responsibility for managing data), data intermediaries (which may act as an independent, non-profit that assesses applications and provides a secure platform for use of data it manages on behalf of others), or other forms of arrangement.



The Infectious Diseases Data Observatory is a global data institution that holds and manages data on behalf of researchers and governments and utilises data governance processes to review access requests and provides access under technical, legal and security arrangements.

Ethics and data governance committees

Ethics and governance committees are organisational structures that oversee the implementation of data governance processes and assess adherence to legal and technical implementations. They help ensure that all data managed across the data journey protects the privacy of individuals and the dignity of communities while improving public health through the most productive use of data.

For a data steward or data processor entity, ethics and data governance committees provide internal oversight and guidance of processes. For a regulator or government, ethics and governance committees and organisational structures provide an accountability mechanism that can penalise or otherwise restrict data sharing and use of data.

In Brazil, for example, health data collected by government should be made available in a de-identified form. This is done first as a provisional publication and six months later as the final quality assured dataset. An independent process is in place for stakeholders to appeal against any government decisions where data is not made available.

The International Diseases Data Observatory (IDDO) has terms of reference for a data access committee that oversees data sharing.

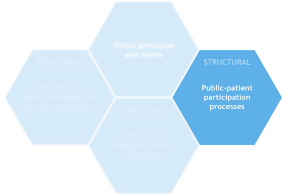
COVID-19 Data Platform:

Data Access Committee Terms of Reference Version: 1 October 2020

1. Date Approved and Governing Body	These Terms of Reference (ToR) will be agreed by the **Data Access Committee (DAC)**. The DAC is an independent body, chaired by a representative of TDR, the Special Programme for Training and Research in Tropical Diseases. Where external guidance is required by the DAC, the IDDO Board and ISARIC Senior Management Team are available for consultation. The DAC formally adopted these TORs on the date of their first meeting.
2. Purpose	The COVID-19 Data Platform ("Platform") has been established to develop and promote research on COVID-19. The Platform fulfils this purpose through: 1. Curation (including de-identification, standardisation and cleaning) of COVID-19 data; 2. Management of requests for access to de-identified COVID-19 datasets; 3. Promotion of scientific collaboration and equitable access to data. The purpose of the Data Access Committee is to: • Provide an independent decision-making committee to evaluate and decide whether requests to access data from the Platform are consistent with the Data Access Guidelines and respond accordingly to applicants. • Define the data sets to be released. • Consider the Platform's Conflict of Interest Policy when making decisions regarding access. • If needed, prioritize applications according to the Data Access Guidelines. In the execution of its responsibilities and decision making, the DAC will apply the principles that govern the use of the Platform, in line with the Data Access Guidelines and missions of the International Severe Acute Respiratory and emerging Infections Consortium (ISARIC) and the Infectious Diseases Data Observatory (IDDO). The members of the DAC will ensure the highest standards of security and privacy are maintained whilst facilitating the ethical, equitable and rapid access to data. Applications for access to data and the deliberations of the DAC are considered confidential until public release as set out below.

Public-patient participation processes

Involving the public, patients and other stakeholders in deciding how data is shared and used is an essential component when creating an open and trustworthy health data landscape.



In partnership with the patient representative organisation, Cystic Fibrosis Trust, UK-based Turing Institute researchers had access to an anonymised extract of UK Cystic Fibrosis Registry data. The Registry is a secure centralised database managed by the Cystic Fibrosis Trust, which holds consented health data from over 99% of the people with CF across the UK. The project utilises machine learning techniques to train a system to learn and make reliable predictions from historical data, creating a method of generating personalised risk scores for people with Cystic Fibrosis.

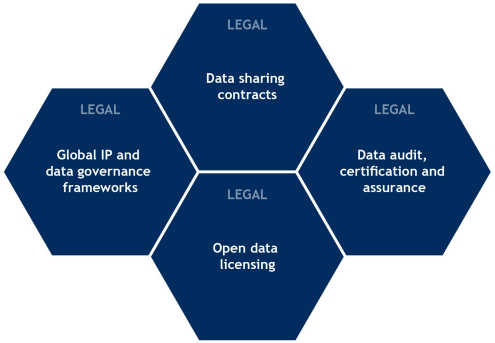
Sources: https://www.turing.ac.uk/research/research-projects/improving-cystic-fibrosis-healthcare, https://www.adalovelaceinstitute.org/blog/strength-in-numbers-building-a-data-based-community-cystic-fibrosis/

Legal components of data governance help set clear boundaries and enable accountability frameworks to be established

Informants noted that in low- and middle-income countries (LMICs), the lack of legislative frameworks remain the biggest gap. Countries may be collecting large amounts of data with no data regulation laws in place.

