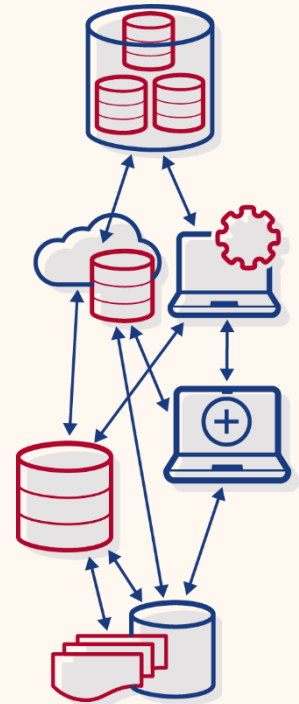




Data Governance in Health

Digital technology, applications, data, and information systems, as part of the ongoing transformation of health and health care can help ensure universal and equitable access to affordable, people-centered, and integrated quality care, contributing to the goal of reaching Universal Health Coverage (UHC). Intelligent use of data and digital technologies can elevate patient experience, improve staff satisfaction, drive operational efficiency, improve patient outcomes, and create new business models, with benefits for both the public and private sectors.

This **Implementation Know-How Brief** provides World Bank Group **staff, country teams, and other organizations involved in the implementation of Digital-in-Health activities** with practical discussions, key terms and considerations, and broad guidance on how to engage with clients on the topic of **data governance in health**.



This Brief Will Help stakeholders to:

- Learn about **key terms, working definitions and types** of health data
- Learn about the **functions and importance of data governance frameworks** in health
- Understand the key steps and considerations when **implementing a health data governance framework**
- Be aware of **existing health data governance frameworks, toolkits and principles**
- Understand what are some of the **challenges and pitfalls** in promoting health data governance

Why Is Data Governance in Health Important?

Data are a double-edged sword (World Bank 2021): they have massive potential for both creating social and economic value as well as for concentrating economic and political power to the detriment of citizens. Promoting the use and reuse of data is crucial to achieving benefits, but the more data are used and reused, also the greater the potential for abuse. This is why data governance is important, especially in the context of sensitive data concerning health.

Data are key to improving health system performance, including (OECD 2022c): the quality, safety, and patient-centeredness of health care services; the discovery and evaluation of new treatments through scientific innovation; and the redesign and evaluation of new models of service delivery. While health data are most valuable when linked and analyzed, often these data are siloed. Moreover, there are still questions over how to link and analyze

personal health data while respecting data protection standards and procedures. Reconciling the potential risks and benefits of collecting and using data concerning health, especially personal data, is what data governance frameworks aim to do, and in doing so, these frameworks serve the interests of both individuals and societies.

Data governance frameworks foster trust, creates robust processes to enable data sharing while protecting individual privacy, and can promote ethical, responsible, quality management of data across the data journey¹. Data governance frameworks also enable the creation of new partnerships that respect and value the positions of low-income countries, especially in the Global South.

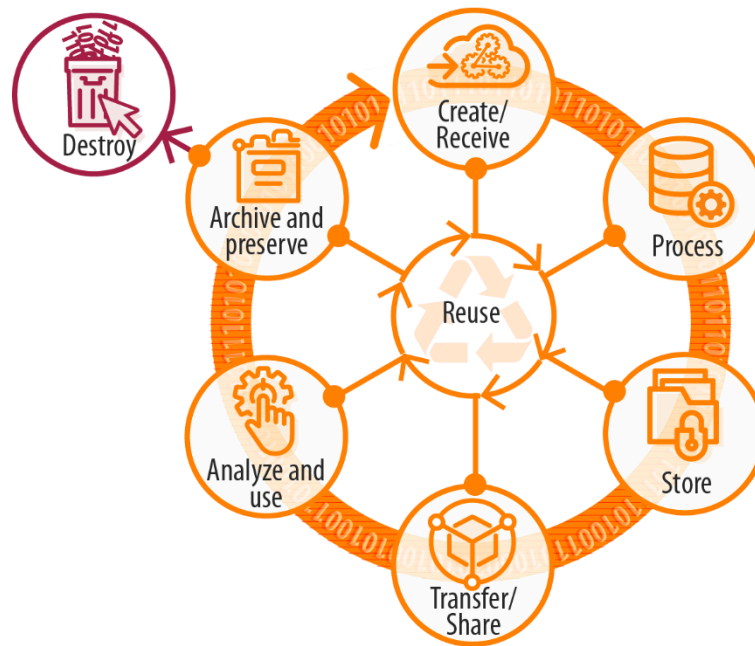
What is Meant by Data?

As the World Development Report (WDR) of 2021 points out, the term data is difficult to define, as it has meant different things at different times, and in different disciplines. Technological advances in computing and creative thinking make it challenging to provide a specific description of data that is not archaic or anachronistic (a few decades ago, most people would not have thought of pictures and sound as data). In the context of the 2021 WDR, data may be (World Bank 2021): quantitative or qualitative; stored on analog or digital media; collected through observation, as part of digital transactions or simply as by-products of digital lives; processed, structured, and analyzed to be converted into information (data are not synonymous with information); about people, things, and systems. The Organization for Economic Co-operation and Development (OECD) definition of data aligns well with the WDR's definition. The OECD highlights **key characteristics of digital data** (OECD 2022b):

- **Intangible:** digital data do not have a physical or financial embodiment
- **Nonrival:** digital data are theoretically infinitely usable, simultaneously by different actors, and without depleting them
- **Potentially non-excludable:** digital data that are made available or circulated on the Internet are not easily controlled and their use is not easily restricted
- **Externalities:** digital data sharing and use can generate wider benefits and costs for those who may not be directly involved in the process of sharing and using data
- **Can exhibit increasing returns to scale:** when used as a factor of production, the output from digital data use may increase by a larger proportion than the increase in data volume
- **Very heterogeneous:** digital data are treated differently in policy frameworks depending in what setting(s) and context(s) they were collected and are used
- **Often co-produced:** digital data are often the product of interactions between many actors, which may complicate conventional notions of ownership and lead to externalities

A key characteristic of digital data is that they are nonrival: they can be used repeatedly, simultaneously by multiple actors, for different purposes, without ever depleting them. The 2021 WDR illustrates this point using the **data life cycle**, depicted below. Data may be used, reused, and repurposed, so long as they are made accessible across users and unless steps are taken to destroy the data (something that may be difficult once data are shared widely). **Data management** is the process by which organizations (large and small) use all stages of the data life cycle to derive value (figure 1).

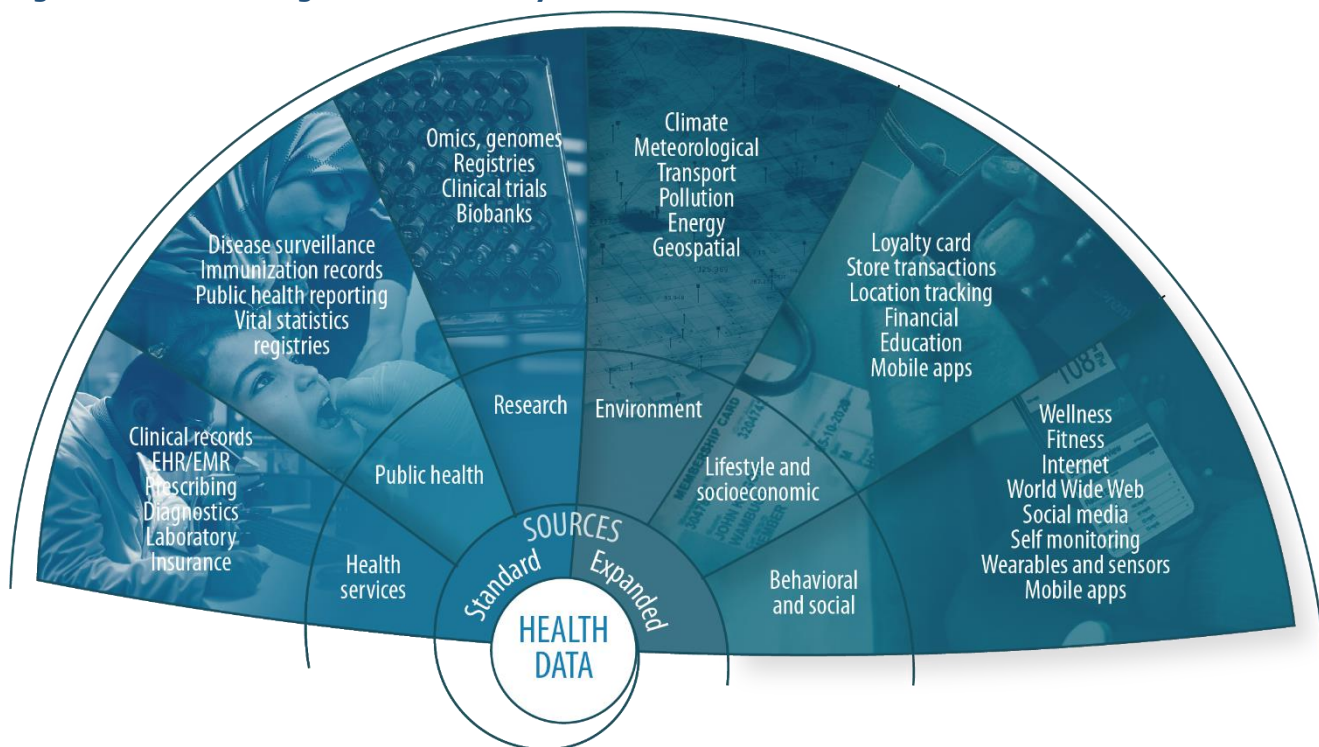
Figure 1 The Data Life Cycle



Source: World Bank, 2021.

