



HEALTH DATA
COLLABORATIVE

August 2022 Webinar

Governance of Health Data

GDHF 2022

Global Digital Health Forum

December 5-7, 2022

Virtual (Asia and East Africa time zones) and In-person at the Crystal City Gateway Marriott in Arlington, Virginia



ABSTRACT SUBMISSION CLOSED

INFORMATION ABOUT REGISTRATION WILL BE SHARED SOON

Driving Effective and Equitable Digital Health Innovation

<https://gdhf2022.dryfta.com/>



HEALTH DATA GOVERNANCE

25 Aug 2022

Global Digital Health Network Meeting



Agenda

Introduction: Why is health data governance important? (5 min)	Teddy Berihun , Director of Information Systems, Palladium Group
Health Data Governance Principles (10 min)	Vidya Mahadevan , Co-chair Digital and Data Governance, Health Data Collaborative
Country Perspectives DRC (15 min)	Trad Hatton , MA/MHS, DRC Country Director and Director of Central Africa Regional Hub, PATH Amadou Fall , Technical Advisor, PATH
Country Perspectives Kenya (15 min)	Dr Joseph Sitienei , Head of Health Sector Monitoring, Ministry of Health, Kenya
Introduction to the HDC and moderated Q&A/feedback (15 min)	HDC secretariat
Closing	

Health Data Governance

healthdatapinciples.org

Why is Health Data Governance Important?

- **Increased digitalisation** of health systems has resulting in an exponential **increase in available and accessible health data**
- to ensure that this **data is safe and secure** (and that individuals that the data pertains to are protected), we need better and more equitable **governance of that data**
- HDG supports equitable and **responsible health data management**, while **safeguarding data privacy, ownership, and security**.

Why is Health Data Governance Important?

- Maximise societal benefits and minimise societal risks (OECD, 2015)
- A ‘common framework and good data governance practices underpinned by a globally unifying set of principles’ (WHO, HDG Summit, 2021)
- A new approach to the collection and use of health data [that prioritises] protecting individual rights, promoting the public good potential of such data (Lancet and FT Commission on Governing Health Futures 2030)
- Context of country ownership (HIS Continuum, WHO, 2011)

DEVELOPMENT



200
Contributors

130
Organisations

5 REGIONAL WORKSHOPS
+3 GLOBAL WORKSHOPS

- Driven and developed by civil society - inclusive and consultative, bottom-up process.
- Reflect perspectives and expertise - and ensured meaningful engagement - of diverse stakeholders across geographies and sectors.
 - Eight global and regional workshops, including a youth consultation.
 - One-month public consultation.
 - Over 200 contributors from over 130 organisations.
- Process stewarded by Transform Health and partners.

- The Health Data Governance Principles **strengthen** the health data ecosystem.
 - apply a human rights and equity lens.
 - Universal Health Coverage is at their core.
 - support sustainable and resilient public health systems
 - have a shared vision of equitable health data governance.
 - maximise the public value of health data whilst protecting individual rights.
 - serve as a critical step towards a global framework for health data governance.
 - are applicable to various stakeholders.

The Principles are:

- Designed to complement and reinforce one another.
- Not weighted or listed in any order of priority.
- Supported by core elements that describe how it can be put into practice.