Alongside legislative frameworks there needs to be independent data protection authorities and commissions. This is included in the structural components.

Informants mentioned that WHO could play a role in helping countries, regions and organisations as a data governance certification body. As data governance legislative frameworks are put in place and technical architectures and processes adopted, a body to review implementations and ensure alignment with best practices and global principles could help strengthen trust in data governance.



Global IP and data governance frameworks

Global and national intellectual property and data governance frameworks provide clarity on individual data privacy rights and can also protect commercial interests and research-based innovation, for example by enabling text and data mining.

However, national data governance frameworks are not in place in many low and middle income countries. This limits the potential for data sharing and limits trust.

Paradigm Initiative's research into data governance frameworks in Africa describes several of the current limitations that impact health data sharing across the continent. The series of reports on digital rights, Londa, also provide further insights.

Sources: https://paradigmhq.org/; World Bank (2021), "World Development Report 2021", https://www.worldbank.org/en/publication/wdr2021

Data sharing contracts

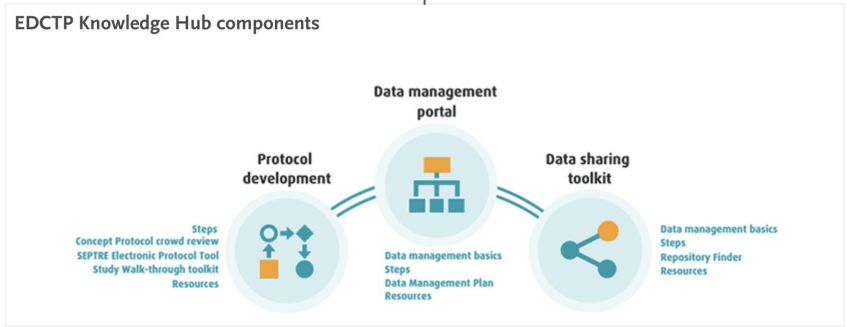
Great advances in science and public health can be achieved through appropriate sharing and reuse of health data.

WHO has developed substantial work on data sharing policies that demonstrates how nuanced data sharing agreements can be created and operationalised:

- Policy Statement on data sharing in the context of public health emergencies
- Policy on use and sharing of data outside the context of public health emergencies
- Joint statement on public disclosure of results from clinical trials

Current work is also underway to develop a policy on sharing and use of health-related data for research purposes.

The EDCTP Knowledge Hub has developed resources for researchers conducting clinical research in low-resource settings. EDCTP's Knowledge Hub provides researchers with the tools and guidance to enable them to undertake high-quality health research. Comprised of the Protocol Development Toolkit, the Data Management Portal and the Data Sharing Toolkit the Knowledge Hub takes a researcher from a research question through to sharing their data. EDCTP's Knowledge Hub is considered state-of-the-art and one of the best practice examples globally of how data systems can be established and managed to support sharing of data for research.



Sources: EDCTP Knowledge Hub https://edctpknowledgehub.tghn.org/

Data audit, certification and assurance

Data audit, certification and assurance processes ensure that data maintains a high quality and that the data governance processes to manage data meet any legal or data sharing agreements created with data stewards, data contributors and data users.