Data Concerning Health

As mentioned, one of the characteristics of data is that they are highly heterogeneous. There are many sources and types of data that concern health, as illustrated in the diagram (figure 2).

Figure 2 The evolving health data ecosystem

Source: Vayena et al. 2018.

Personal Data Concerning Health

Not all data concerning health are considered in the same way in policy frameworks (for example, pollution data are not treated the same way as clinical data). The European Commission² defines *personal data* as any information that relates to an identified or identifiable living individual, including different pieces of information that together **can lead to the identification of a particular person** (examples of personal data include name and address). Personal data that have been de-identified, encrypted, or pseudonymized but can be used to re-identify a person are still considered to be personal data, while personal data that have been anonymized in a way that the individual is not identifiable are not considered personal data.

The European Union General Data Protection Regulation (GDPR)³ defines *personal data concerning health* as all data pertaining to the health status of a data subject which reveal information relating to that data subject's past, current, or future physical or mental health status. The GDPR's definition is very comprehensive. It includes not only personal identifiers and genetic and biological samples, but also any information on, for example, a disease, disability, disease risk, medical history, clinical treatment or the physiological or biomedical state of a data subject independent of its source, for example from a physician or other health professional, a hospital, a medical device, or an in vitro diagnostic test. The GDPR recognizes that **personal data concerning health are a special category and merit the highest standards of protection**. The 2021 WDR suggests that a rights-based approach to data protection—one that emphasizes the rights of data subjects as well as the obligations of data

users—is appropriate for personal data, while intellectual property rights—which weigh the balance of economic interests between safeguards and enablers—are more appropriate for non-personal data.

What is Data Governance?

There is no one definition for data governance, but definitions from different organizations do share elements. As per the 2021 WDR, *data governance* entails creating an environment of implementing norms, infrastructure policies and technical mechanisms, laws, and regulations for data, related economic policies, and institutions that can effectively enable the safe, trustworthy use of public intent and private intent data to achieve development outcomes (public intent data are data collected for public purposes while private intent data are data collected for private purposes).

For the OECD Project on Data Governance for Growth and Well-being, *data governance* refers to diverse arrangements, including technical, policy, regulatory or institutional provisions, that affect data and their creation, collection, storage, use, protection, access, sharing and deletion across policy domains and organizational and national borders. While the exact ways in which data can be governed are many, **the aim is to maximize the benefits from data, while addressing associated risks and challenges**. The Pan American Health Organization (PAHO) defines *data governance* as a set of practices for making decisions about data and for managing data throughout its life cycle to optimize an organization’s capability to use data to generate insights that inform policy, strategy, and operational management (PAHO 2021a).

Data governance is one type of public governance (other types include infrastructure governance, risk governance, and corporate governance). As per the OECD, sound public governance consists of the formal and informal rules, procedures, practices, and interactions within the State, and between the State, non-State institutions and citizens, that frame the exercise of public authority and decision-making in the public interest (OECD 2020). Health data governance is part of digital health governance.

Data governance is an integral part of data management, which also includes data processing, data storage, and data security⁴. Data management relies on data governance frameworks to guide and structure decisions concerning data. Table 1 illustrates some of the data management decisions that data governance frameworks can help guide.

Table 1 Data management and data governance along the data life cycle**Stage of life cycle: Create/receive**

- Establish lawful use (such as obtaining consent for data collection and sharing)
- Determine and collect identifications that allow data to be merged with other datasets

Stage of life cycle: Process

- Establish/adopt standards for units and categories (such as industry classifications)
- Determine/implement data formats that are widely compatible and accessible
- Set processes for validating the quality (accuracy), relevance, and integrity of data

Stage of life cycle: Store

- Establish standard rules and procedures to encrypt data; use secure servers; back up and archive data

Stage of life cycle: Transfer/share

- Establish verification processes to determine whether consent allows for data to be shared
- Determine when appropriate to deidentify data
- Sign confidentiality agreements for use of identified data
- Set rules for publishing data via bulk downloads or application programming interfaces (APIs)

Stage of life cycle: Analyze and use

- Establish ways to promote reproducibility; publish code or algorithms
- Set constraints on publishing identifiable data
- Visualize and communicate insights from data

Stage of life cycle: Archive and preserve

- Set mechanisms to classify and catalog data systematically so they can be found easily
- Include data dictionaries and notes on how data were created
- Establish rules to maintain access to data and their security and integrity over time

Stage of life cycle: Destroy or reuse

- Establish when and how to keep records of destruction processes
- Determine how to verify that consent for use is still valid

Source: Based on World Bank 2021.

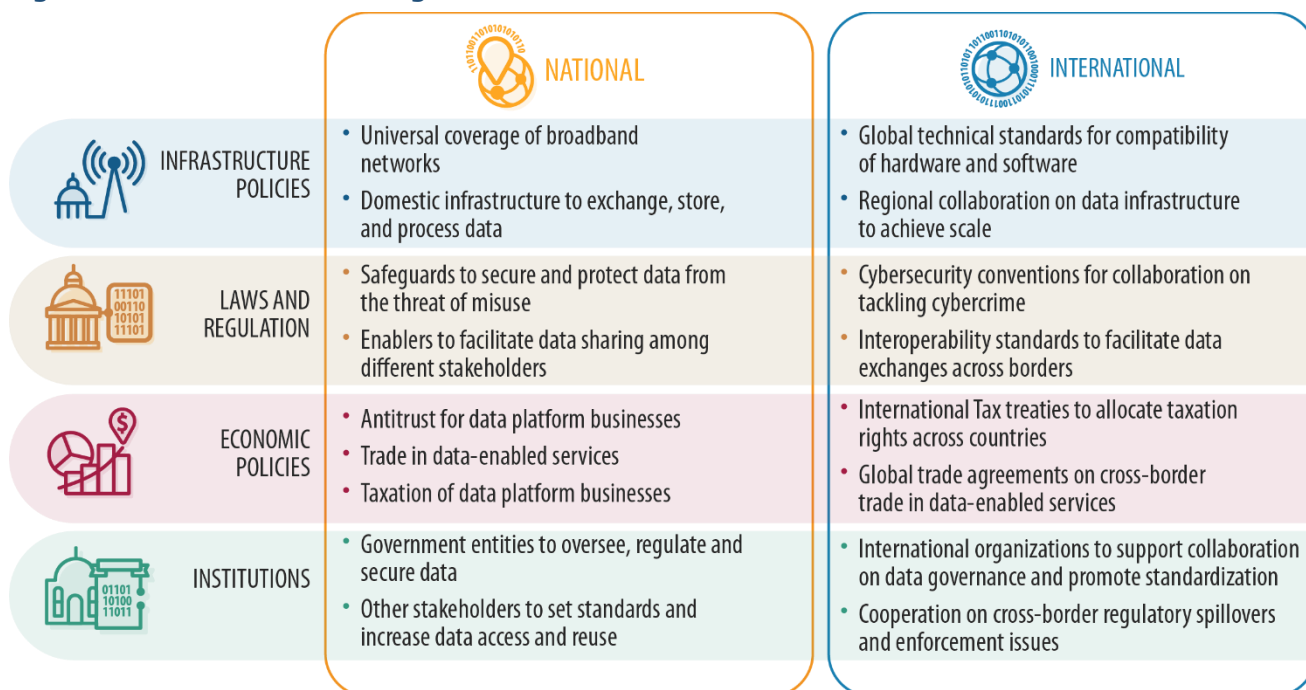
Data governance frameworks

A *data governance framework* is **the tangible expression of a country's social contract around data, allowing data governance to go from theory to practice** (World Bank 2021). Well-designed, robust, and effectively implemented data governance frameworks create trust in data systems and incentivize the use of data-driven products and services. Data

governance frameworks help answer questions like (OECD 2022a): how to ensure data can be open while maintaining control and trust? How can multiple and potentially conflicting data interests and regulations co-exist? How to incentivize investments in data use and reuse for the benefit of all?

The 2021 WDR data governance framework (illustrated in figure 3) is made up of **four distinct layers that build on and support one another**. The foundational layer is the policy framework for data infrastructure to collect, exchange, store, process, and distribute data. Access to the data infrastructure is a prerequisite for both contributing one’s own data and accessing the data of others. The next layer consists of the legal and regulatory environment for data, which creates rules to enable the reuse and sharing of data while safeguarding against their potential abuse and misuse. The legal and regulatory environment for data interacts with wider economic policy issues represented in the third layer, which affect a country’s ability to harness the economic value of data through competition, trade, and taxation. The fourth and final layer is the institutional ecosystem that ensures that data can deliver on their potential and that laws, regulations, and policies are effectively enforced. While there is no single institutional blueprint for the implementation of data governance frameworks, common challenges include capacity and resource constraints, lack of institutional autonomy, difficulties adopting a data-driven culture, and problems of coordination across stakeholder groups.