OBJECTIVES

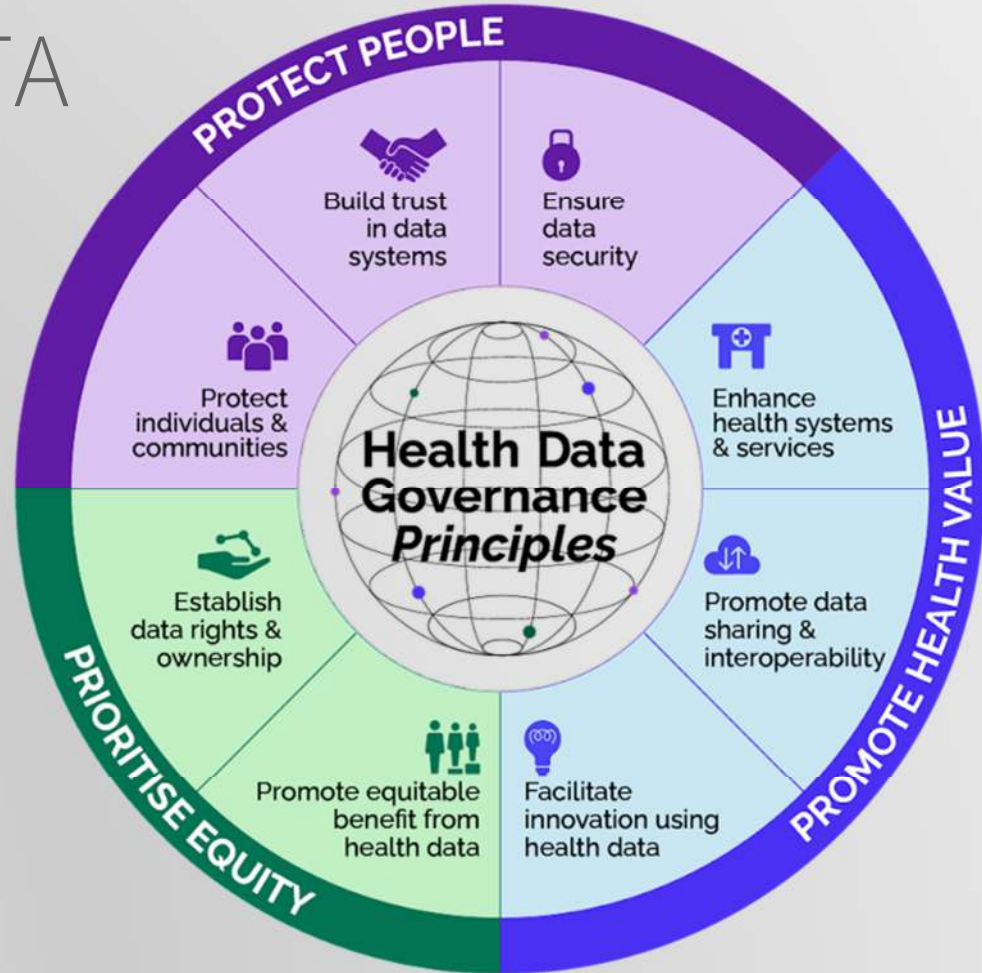
The Principles are clustered around three interconnected objectives:

Protect people – as individuals, as groups, and as communities

Promote health value – through data sharing and innovative uses of data

Prioritise equity – by ensuring equitable distribution of benefits that arise from the use of data in health systems

THE HEALTH DATA GOVERNANCE PRINCIPLES





PROMOTE HEALTH VALUE

- Enhance health systems and services
- Promote data sharing and interoperability
- Facilitate innovation using health data





PROTECT PEOPLE

- Protect individuals and communities
- Build trust in data systems
- Ensure data security