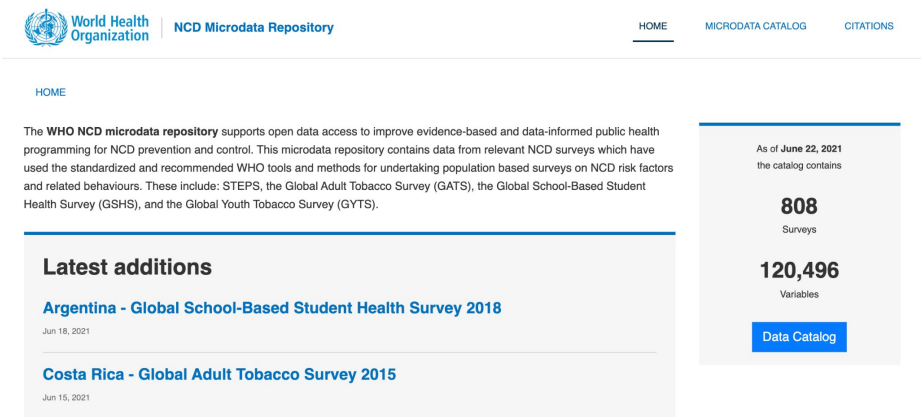
Several informants suggested WHO could take a role in providing a certification service that enables entities to demonstrate their adherence to data governance best practices and use of health data standards.

Open data licensing

Recent data licensing approaches for health data have sought to move beyond CC BY 4.0, an international licence that allows reuse as long as attribution is given to the original data contributors, and any changes made to the data are described.

New methods of describing licence terms are being generated that allow for greater nuance, and alignment with FAIR principles. For example, the above Creative Commons licence does not require that the original researcher or data contributor be contacted about the use of the data.

The WHO Non-Communicable Diseases (NCD) Microdata Repository uses data sharing agreements that require users of data to contact the data contributors. The NCD platform encourages data reusers to attribute data contributors as co-authors of research and to invite data contributors to any ongoing research based on the data.



Sources: Attribution 4.0 International — CC BY 4.0 https://creativecommons.org/licenses/by/4.0/, https://extranet.who.int/ncdsmicrodata/index.php/home

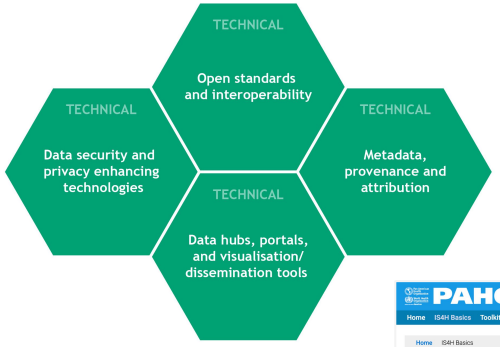
Technical components help operationalise data governance and give data stewards and data processors promising practices that can be adapted to the local context

Data standards and interoperability capabilities are an essential element in enabling quality data to be generated and shared for reuse. Informants again highlighted the WHO role as a harmonising entity that encourages collaboration on defining standards and then assists stakeholders to implement standards when building health data systems.

Establishing metadata, provenance and attribution measures were seen as an urgent priority for two audiences:

- For **individual researchers**, particularly in LMICs, attribution recognises the value they contribute and could lead to greater global participation in research and solution building
- For **the private sector**, clear data governance that enables data sharing and provides incentives for opening data for other stakeholders to use can broaden the value generated from health data, and clarify legal arrangements when opening data between industry, government, research and civil society networks.

Data security was also highlighted as a priority by informants, who again noted that WHO's harmonisation role can embed cybersecurity in standards discussions. Time-limited access to data and boundaried use technologies can also help foster trust and ensure data governance processes are implemented through technology.



PAHO Information Systems for Health (IS4H) resources were mentioned by several informants as being high value country-level guides for implementing data governance technical processes.

Sources: https://www3.paho.org/ish/index.php/en/is4h-basics

Open standards and interoperability

Open standards are at the core of what makes data governance possible. One informant noted that "'without standards that are global, usable, interoperable and sensible and pragmatic, the use of health data isn't possible".

There are a number of global standards including used in health data systems:

- WHO's approved standards such as ICD10, SNOMED, LOINC and HL7
- UN Fundamental Principles of Official Statistics
- UN Handbook of Statistical Organization
- ISO standards
- OECD Fair Information Principles
- SDMX standard
- JSON-stat

HDRUK
Health Data Research UK

Principles for Data Standards

These principles are encouraged for organisations that are participating in any part of HDR UK's activities, including contracted services or activities managed by members of the HDR UK community. Further details on the principles are given in the following section.