Figure 3 The 2021 WDR Data governance framework



Source: World Bank 2021.

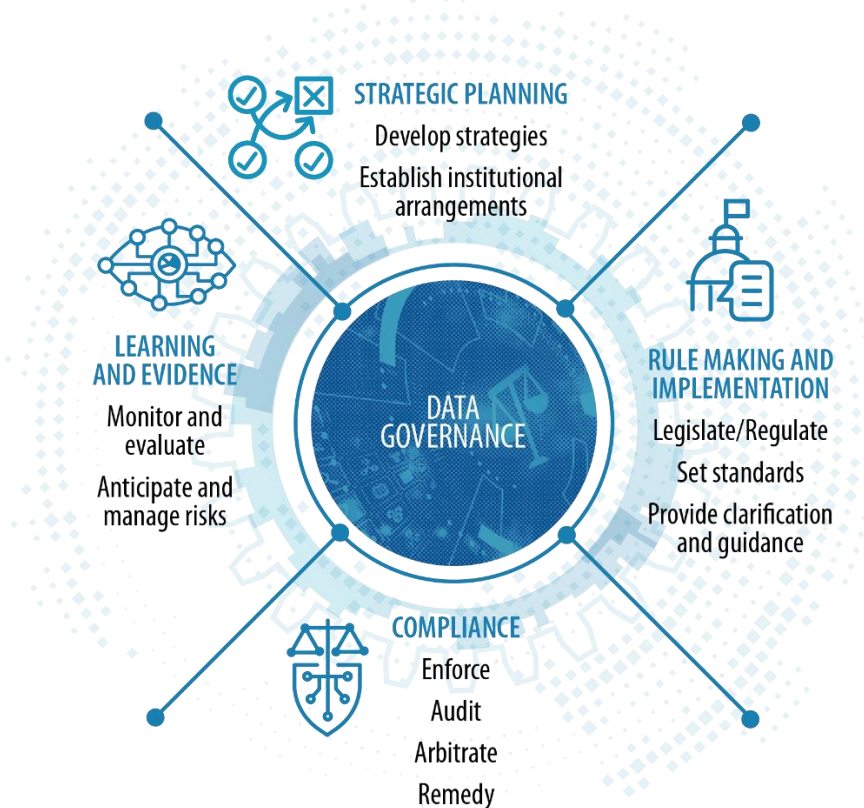
While data governance frameworks are rooted in the domestic environment, data are not typically contained within national borders. The cross-border nature of data infrastructure, the market power of data-driven global businesses, questions over how to treat cross-border data

flows in trade, or how to allocate taxation rights for data transactions; all these issues underscore **the importance of cross-border cooperation in addressing common data governance challenges**. More specifically, international cooperation on standards and guidelines for statistical activities can contribute to cross-country benchmarking and assessment of national/regional strengths and weaknesses.

Functions of data governance Frameworks

The 2021 WDR groups the functions of data governance into four thematic clusters: **strategic planning; rule making and implementation; compliance; and learning and evidence** (as illustrated in figure 4). Data governance frameworks help to safely realize greater social value from data through strategic planning and institutional arrangements that allow the general principles of the social contract for data to be implemented in practice. The mechanisms through which strategies become actionable within data governance frameworks include legislating and regulating, setting standards, and providing clarity and guidance. To ensure implementation is effective, data governance frameworks use enforcement, audits, arbitration (to deal with questions not answered by existing rules) and remedies (to correct or compensate for breaches). Finally, to promote learning, continuous improvement, and innovation, data governance frameworks employ both backward-looking monitoring and evaluation, as well as forward-looking horizon scanning and scenario planning.

Figure 4 The 2021 WDR functions of health data governance frameworks



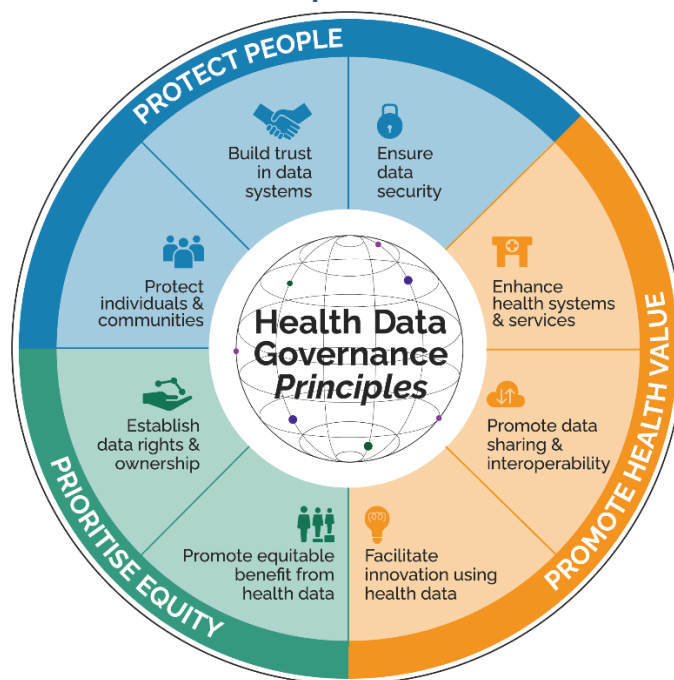
Source: World Bank 2021.

PAHO highlights the following functions for data governance frameworks (PAHO 2021a): defining accountabilities, prioritizing investment requirements, establishing policies, implementing processes, setting standards, managing risks, and monitoring performance related to data throughout its life cycle.

Implementing a National Health Data Governance Framework

PAHO recommends that **any organization that collects, manages, or uses health data should implement data governance practices** (PAHO 2021a). Because so many different organizations are involved in the collection, management, and use of data concerning health, it is crucial that central and subnational governments act as stewards, working at a higher level to align disparate data governance practices. To achieve this, countries should design and implement national health data governance frameworks and, whenever possible, align these across sectors and at the international level.

The Health Data Governance Principles⁵ (figure 5)—a comprehensive, **global set of principles to guide the governance of health data** across public health systems and policies—may be helpful in providing a high-level framework for the design and implementation of a national health data governance framework (and eventually align them globally). They have been endorsed by the World Bank Group, among many other organizations. The principles are meant to inform and strengthen governance models, instruments, treaties, regulations and standards across countries and regions around a shared vision of equitable health data governance. They are designed to complement and reinforce one another (they are not weighted or listed in any order of priority) and are clustered around three interconnected objectives (see illustration below): protecting people—as individuals, as groups, and as communities; promoting health value—through data sharing and innovative uses of data; and prioritizing equity—by ensuring equitable distribution of benefits that arise from the use of data in health systems.

Figure 5 The Health Data Governance Principles

Source: The Health Data Governance Principles are available from <https://healthdataprinciples.org/principles>.

The design and implementation of a national health data governance framework should be well-aligned with the Principles for Digital Development⁶, specifically: designing with the user; designing for scale; being data driven; using open standards, open data, open source, and open innovation; addressing privacy and security; and being collaborative.

The 2016 OECD Council Recommendation on Health Data Governance provides **a roadmap towards more harmonized approaches to health data governance across countries** (OECD 2022c). It recommends that countries implement national health data governance frameworks to encourage the availability and use of personal health data to serve health-related public interest purposes while promoting the protection of privacy, personal health data and data security. The recommendation also urges countries to engage in cross-border cooperation, including developing mechanisms to enable the efficient exchange and interoperability of health data, and encourages non-governmental organizations to follow the recommendation. To help countries achieve all this, the recommendation sets out 12 key principles, according to which national health data governance frameworks should provide for:

- **Engagement and participation of all relevant stakeholders** in the development of a national health data governance framework
- **Co-ordination within government and co-operation among organizations** processing personal health data to encourage common data-related policies and standards
- Reviews of the **capacity of public sector health data systems** to serve and protect public interests