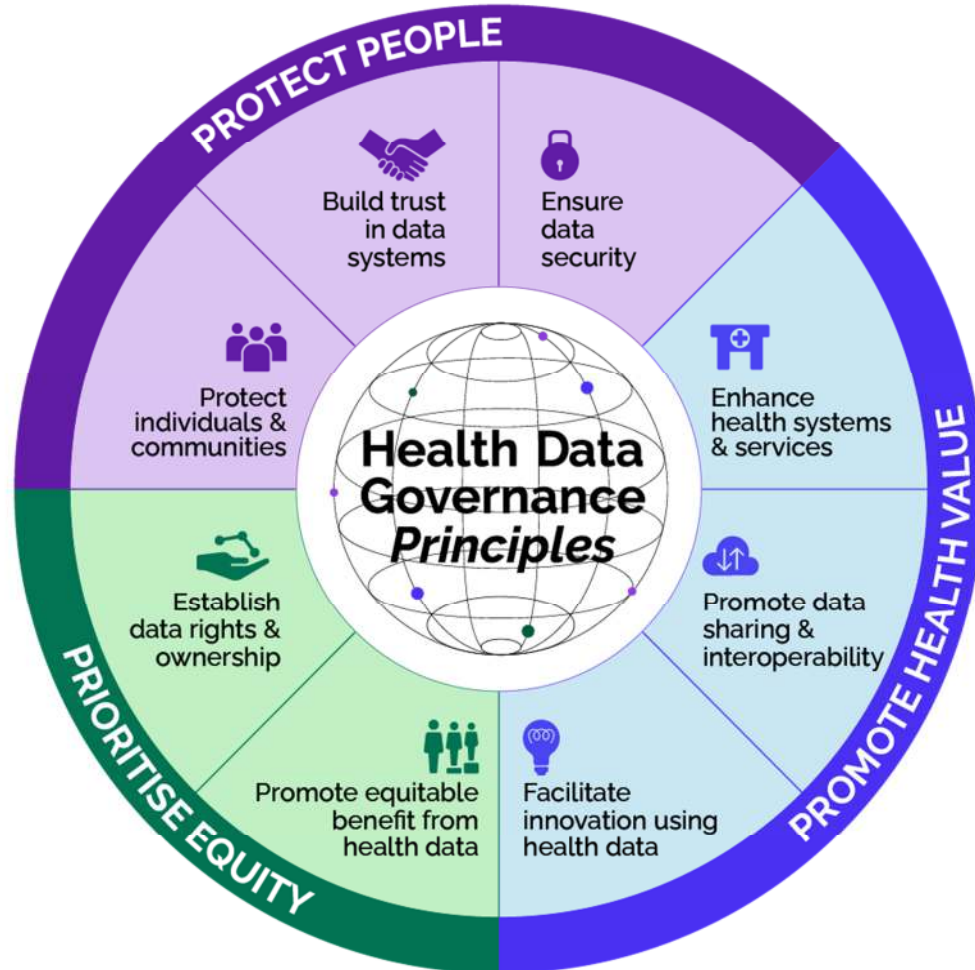


PRIORITISE EQUITY

- Promote equitable benefits from health data
- Establish data rights and ownership



THE PRINCIPLES



August 2022

Digital Square/USAID DRC Project

Supporting the Democratic Republic of Congo's digital and data initiatives for health systems strengthening

Trad Hatton
DRC Country and Regional Director for Central Africa Hub
thatton@path.org



“Investing in digital technology is no longer a choice in the Democratic Republic of Congo, it is now a strategic vision supported by political will at the highest national level.”

“The DRC digital health investments roadmap is a valuable document and presents clear orientations in terms of investments priorities for the country. I believe that by being better coordinated and aligned behind this common vision, we will be able to offer the DRC a health system that performs well within the framework of Universal Health Coverage and more resilient than before”

Dr Jean-Jacques MBUNGANI MBANDA

Minister of Public Health, Hygiene and Prevention

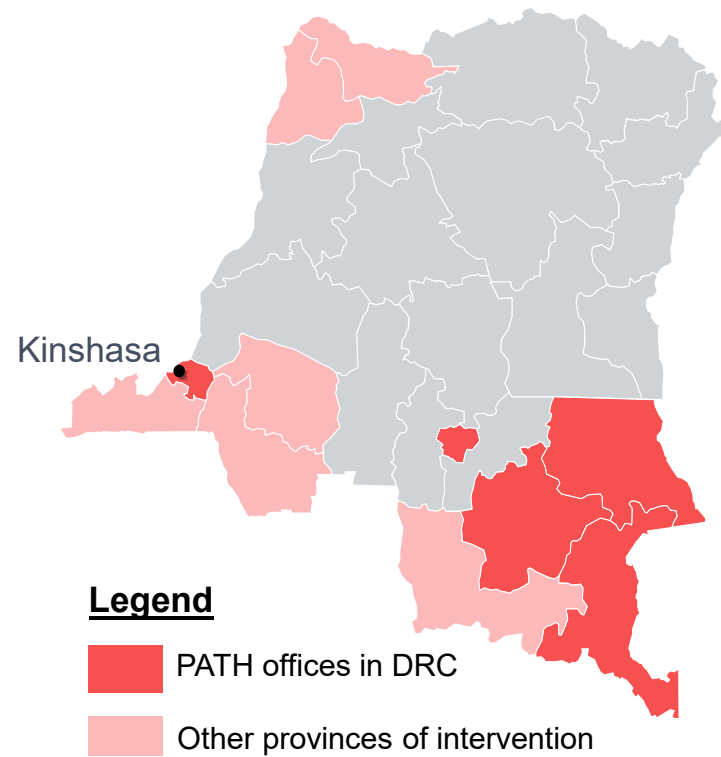


PATH DRC has been supporting the DRC government to improve health outcomes since 2010.

120

Staff in 5 provinces- Kinshasa, Haut Katanga, Kasai Oriental, Tanganyika and Haut Lomami

- PATH DRC is a **trusted and close partner of the DRC MoH and the Presidency, and most specifically the Universal Health Care Council.**
- PATH DRC is known for its strong relationships, unique convening power and ability to build innovative and energetic partnerships.
- PATH DRC **supports DRC's UHC and digital health transformation and technical assistance to through USAID-funded Digital Square.**
- Since 2010, our portfolio covers other health areas, such as **data systems strengthening, malaria and NTDs, immunization systems and advocacy, digital health, epidemic preparedness and response, financed by USAID, Bill and Melinda Gates Foundation and Gavi**





**Supporting the Democratic Republic of
Congo's digital and data initiatives for
health systems strengthening**

Digital Square is a PATH-led initiative funded by the United States Agency for International Development (USAID), the Bill & Melinda Gates Foundation, and a consortium of other partners.