0. As described in the Health Data Research UK's Principles for Participation, data should be **Findable, Accessible, Interoperable and Reusable (FAIR)**
1. This work is to be **minimally interventionist**, and to only prescribe specific actions or specific standards where this is deemed necessary. Where principles alone will suffice (when multiple standards would meet the requirements), no specific standards will be mandated
2. Standards that are used should be **explicitly described**, including the descriptions of any export which should include the model/schema, syntax and data dictionary or reference. This should include provenance tracking where possible
3. **Open** standards should be adopted wherever possible, minimising the proliferation of proprietary data standards
4. Organisations should aim to maintain a **consistent, internal approach** to data standards, explicitly referencing their approach to standards in their data strategy
5. Data should be able to be used according to the principle of **without special effort** as a result of the standard used
6. Standards adopted should be **aligned with existing and provisional standards proposed by national and international bodies** where possible, recognising that the remit and aims of HDR UK and other bodies may overlap but differ
7. Ideally, standards should be **common for both research and clinical or operational uses**, in order to optimise both research and clinical benefits of data, recognising that the primary focus of HDR UK is research use of health data
8. Organisations forming part of the HDR UK network should have **established and aligned data strategies**, including how these improve the usefulness of data
9. Benefits of standards should be widely disseminated through **communication and educational** events, both to researchers and the public

The Health Data Research UK body has developed a set of principles that can govern with decisions on which standards to adopt.

Sources: HDRUK (2020), 'Principles for Data Standards', https://www.hdruk.ac.uk/wp-content/uploads/2020/06/200630-Data-Standards-Principles-FINAL.pdf

Data security and privacy enhancing technologies

Data security and privacy enhancing technologies ensure that data is collected, stored, protected, shared and used in alignment with agreed data governance policies and aligned with data sharing agreements.

Security and identity management technologies can be embedded into platforms to ensure that access is only granted to those with appropriate permission and authorisation.

For example, technologies that pseudonymise, anonymise, de-identify, and protect sensitive data, can be integrated into technology platforms so that code and technology becomes an implementation channel for the governance processes. One informant quoted Lessig's "code is law" when describing how technology can be leveraged to reinforce data governance.

Data localisation policies were also noted by informants as an influencing factor on the adoption of technologies. As digital systems increase for surveys and other health data, country-level policies that require data storage within the country are confusing the potential to use cloud-based technologies for remote and mobile health data collection.

Data hubs, portals, and visualisation/ dissemination tools

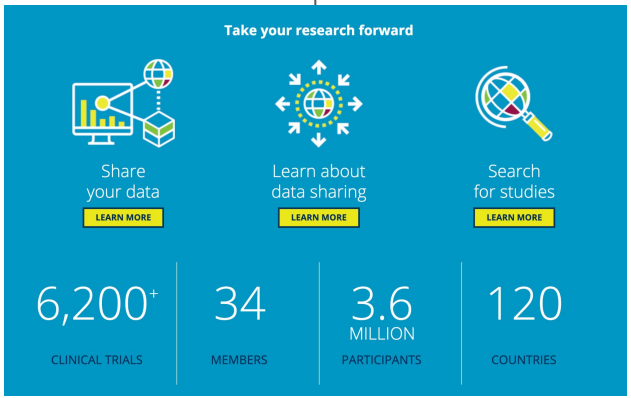
Technology platforms and tools enable data to be contributed and shared in a self-serve format in order to reduce friction in accessing data in a timely manner.

The majority of examples and case studies reviewed in this research made use of visualisation tools and dashboards are used to enable greater data sharing and reuse. The Tanzania Ministry of Health, for example, has dashboards for individual data sharing platform work, as well as dashboards that describe the progress of implementing data governance and enterprise architecture initiatives.

However, for data stewards looking to make this data available using technologies, there are concerns that the vendor and supplier contracts to use data technologies and platforms may include data sharing rights beyond what would be expected. Technology platforms, for example, regularly share logging data with third-party analytics and DevOps services that may include datasets within the logging records.

Vivli
CENTER FOR GLOBAL CLINICAL RESEARCH DATA

Vivli is an independent, non-profit organization that has developed a global data sharing and analytics platform. The focus is on sharing individual participant-level data from completed clinical trials to serve the international research community.