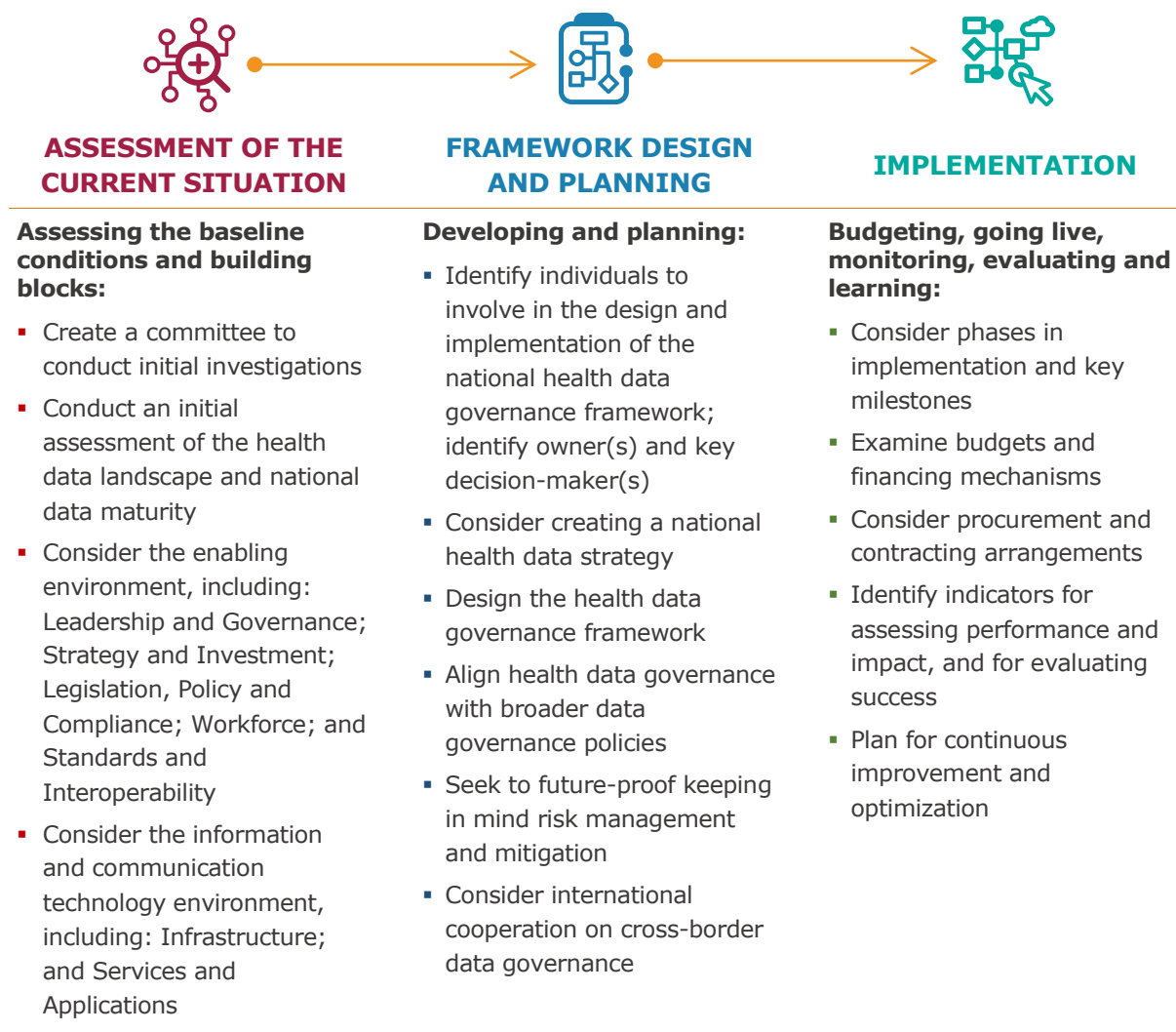
- **Clear provision of information** to individuals about the processing of their personal health data including notification of any significant data breach or misuse
- The **processing of personal health data by informed consent** and appropriate alternatives
- The **implementation of review and approval procedures** to process personal health data for research and other health-related public interest purposes
- **Transparency through public information** about the purposes for processing of personal health data and approval criteria
- **Maximizing the development and use of technology** for data processing and data protection
- Mechanisms to **monitor and evaluate the impact of the national health data governance framework**, including health data availability, policies and practices to manage privacy, protection of personal health data and digital security risks
- **Training and skills development** of personal health data processors
- Implementation of **controls and safeguards within organizations processing personal health data** including technological, physical, and organizational measures designed to protect privacy and digital security
- Requiring that organizations **processing personal health data demonstrate that they meet the expectations** set out in the national health data governance framework

There are multiple sets of health data governance principles, frameworks, and toolkits available (see table in annex). Task Teams advising clients on the design and implementation of health data governance frameworks could consider exploring one or more of these principles, frameworks, and toolkits, after reading this implementation know-how brief.

Key Steps in Implementing Health Data Governance Frameworks

Generally, there are key steps when designing and implementing, or reviewing existing, national health data governance frameworks. These elements can be grouped into three broad stages: an initial assessment of the current situation; a planning and design stage based on the baseline conditions and building blocks; and finally, execution of the plan through budgeting, implementation, monitoring, evaluation, and continuous learning.

Figure 6 Key steps/Considerations when implementing national health data governance frameworks



Assessment of the Current Situation

It is best to **start with an assessment of the health data landscape and data maturity at national level**, which is in line with the Principles for Digital Development. In this first step, the Task Team and the client(s) work together to determine what the assessment will accomplish and how its results will be used to inform the design and implementation of a national health data governance framework. Creating a committee to conduct the initial investigations is advisable.

The **health data landscape assessment** should help identify public and private sources of data concerning health, the data stewards responsible for managing and ensuring access to health data, the different types of health data users, and the relationships between them⁷. It is important to consider the private sector, as it will likely be a key player in many countries' health data landscape. Regardless of how the assessment is conducted, the WHO/ITU building

blocks for electronic/digital health (see figure 6 and table 2) are useful for framing questions and objectives. Task Teams should seek and review previous assessments (including broad digital health maturity assessments) to fill gaps and achieve efficiencies (i.e., to avoid conducting unnecessary duplicative assessments).

Table 2 Considerations on digital health building blocks and health data governance

Building block: Legislation, policy, and compliance

- What policies are in place regarding the sharing of data concerning health? Are there consent mechanisms?
- Are there laws, regulations, or guidelines to ensure data privacy and data protection?
- Are there policies and procedures for secondary uses of health data?

Building block: Leadership and governance

- Is there a basic level of political stability in the country/region? How would this affect data governance promotion?
- What are the institutions involved in governing personal data and data concerning health?
- Is there cross-border cooperation on (health) data governance?

Building block: Interoperability and standards

- Are there registry services in place? Do all patients, health care professionals and facilities have a unique identifier?
- Are there mechanisms for enabling data transfer and exchange between health care providers and government?
- Are medical terminologies and coding systems in use?

Building block: Workforce

- Is there adequate staffing? Are health care professionals under pressure from multiple demands on their time?
- Is there appropriate training and skills development in privacy and security for staff processing personal health data?
- Do health organizations have designated employees to coordinate and be accountable for data security?

Building block: Strategy and investment

- Are there sufficient financial resources for all health organizations to implement data governance practices?
- Given the enabling environment and existing infrastructure, how could data governance affect health inequities?
- Are there well-funded mechanisms for monitoring the effective use of health data governance practices?

Table continued...

Table 2 Considerations on digital health building blocks and health data governance (continued)**Building block: Infrastructure**

- Is there an inventory of health databases and registries?
- Is current access to electricity and internet connectivity sufficient to ensure data use benefits all?
- Are privacy-enhancing technologies in use? Are these technologies widely available to all?

Building block: Services and applications

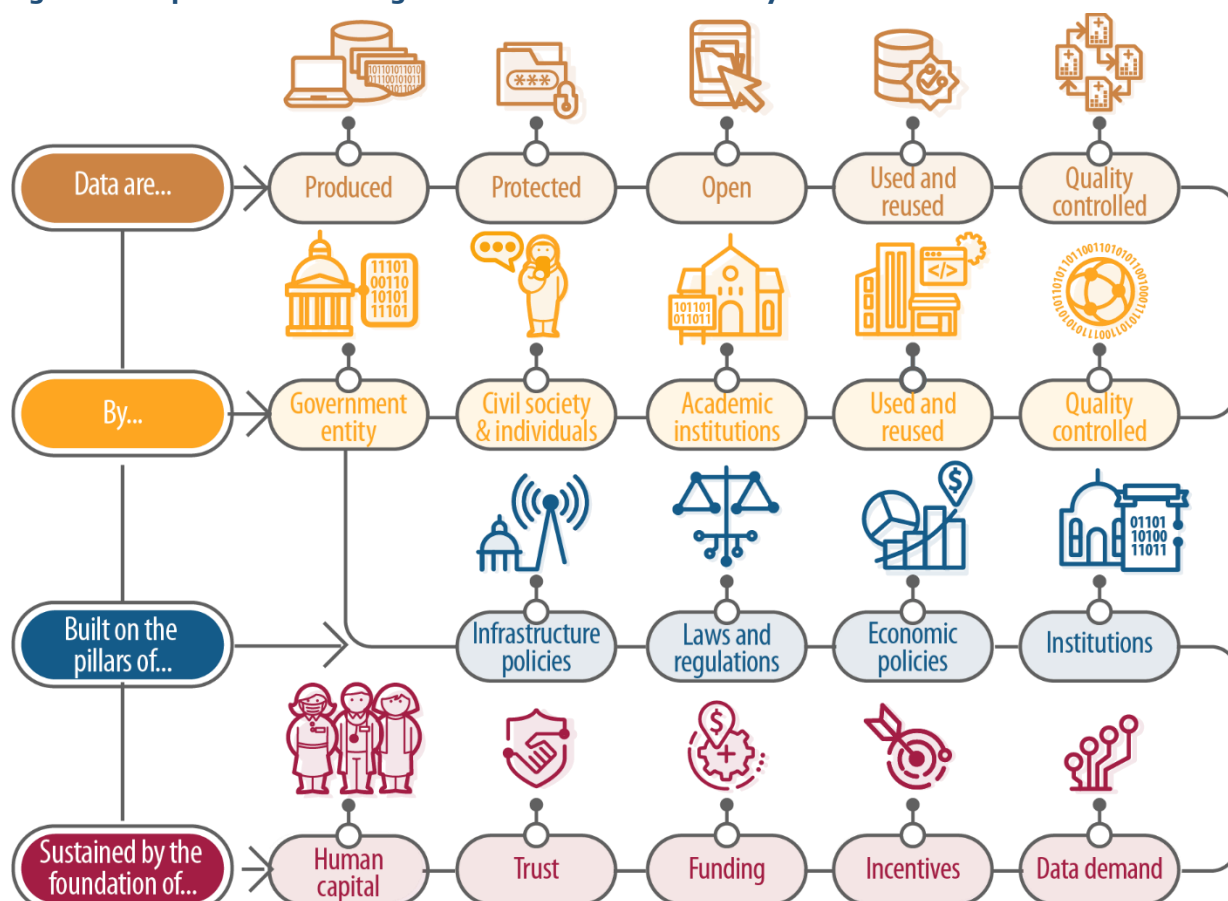
- How are existing software applications making use of health data? Do they protect privacy? Are they secure?