Sources: Vivli - Center for Global Clinical Research Data https://vivli.org/

Metadata, provenance and attribution

Global best practices suggest that metadata standards for datasets should include as a minimum:

- Name of original source
- Specific name of data referred to
- Name of contributor
- Location
- Data licence
- Methodology
- Expected frequency

There are a number of global standards for metadata including the UNECE common metadata standards. For APIs, there are also API specification standards such as OpenAPI and AsyncAPI which help data API providers use metadata standards to describe both the data and the data exchange functionalities available.

In Tanzania, building technological health data information systems has reduced fragmentation and strengthened data governance overall

The Tanzania Health Ministry worked with the global NGO PATH to document a joined-up health policy and technology environment that can enable the shared use of health data for public good. This process included documenting an overall digital health strategy and identifying fragmentation issues in current data systems (where over 160 systems collect health data) before establishing an enterprise architecture strategy to modernise and improve health data systems.

The value of health data

New health data systems are enabling:

- **Improved health service delivery:** Faster turnaround time of HIV viral load tests and early infant diagnosis speeds up treatment care planning
- **Optimised health resource management:** Collection and reporting of facility level basic patient care information allows better health financing decisions
- **Improved public health systems surveillance:** Digitised sanitation systems allow for disease detection and response

Stakeholders

Modernising health data systems and technologies has involved civil society networks, PATH, government regulators, Tannzania Buereau of Standards and other standards bodies; the Prime Minister's Office, private, public and community-based health service providers, research and academia, Association of Private Health Facilities in Tanzania, National Muslim Council, and the Christian Social Services Council.

Governance processes

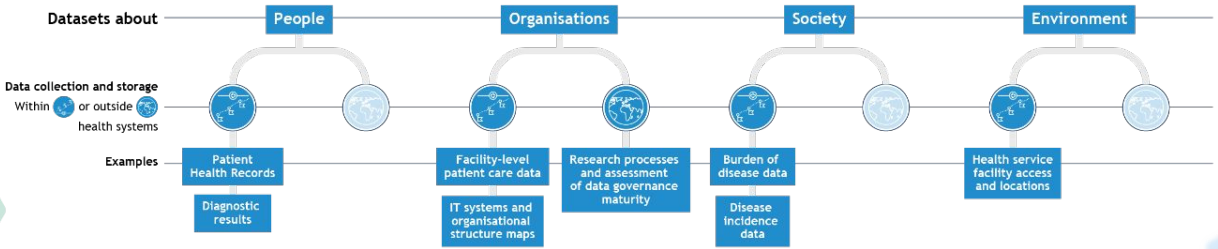
Structural: National digital health policies prioritise the development of health enterprise architecture and align with whole-of-country policy goals focused on the health of the population as a necessary resource for economic development. Governance structures were established with National NGO participation, multiple government ministries and the Prime Minister's Office.

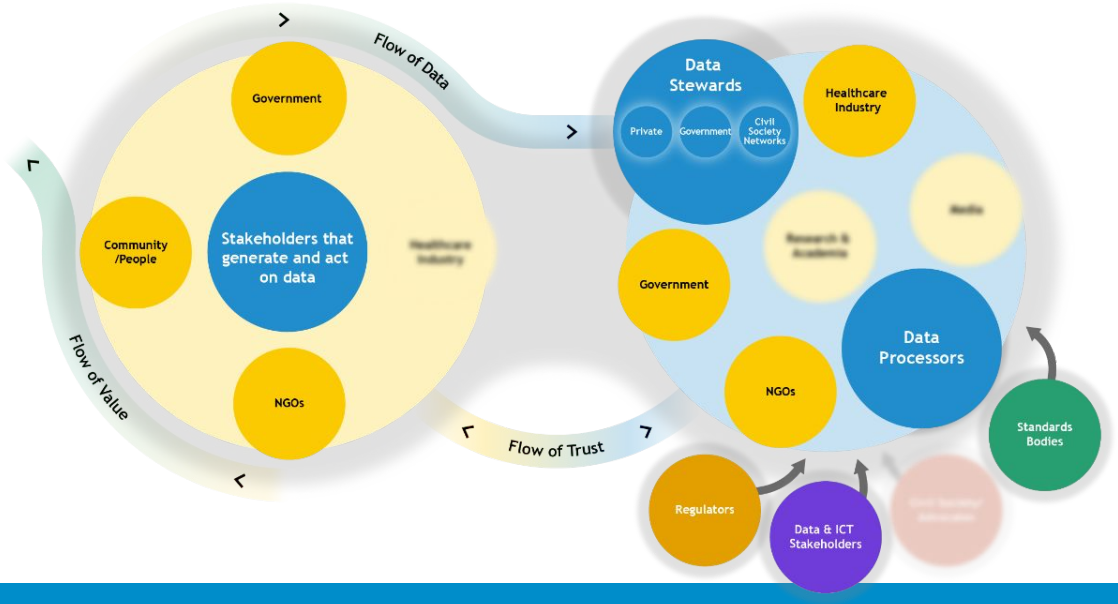
Legal: Business architecture principles were established. The enterprise architecture strategy noted that currently there is a gap created due to lack of data sharing contracts between entities in the landscape.

Technical: Standards bodies are involved in the development of the data governance systems and technologies. Governance processes established to oversee modernisation of the architecture are also ensuring alignment with standards, identifying and addressing gaps in data sharing, building data quality assurance processes and introducing privacy enhancing technologies.

Information shared by Dr Henry Mwanyika, Laurie Werner, Dr. Seif Rashid, Neema Ringo, and Dykki Settle.

Key elements of the Tanzania health data landscape evident in this use case





WHO's efforts have built a global Non-Communicable Disease (NCD) surveillance system that supports countries to generate data for NCD prevention and control policies and programs

WHO STEPS surveillance of NCDs and risk factors aims to enhance country capacity to generate data to support the design, implementation, monitoring and evaluation of NCD prevention and management interventions.

STEPS surveys enable countries to collect and report on key behavioural and biological risk factors for NCDs in adults, including alcohol, tobacco, unhealthy diet, physical inactivity, BMI, hypertension, diabetes, heart disease and cancer.

The value of health data

- **Optimised health system:** Data has helped country policy plans to invest in interventions with known potential to positively impact health outcomes
- **Reduced inequality:** Data allows insight into differential health outcomes by gender and socioeconomic status
- **Expanded innovation:** The capacity building STEPs model helps strengthen in-country data governance and data collection processes

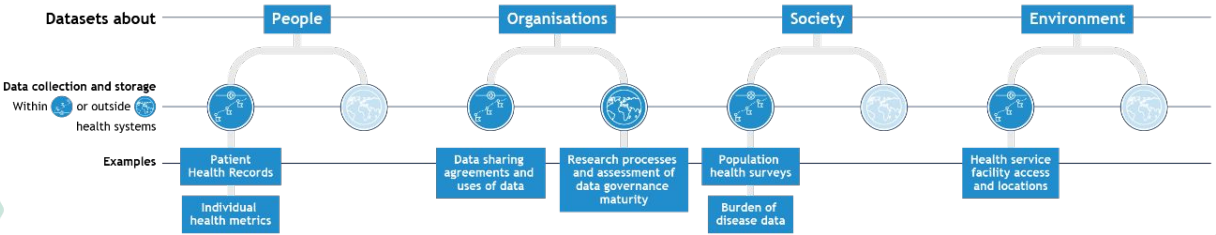
Information shared by Leanne Riley.

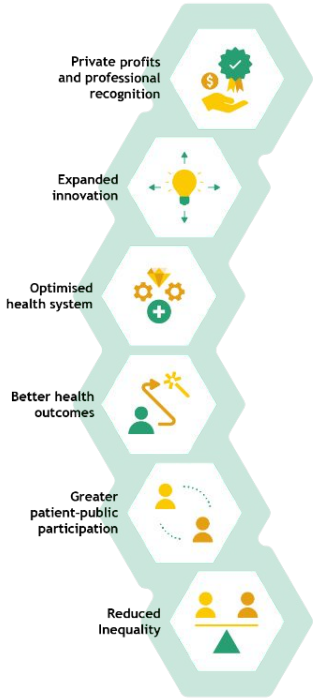
Stakeholders
Governments, country health ministries, policymakers, research and academia, NGOs, civil society networks, advocates, public-patient organisations