Source: Based on World Health Organization and Union 2012; PAHO 2021b; OECD, 2016.

Note: there is some overlap between categories (e.g., workforce issues are also often legislation and policy issues). According to the World Bank ID4D project, *data privacy* is the right to have control over how personal information is collected and used, while *data protection* focuses on protecting data from malicious attacks and the exploitation of stolen data for profit (while security is necessary for protecting data, it's not sufficient for addressing privacy).

The 2021 WDR proposed a **data maturity model to help countries assess progress** towards an integrated national data system (figure 7 shows what an integrated national health data system could look like, and how a health data governance framework would fit in it; see also annex for a description of the data maturity model). Countries in the initial stages of data maturity would benefit most from establishing the foundations for health data governance, including focusing on: policies and strategies for data governance; technical capacity; and data literacy. Countries that are more advanced can focus on data flows within the national data system, by promoting: interoperability and secure exchange of data. Countries at the highest levels of maturity would benefit from optimizing the system through better coordination and alignment across all stakeholders, including from the private and international sectors.

Figure 7 Depiction of an integrated national health data system



Source: World Bank 2021.

At the institutional level, a **baseline assessment of the capabilities of existing institutions** to facilitate the secure generation and flow of data among all data producers and users could spur the development of institutional arrangements that promote the production and flow of data between actors (World Bank 2021). The analysis should distinguish between the stated function of institutions and what they deliver in practice.

The results of the initial assessments of the health data landscape and the basic building blocks of electronic/digital health provide crucial inputs into the development and implementation of a national health data governance framework. Among other things, these **initial assessments will provide goalposts for what is possible to achieve through a health data governance framework**, who are the key players that need to be involved throughout to ensure success, what key investments and institutions are needed, and how long will it take to start seeing the framework's benefits in practice.

It is **crucial to systematically address challenges arising from these initial assessments and to temper expectations** of what a health data governance framework can achieve when there are deficiencies in the basic building blocks of digital health. Low-income countries typically have poor infrastructure (lack of stable electricity, unreliable Internet

connectivity, inadequate computer equipment), limited technical support, low computer skills and training, and insufficient funding. The design and implementation of health data governance frameworks should take these challenges into account, for example by making initial investments in health data infrastructure.

Framework Design and Planning

Based on the results of the initial assessments, especially the assessment of the health data landscape, the next step is to identify the individuals (or organizations) that should be involved in the design, planning, and implementation of a national health data governance. The solution owner and the decision-maker are especially important to pinpoint, to ensure strong leadership and commitment. Given the broad scope of health data governance, task forces, committees, and consultative bodies may be formed to better tackle different dimensions in detail. The health data governance framework program could include multiple teams, such as a planning task force, a steering committee, and technical working groups and sub-committees focusing on specific topics, like data protection, data infrastructure, workforce, cross-sector, and cross-border issues, etc. **The objective is to achieve participation, alignment, and coordination across a diversity of stakeholders.** This is essential to achieving buy-in and ownership from all stakeholders, and to start building up trust.

Once key stakeholders have been identified, and teams have been assembled, the next step is to **consider developing a national health data strategy** in line with the country's priorities for data across all sectors, as well as any existing broader digital strategies (including digital health strategies). All strategies should set clear targets and action plans to promote effective implementation, identifying institutional arrangements and mapping governance functions to existing or new institutions (World Bank 2021). The main objective of the national health data strategy is to achieve an integrated national health data system.

The next step is to **design the health data governance framework**, meaning to decide on its principles, objectives, elements, and institutions. The sets of health data governance principles, frameworks, and toolkits already discussed above are helpful in guiding these decisions. The Health Data Governance Principles provide ideas for what should be included in national health data governance frameworks (see table 3).

Table 3 Health data governance principles

Protect people	
Protect individuals and communities	<p>Health data governance must protect individuals, groups and communities against harm and violations at every stage of the data lifecycle. It should balance protection and rights with the societal value of data use for health.</p> <ul style="list-style-type: none"> ▪ Address individual and collective risk ▪ Collect data with a defined purpose ▪ Collect personal or sensitive data only when necessary and with informed consent ▪ Use secure data collection and storage mechanisms

Table continued...

Table 3 Health data governance principles (continued)

Protect people (continued)	
Protect individuals and communities	<ul style="list-style-type: none"> Use de-identification and anonymization Define inappropriate uses of health data Institute safeguards against discrimination, stigma, harassment, and bias Provide guidance specific to marginalized groups and populations
Build trust in data systems	<p>Health data governance should reinforce trust in data systems and practices.</p> <ul style="list-style-type: none"> Align with best practices for data protection and privacy Ensure consent is informed and understood in all its complexities Obtain collective consent where appropriate Define concrete exceptions to informed consent Ensure data quality, availability, and accessibility Reinforce health data governance with evidence Establish transparent and accessible processes and systems Institute feedback and accountability mechanisms
Protect people	
Ensure data security	<p>Processes for collecting, processing, storing, using, sharing, and disposing data should all employ robust security mechanisms</p> <ul style="list-style-type: none"> Require strong technical security measures for data processing Mitigate risks related to security threats. Ensure transparency around data breaches. Consider federated data systems
Protect health value	
Enhance health systems and services	<p>Health data governance should enhance health system efficiency and resilience, improve health access, and advance health equity towards universal health coverage</p> <ul style="list-style-type: none"> Evaluate the benefits of health data Use data to enhance health services for individuals and communities Encourage a culture of data-led insights and action Address health system efficiency, effectiveness, and resilience Strengthen community ownership of health data Enable and empower frontline health workers
Promote data sharing and interoperability	<p>Data collection and sharing is a prerequisite for creating value from health data but must be done in ways that support equity and human rights.</p> <ul style="list-style-type: none"> Define common data structures across health systems Define multiple levels of data access

Table continued...

Table 3 Health data governance principles (continued)

Protect health value (continued)	
Promote data sharing and interoperability	<p>Data collection and sharing is a prerequisite for creating value from health data but must be done in ways that support equity and human rights.</p> <ul style="list-style-type: none"> Use common definitions and global standards Support multi-sector partnerships
Facilitate innovation using health data	<p>Governance approaches must enable innovation and flexibly accommodate new technologies and uses of data</p> <ul style="list-style-type: none"> Apply health data governance to emerging technologies Address the use of non-health data in health contexts Build public health data infrastructure Employ policy innovation
Protect equity	
Promote equitable benefits from health data	<p>Equity in health data governance must ensure equitable representation in data of all individuals, groups and communities; extend to include meaningful participation of all groups in decision-making; and equitable access to data-generated health value about health data systems</p> <ul style="list-style-type: none"> Represent all groups and populations equitably in data Consider the unique needs of marginalized groups and populations Mitigate data bias Use accessible language and plug knowledge gaps Implement inclusive data feedback mechanisms Promote equitable impact and benefit
Establish data rights	<p>Health data governance should be rooted in strong and clear data-related rights.</p> <ul style="list-style-type: none"> Apply a human rights lens to health data governance Define clear governance roles and responsibilities Codify data rights Extend data rights to products and services Develop health data trusts and health data cooperatives Employ participatory data governance mechanisms Connect to broader accountability mechanisms

Source: Based on the Health Data Governance Principles, available from <https://healthdataprinciples.org/principles>

Note: the World Bank does not adhere to the notion of personal data “ownership” and considers it incompatible with a rights-based approach to personal data protection; see spotlight 6.2 in World Bank 2021. As stated by UNCTAD, “rather than trying to determine who “owns” the data, what matters is who has the right to access, control and use the data” (UNCTAD 2021).