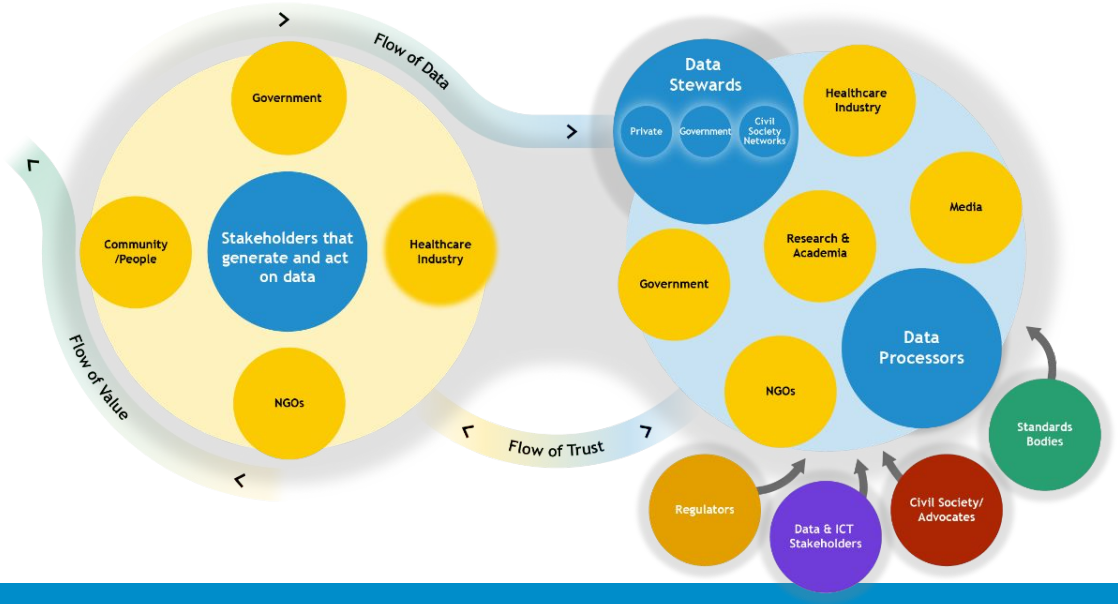
Governance processes
Structural: The 'WHO "Best buys" and other recommended interventions for the prevention and control of noncommunicable diseases', together with the NCD Global Monitoring Framework and set of 9 global voluntary targets help guide global priorities and are used by countries to guide national and local actions.
Legal: Data sharing agreements are in place between countries and WHO. Data sharing agreements encourage making data publicly accessible, and ensure data contributors are aware where and how data are accessed for reuse. All STEPS survey data are stored in an NCD Microdata Repository hosted by WHO. Data users are encouraged to invite data contributors as research partners or co-authors.
Technical: Global standards are used to ensure data quality controls and data are comparative. Technology platforms are used to host and share data. Application tools have been built to enable policy relevant analysis of data.

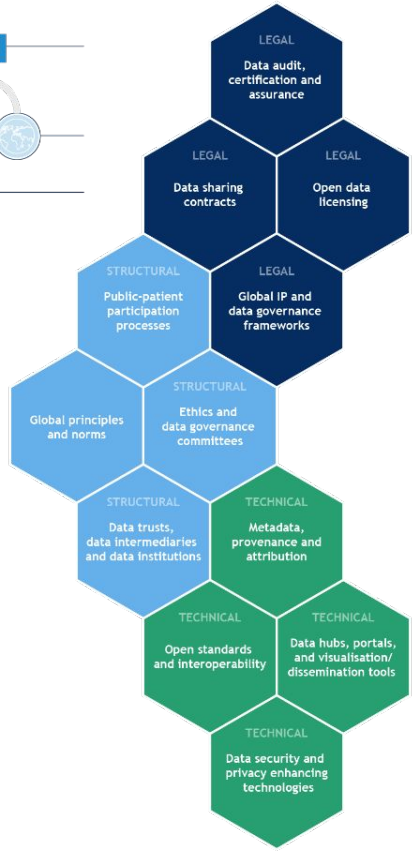
Sources: https://apps.who.int/iris/handle/10665/259232, https://www.who.int/teams/noncommunicable-diseases/surveillance/systems-tools/steps, https://extranet.who.int/ncdsmicrodata/index.php/home

Key elements of global data sharing initiatives to monitor non-communicable disease impacts on public health









Thank you to all informants and participants for sharing your time and expertise

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Last updated: 23 June 2021