Health data governance relies on a comprehensive legal and regulatory framework that includes both safeguards and enablers to the collection, use and reuse of health data,

developed within a specific context and in consultation with relevant stakeholders. The 2021 WDR recommends that a holistic legal and regulatory framework include⁸:

Safeguards

- Adoption and implementation of **personal data protection legislation** (applying to personal health data) following a rights-based approach
- Introduction of **meaningful consent models**, fit for the digital age, including new models that shift responsibility from data subjects to collectors and users of data
- Protection against **reidentification of individuals** through, for example, linking datasets, and protection against *group discrimination* using non-personal data
- Adoption of **data protection by design and by default**, coupled with and enabled by privacy-enhancing technologies
- Prioritization of **cybersecurity measures within legal frameworks** in a way that balances security concerns with other fundamental rights



Enablers

- A robust but flexible **foundation for electronic transactions**, granting legal equivalence between analog and digital transactions, with limited exceptions
- Adoption of **open data policies**, so that data are open by default and easy to access, including by limiting or even eliminating charges for end users of public intent data
- Reasonable and consistent application of **data classification norms**, to support open data
- Adoption of **open standards and sharing-friendly licenses**, to support open access
- Access to **information provisions**, including proactive and transparent disclosure of non-sensitive data with only necessary and proportionate exceptions to disclosure
- Promotion of **interoperability of data and systems**, enabling the sharing of data
- Support for **data portability**, requiring data to be in a structured, commonly used, and machine-readable format
- Incentives for **sharing private intent data**, by promotion of data sharing agreements and enhancing intellectual property rights



It is **important to be forward-looking in the design and revision of national health data governance frameworks** to future-proof them as much as possible. Emerging technologies – from artificial intelligence to the Internet of Things – are enabling more extensive data collection and use, and cross-border data flows are on the rise. Privacy-by-design is an approach that embeds data privacy and security into information technology systems architecture and functionalities, so that risks are anticipated and mitigated (OECD 2022c). Cybersecurity is crucial to achieving privacy-by-design and goes hand in hand with data governance practices (understanding the data landscape, the actors and the uses of data are key to designing effective cybersecurity practices).

A 2022 OECD Data Governance Guide for Policy Makers provides **a checklist designed to help policy makers assess whether data governance policies address key policy tensions and achieve related objectives effectively** (see table 4). The first column provides specific questions relating to each tension (in headers) and the second column highlights promising policy approaches.

Table 4 OECD checklist for data governance policies

Balancing data openness and control while maximizing trust	
Does the policy foster a culture of risk management and transparency across the data ecosystem?	Recommend the systematic implementation of risk management measures throughout the data value cycle. Promote transparency, considering the risk of information overload and other cognitive biases.
Does the policy leverage the full spectrum of the data openness continuum?	Design data governance arrangements that leverage different possible degrees of data openness, striving to be as open as possible and as closed as necessary.
Does the policy provide options and tools to enhance users' agency and control over data?	Formulate different consent models that allow individuals to exercise control while enabling business opportunities to benefit from data openness. Empower stakeholders through appropriate mechanisms such as data portability.
Does the policy support adoption of technological and organizational measures to maximize trust?	Provide data access control mechanisms, data intermediaries (e.g., data trusts, data commons, Personal Information Management Systems) and privacy-enhancing technologies.
Does the policy enhance the interoperability of data across organizations, including within and across the public and private sectors?	Provide data together with any required complementary resource, including metadata, documentation, data models and algorithms.
Managing overlapping and potentially conflicting interests and regulations	
Does the policy identify and consider the contribution of different stakeholders in the data value cycle, including by promoting multi-stakeholder engagement?	Map impact on different stakeholders at different phases of the data value cycle to assess whether it reflects reasonable expectations and the public interest. Engage relevant stakeholders in the data ecosystem to identify their different interests and roles in data-driven value creation through open and inclusive processes.
Does the policy support cross-agency co-operation to help reconcile different domestic frameworks affecting data governance?	Encourage co-operation across the various regulatory and policy areas, including competition, privacy, consumer protection, as well as sector-specific regulators.

Table continued...

Table 4 OECD checklist for data governance policies (continued)

Managing overlapping and potentially conflicting interests and regulations (continued)

Does the policy leverage contract to clarify and strengthen data governance?	Collaborate with the private sector on voluntary guidance, codes of conduct, ethics frameworks and model contracts. Use public procurement to promote good data governance standards.
Does the policy promote international regulatory co-operation to reconcile data governance across countries and enable cross-border data flows with trust?	Promote interoperability of data governance frameworks to enhance cross-border data flows while protecting legitimate interests. Promote continued dialogue and international co-operation on ways to foster data access and sharing across countries.

Incentivizing investments in data and complementary resources

Does the policy promote appropriate knowledge and skills for responsible data sharing and use?	Identify gaps and formulate strategies to develop and maintain the skills and infrastructures needed. Establish partnerships and data analytic support centers for development of data-related skills and the supply of data analytic expertise.
Does the policy foster investments in and adoption of financially viable information and communication technology infrastructures for data openness?	Promote adoption of data storage, processing, and analytic services, especially for small and medium-sized enterprises. Promote adoption of new business and revenue models needed for data openness infrastructure. Promote adoption of shared data infrastructures. (e.g., interoperability buses) in the public and private sector and of the “once-only” principle in the public sector.
Does the policy foster competition in data-driven markets and address barriers to entry for new firms?	Assess the contribution of data to market power. Consider asymmetric approaches to ensure that competition measures address large incumbents and do not create barriers to entry for new firms.
Does the policy promote standardized approaches for evaluating the social and economic value of data?	Support promising approaches for valuing data, including in the context of the System of National Accounts, and including efforts to measure their social value.

Source: OECD 2022a.

Because of the characteristics of data in general (e.g., non-rivalry, externalities, co-generation, etc.), and the many sources of data concerning health, it is **important to take a whole-of-government approach when designing and implementing a national health data governance framework**⁹. Most of the policy questions presented in the table above are not sector-specific. Having a national data strategy (not specific to health) can help promote a holistic approach to data governance policies across sectors (naturally, the national health data strategy should be well-integrated with the national data strategy). At the very least, it is crucial to note that health data may be governed by multiple, and sometimes overlapping,

policy and regulatory frameworks (e.g., privacy and personal data protection frameworks, open government data regulations, open science regulations, and even international regulations like the GDPR). Health policy makers should be aware of possible overlap and conflict between different policies and frameworks so that a national health data governance framework provides legal certainty for stakeholders involved in health. Involving experts in data governance from other sectors in the design of the national health data governance framework is advisable.

Beyond aligning and coordinating national policies and frameworks for data governance across sectors, and in the interest of future-proofing national health data governance frameworks, it is recommended that countries adopt an international approach as well. The reality is that data, even personal data concerning health, increasingly know no borders. To realize the benefits of data for all, policy makers should **ensure that the design of national health data governance frameworks benefits from international cooperation and dialogue.**

Interoperability of privacy regulations is becoming a key concept for countries seeking to reconcile differences in data governance. For countries looking to contribute to a global approach to health data governance and cross-border data flows, the United Nations Conference on Trade and Development (UNCTAD) has identified the following key policy areas and priorities (UNCTAD 2021):

- Developing a common understanding about definitions of key data-related concepts
- Establishing terms of access to data
- Strengthening the measurement of the value of data and cross-border data flows
- Dealing with data as a (global) public good
- Exploring emerging forms of data governance (such as data cooperatives, data commons, data collaboratives, data trusts, data fiduciaries, indigenous data sovereignty and data marketplaces)
- Agreeing on digital and data-related rights and principles
- Developing data-related standards
- Increasing international cooperation related to platform governance, including with regard to competition policy and taxation in the digital economy

Implementation, Budgeting, Monitoring & Evaluation

Implementation of a national health data governance framework is **likely to require significant financial and human resources.** For countries without a health data governance framework, the process of designing and implementing a new framework will probably be long and complex, involve many stakeholders and require much of their time. In lower resource contexts, it is plausible that major investments in basic building blocks (e.g., supply of electricity or broadband connectivity, capacity building) will be needed before the benefits of a national health data governance framework can start to be felt by the entire population. New laws, regulations, and institutions may be needed, and these will depend on there being experts and professionals with the required skills in the country.

Translating principles in national health data governance frameworks to organizational data governance practices

might require the creation of new roles and responsibilities in health care organizations, investments in infrastructure (hardware and software), training of frontline staff, and possibly engagement with patients and their families. It is important to consider that many health care providers will not have the resources to implement advanced data governance practices. Financial incentives to promote implementation should be included in the national budgeting process. If appropriate, incentives should be tied to performance metrics to ensure good value for money (e.g., use of certified privacy enhancing technologies).

Implementing data governance practices for the first time is **only the beginning of a journey of continuous improvement and optimization**. Monitoring, evaluation, and learning are crucial to ensuring that practices are achieving their intended goals, are comprehensive, and are not leading to unintended consequences. A first step in this process is determining what success looks like, how it will be measured, and what are the key indicators that need to be collected, potentially for the first time ever. Monitoring and evaluation should then lead to continuous learning and improvement.

Key Challenges and Pitfalls

Decentralized or federated countries face unique challenges in designing and implementing a national health data governance framework. Because responsibilities for health are shared between the central government and the subnational (regional, municipal, and even metropolitan) governments, the number of stakeholders involved can be very large (for example, in a World Bank project in Vietnam, a major challenge was multi-sectoral involvement in personal data concerning health with the Ministry of Public Security managing citizen data, the Ministry of Justice managing civil registration and vital statistics data, the Ministry of Social Affairs managing health insurance data, and private suppliers managing data generated from wearable devices). In some countries, central governments may not be legally able to effectively enforce the provisions contained in the national health data governance framework and must work with subnational governments to do so. Without coordination and dialogue, it is likely that many data governance frameworks and policies will emerge, increasing the risk of overlap and conflict. This can hinder cross-country data sharing and make it harder to make the social contract for data a reality. Task Teams should consider carefully all the ways in which the decentralized nature of the health care system may affect the design and implementation of a national health data governance framework and adjust client expectations, including in terms of timelines and budgets. Special consideration should be given to disparities (e.g., in wealth and health) between all stakeholders involved.

Challenges to the success of a national health data governance framework

Legal or policy barriers to sharing data among public authorities

Legal or policy barriers to public authorities undertaking data linkages

Legal or policy barriers to public authorities extracting data from digital health records

Legal or policy barriers to sharing de-identified data with university or non-profit research organizations

Legal or policy barriers to sharing de-identified data with a foreign government or a foreign researcher

Lack of person identifiers to link the data

Concerns with the quality of the data that limit their usefulness

Lack of resources or technical capacity to process data or make data accessible for research and statistics

Limited involvement of all stakeholders, especially civil society

Lack of resources of technical capacity to enforce provisions in the national health data governance framework

Poor information technology infrastructure and inequities in access and use of (digital) health services

Source: expanded from OECD 2022c.

Other resources

American Health Information Management Association Healthcare Data Governance: <https://www.ahima.org/media/pmcb0fr5/healthcare-data-governance-practice-brief-final.pdf>

Health Data Collaborative Data and Digital Governance: <https://www.healthdatacollaborative.org/our-response/working-groups/data-and-digital-governance/>

United Nations System Chief Executives Board for Coordination International Data Governance – Pathways to Progress: <https://unsceb.org/international-data-governance-pathways-progress>

Canadian Institute for Health Information Health Data and Information Governance and Capability Framework: <https://www.cihi.ca/sites/default/files/document/health-data-info-capability-framework-en.pdf>

Open Data Institute (ODI) Health Data Governance Playbook: <https://open-data-institute.gitbook.io/data-governance-playbook/>

ODI's Data Ecosystem Mapping: <https://theodi.org/article/data-ecosystem-mapping-tool/>

CABI, ODI and Bill and Melinda Gates Foundation Data Sharing Toolkit's Checklist on How to Create a Data Inventory: <https://gatesopenresearch.org/documents/5-56>

Besides the OECD Council Recommendation on Health Data Governance (already cited above), other OECD Council Recommendations relating to data governance include:

The [OECD Recommendation of the Council on Enhancing Access to and Sharing of Data](#) provides the foundation of the OECD approach to data governance and is the most recent and overarching instrument in this field.

The [OECD Recommendation of the Council concerning Guidelines Governing the Protection of Privacy and Transborder Flows of Personal Data](#) launched in 1980 (revised in 2013) was the first internationally agreed-upon set of privacy principles.

The [OECD Recommendation of the Council concerning Access to Research Data from Public Funding](#) provides guidance on enhancing access to research data and other research-relevant digital objects from public funding.

The [OECD Recommendation of the Council on Digital Government Strategies](#) and the [OECD Recommendation for Enhanced Access and More Effective Use of Public Sector Information](#) support the development and implementation of digital government strategies and the access/use of public sector information and data.

Relevant World Bank Case Studies



Relevant External Case Studies

Digital Health Technology - Global Case Studies of Health Care Transformation:

<https://www2.deloitte.com/us/en/insights/industry/health-care/digital-health-technology.html>

National Health Data Governance Checklist

This checklist is for national and subnational levels; it can be printed as a stand-alone document.

ASSESSING THE CURRENT SITUATION

The baseline conditions and building blocks

- Create a committee to conduct initial investigations
- Conduct an initial assessment of the health data landscape
- Consider the enabling environment, including: Leadership and Governance; Strategy and Investment; Legislation, Policy and Compliance; Workforce; and Standards and Interoperability
- Consider the information and communication technology environment, including: Infrastructure; and Services and Applications

FRAMEWORK DESIGN AND PLANNING

Developing and planning

- Identify individuals to involve in the design, management, and implementation of the national health data governance framework; identify owner(s) and key decision-maker(s)
- Create a national health data strategy
- Design the health data governance framework
- Align health data governance with broader data governance policies
- Seek to future-proof, keeping in mind risk management and mitigation
- Consider international cooperation on cross-border data governance

IMPLEMENTATION

Budgeting, going live, monitoring, evaluating and learning

- Consider phases in implementation and key milestones
- Examine budgets, financing mechanisms, procurement and contracting arrangements
- Identify indicators for assessing performance and impact, and for evaluating success
- Plan for continuous improvement and optimization

Project level considerations

The checklist below is based on a checklist included in the Health Data Governance Playbook for Non-Technical Leaders, published in February 2022. The playbook was created by the Open Data Institute (ODI) and was commissioned by Roche¹⁰.

How to Support Trustworthy Data Sharing: Checklist

Setting up and supporting trustworthy data sharing systems is a complex process. When embarking on a health care project that will be collecting, using, or sharing data, consider the following elements:

- 1. Define the data to be collected, used and shared.** To get started, it is useful to conduct an inventory of the data assets and infrastructure you will draw on. Key actions to take:
 - Define the data you will be collecting, using and sharing
 - Define who will be involved and what role they will play
 - Assess data policies and processes related to this assets
 - Identify data standards and data models being used (planned) to access, use and share this data
- 2. Map the health data ecosystem.** Engage with various people and organizations and enlist their support. It can be helpful to visualize this to consider priority relationships to build. *Key actions to take:*
 - Map the current state of the health data ecosystem: who are the people and organizations and where are the current data and value exchanges between them?
 - Map the desired state: how will relationships, data and value exchange look when the data ecosystem is matured in the way you are working towards?
- 3. Consider legislation, regulations, and cultural values for sharing health data.** Make sure all data being accessed, used, and prepared for sharing is permitted under data privacy, intellectual property, and other legislation. Data use should also match community expectations and norms related to societal values around the use and sharing of health data. *Key actions to take:*
 - Consider the legal, regulatory and policy context
- 4. Manage risks around personal data.** Consider how to maximize the use of personal data while protecting the rights of individuals and avoiding harmful impacts. There are particular concerns that need to be addressed when handling health data, as it often contains personal and sensitive information about individuals. *Key actions to take:*
 - Assess whether the data you are using has personally identifiable information
 - Identify data protection officers in the organization with expertise on how to manage personal data

- Assess the potential negative impacts from using health data
- Think of actions to minimize the risk of personal data exposure (e.g., through techniques like data minimization and data anonymization)

5. Set up successful data sharing partnerships. When deciding on sharing data with other people and organizations in the health data ecosystem, a variety of agreements and approaches can be used, depending on the nature of the relationship. *Key actions to take:*

- Define what you want to achieve by sharing data
- Identify which principles will guide data sharing
- Define how you will communicate with data sharing partners

6. Make sure data is interoperable. To enable greater reuse and sharing of data, it is important to ensure that data is integrated and can be exchanged through systems and platforms. This means that, when data is collected and managed, it is best if it is organized in a way that enables interoperability. Internally, this can help make better use of data in various contexts, but when preparing data for potential external use, it becomes essential. *Key actions to take:*

- Identify standards and data models that have been used to define the dataset and data fields
- If data is not standardized, evaluate which techniques could be used to standardize data to a single format

7. Select the most appropriate data sharing methods. Select the best methods for establishing data sharing agreements and choose the technology platforms that can facilitate data sharing. *Key actions to take:*

- Identify the data sharing partnership already in place
- Assess what types of data agreements support this type of partnership
- Evaluate whether you can use a standard agreement or do you need to create a bespoke one
- Identify the platform in which data will be stored and made available
- Define types of functionalities data partners will need for accessing and using the shared data

Acknowledgements

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Background on Implementation Know-How Briefs

What is an Implementation Know-How Brief and What is it For?

The World Bank's Digital-in-Health: Unlocking the Value for Everyone report calls for a new digital-in-health approach where digital technology and data are infused into every aspect of health systems management and health service delivery for better patient outcomes. The report proposes ten recommendations across three priority areas for governments to invest in: prioritize, connect and scale. The Implementation Know-How Briefs serve as practical, implementable extensions to the Digital Health Flagship report. The Implementation Know-How Briefs take a practical approach to discussing a topic with the aim of describing the topic, the key terms and technical considerations, guidance on how to start an operational engagement with clients on the topic, relevant checklists (if applicable), links and places to go for help.

The aim of the Implementation Know-How Briefs is to give Task Teams enough information to figure out how a given topic fits into Health, Nutrition and Population (HNP) investments, and what are the right questions to ask. The aim is not to make Task Teams topic experts. The Implementation Know-How Briefs also tackle the dependencies between different topics.

Who is this Implementation Know-How Brief For?

The Implementation Know-How Briefs are focused on World Bank Task Teams, countries, and other organizations involved in implementation of Digital-in-Health activities and extend the discussion on the topics covered in the Digital Health Flagship report.

Who is Responsible for Implementation Know-How Briefs?

Digital Health Flagship Research Program: digitalinhealth@worldbank.org.



Annex 1

Theory of Change

Data Governance in Health Theory of Change



Gaps in governance of data concerning health

- Lack of comprehensive data protection and data privacy regulations and their enforcement
- Potential to increase inequality within and among countries
- Potential for exploitation of individuals and misuse of personal data concerning health
- Potential to increase the propensity for dominant firms to emerge
- Limited or no data to improve health system performance



Implementation of data governance frameworks in health

- Create a national health data strategy
- Design a national health data governance framework
- Align health data governance across sectors and internationally
- Future-proof data governance framework to manage risks and mitigate their impact
- Plan for continuous improvement and optimization, revising framework as appropriate



Outcomes

- Shorter- and medium-term**
- Greater accountability, enhanced trust
 - Better policy making and service delivery
 - Increased business opportunities
 - Improved collection and use of quality data and information
 - Increased investments and donor funding
 - Strengthened collaboration between client countries
- Longer-term**
- Enhanced capacity to develop and execute national digital health strategies



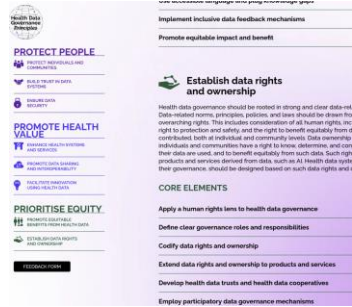

Impact

- Universal and equitable access to affordable, people-centered, and integrated quality care
- Good governance of health systems for sustainable financing and accountability for health outcomes
- Augmented service delivery value chain
- Reinvigorated essential public health functions

Health Data Governance Principles, Frameworks, and Toolkits

There are multiple sets of health data governance principles, frameworks, and toolkits available (see table in annex). Task Teams advising clients on the design and implementation of health data governance frameworks could consider exploring one or more of these principles, frameworks, and toolkits, after reading this implementation know-how brief.

Examples of health data governance principles, frameworks, and toolkits

Resource	Overview, focus and purpose
<p>Health Data Governance Principles Led by Transform Health, 2022</p> <p>Link here</p> 	<p>Countries and regions around the world are instituting health data governance policies and legislation. However, there is not yet a comprehensive, global set of principles to guide the governance of health data across public health systems and policies. The Health Data Governance Principles respond to that need. The Principles are intended as a resource for, and have applicability to, a range of stakeholders involved in the collection and use of health data, including governments, the private sector, international organizations, civil society, among others. All stakeholders – governments, technology companies, and other institutions responsible for collecting and managing health data – are encouraged to endorse and adopt the Principles. The World Bank Group has endorsed the Principles.</p> <p>👍 BEST FOR: high-level guidance, developed and driven by civil society</p>
<p>Recommendation of the Council on Health Data Governance Organisation for Economic Co-operation and Development, 2016</p> <p>Link here</p> 	<p>The Recommendation was adopted by the OECD Council on 13 December 2016, and was welcomed by OECD Health Ministers at their meeting in Paris on 17 January 2017. The Recommendation aims to guide Adherents in setting the framework conditions for enabling the availability and use of personal health data to unlock its potential. In so doing, it also provides a roadmap toward more harmonized approaches to health data governance across Adherents. It was designed to be technology neutral and robust to the evolution of health data and health data technologies.</p> <p>👍 BEST FOR: design of national data governance frameworks</p>

Continued on next page...

Examples of health data governance principles, frameworks, and toolkits (continued)

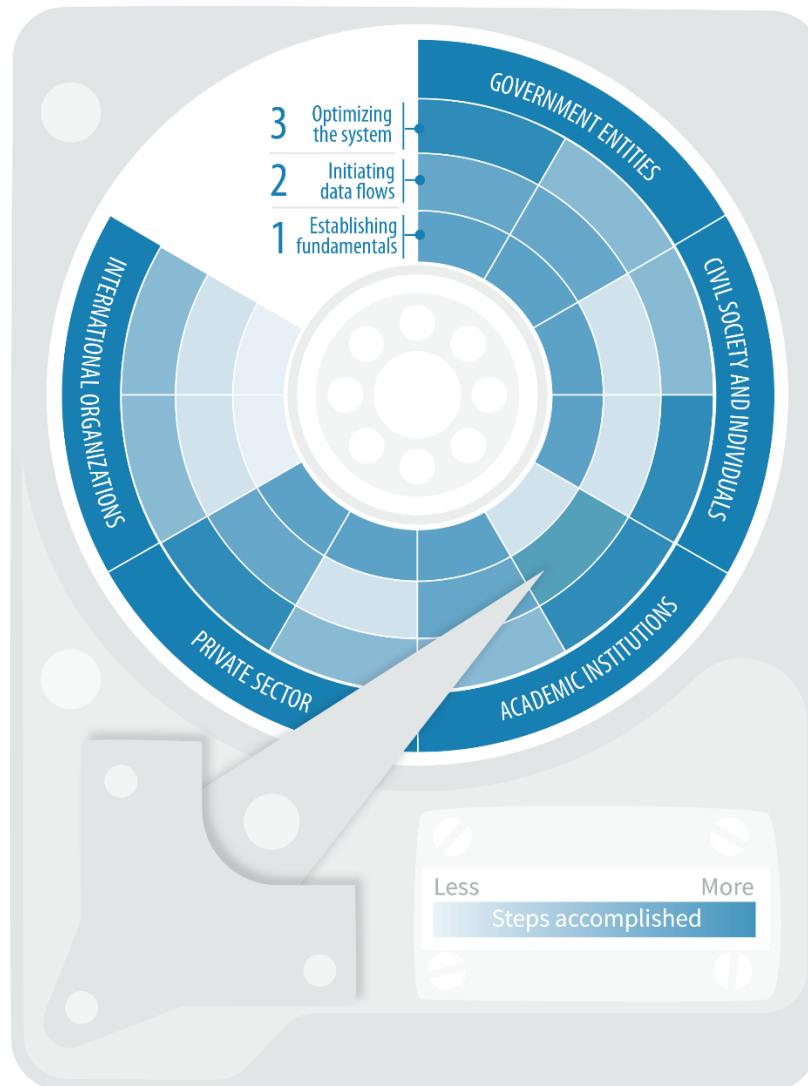
Resource	Overview, focus and purpose
<p>National IS4H Data Governance Framework WHO/PAHO, 2019</p> <p>Link here</p> 	<p>The National Information Systems for Health (IS4H) Data Governance Framework is part of PAHO’s IS4H toolkit. It introduces health data governance frameworks, and supports the creation of a national framework, including guidance on setting premises, assessing existing elements of data management in the country, scope, goal, institutional roles and responsibilities for data management, monitoring and evaluation, and guiding principles.</p> <p>👍 BEST FOR: more detailed guidance at organizational level</p>
<p>WHO Data Principles WHO/Geneva, 2020</p> <p>Link here</p> 	<p>The data principles of the World Health Organization (WHO) provide a foundation for continually reaffirming trust in WHO’s information and evidence on public health. The five principles are designed to provide a framework for data governance for WHO. The principles are intended primarily for use by WHO staff across all parts of the Organization in order to help define the values and standards that govern how data that flows into, across and out of WHO is collected, processed, shared and used. These principles are made publicly available so that they may be used and referred to by Member States and non-state actors collaborating with WHO.</p> <p>👍 BEST FOR: inspiration on high-level principles from leading health agency</p>
<p>Data governance: Driving value in healthcare KPMG International, 2018</p> <p>Link here</p> 	<p>The purpose of this paper is to help demystify the role of data governance in helping health care organizations and systems use data to achieve their full potential. The paper discusses the core data governance capabilities required and outlines a data governance maturity model. Together, these provide the frameworks and initial key steps that can enable health care organizations and systems to begin building capacity, as a foundation for advanced analytics.</p> <p>👍 BEST FOR: subnational and provider-level data governance frameworks</p>

Data Maturity Model

The 2021 WDR data maturity model is used as an organizing framework to help determine the strengths and weaknesses of the existing data system and identify the sequential steps that can be taken to establish an integrated national data system. The model has three levels of data maturity. At low levels, countries should establish the fundamentals of a national data system.

Once the fundamentals are in place, countries should seek to initiate data flows. Only then, at advanced levels of data maturity, the goal is to optimize the system. To illustrate, the figure below shows steps in a data maturity model for a hypothetical national data system. The inner circle is the first stage of maturity, the second the middle stage, and so forth. Darker colors indicate steps accomplished; lighter colors indicate steps not accomplished. Thus, for each stakeholder, segments may be dark or light. In this way, the figure illustrates that countries may be at different data maturity stages at the same time and that some participants may be more integrated than others.

A data maturity model for an illustrative national data system



Notes

- ¹ See Health Data Governance Summit pre-read on the health data landscape available from 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.
- ² See the European Commission's webpage on what is personal data available from https://commission.europa.eu/law/law-topic/data-protection/reform/what-personal-data_en.
- ³ See Recital 35 of the General Data Protection Regulation available from <https://gdpr-info.eu/recitals/no-35/>.
- ⁴ See IBM's webpage on what is data management available from <https://www.ibm.com/topics/data-management>.
- ⁵ The Health Data Governance Principles are available from <https://healthdataprinciples.org/principles>
- ⁶ See the Principles for Digital Development available from <https://digitalprinciples.org/principles/>; the World Bank Group endorsed these principles in 2016.
- ⁷ See Health Data Governance Summit pre-read on the health data landscape available from 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.
- ⁸ See spotlight 6.2 in (World Bank 2021) for a discussion of "ownership" and a rights-based approach.
- ⁹ See (OECD 2022a; 2022b) for more details.
- ¹⁰ The online resource "Health Data Governance: a playbook for non-technical leaders" can be accessed from <https://open-data-institute.gitbook.io/data-governance-playbook/>.

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