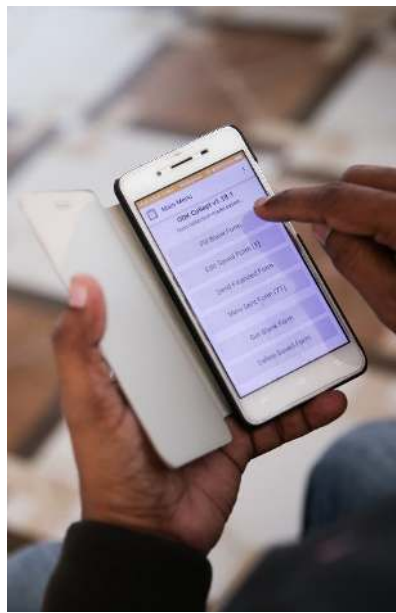
Digital Square creates resources, advances technology, and fosters alignment to improve how countries and the global health community design, use, and pay for digital health tools and approaches.

How?

- **Identify** promising investments and provide operational support to streamline procurement and getting started.
- **Promote** the development, adoption, and reuse of global goods, and help increase their availability, adaptability, and maturity.
- **Strengthen** national-level digital health expertise to enable informed decision-making and sustainable implementation.

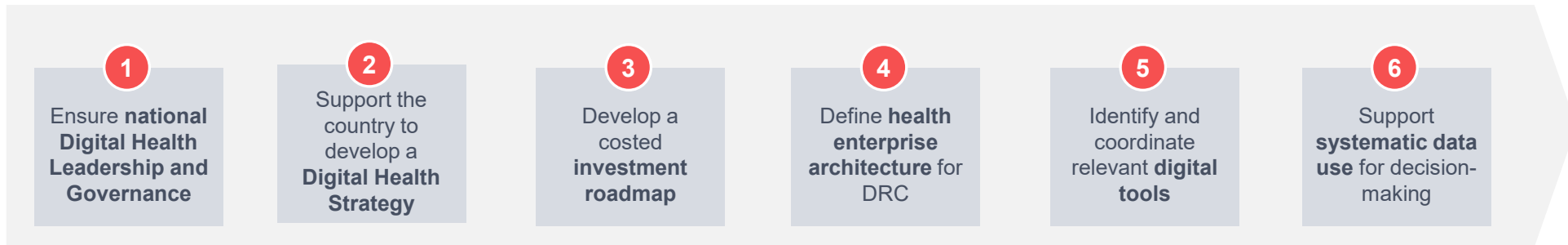
Why?

To improve health and well-being through achieving health equity, which increasingly relies on ensuring equitable access to digital health.



The DRC is on the cusp of a digital transformation with strong political buy-in and leadership to accelerate the use of digital tools to improve health outcomes. With support from USAID and the Goldsmith Foundation, PATH has supported the DRC's digital health transformation, resulting in the creation of ANICNS and the development of a digital health strategy

Our approach



Notable achievements

1 Creation of a Digital Health Agency (2018)

- In 2018, the *Agence Nationale d'Ingenierie Clinique de l'Information et d'Informatique de la Sante (ANICiis)* was formed to coordinate and promote digital health in the DRC.



2 DRC Digital Health Strategy

- PATH worked with the Ministry of Health/ANICiis to develop **DRC's digital health strategy 2020-24 PNDIS II**



3 Costed investment roadmap

- As part of the **USAID-funded Digital Square project**, PATH supported DRC to develop a **costed digital health investment roadmap** to prioritize and cost potential investments in digital health.



Through Digital Square, a USAID project implemented by PATH, USAID/DRC is supporting the Ministry of Health to achieve three main objectives related to the digital transformation plan of the DRC: (1) strengthen ANICNS institutional capabilities, (2) develop an investment roadmap and, finally, (3) develop the e-health architecture.

Digital Square project objectives in 2022

	1 ANICNS capacity building	2 Investment roadmap	3 Enterprise architecture
Overview of activities	<p>Strengthen ANICNS capacities to lead the digital transformation of DRC's health system:</p> <ul style="list-style-type: none">• In partnership with the MoH, strengthen ANICNS capacity, particularly in training, networking, continuous leadership, governance and technical mentoring.• Support ANICNS through the acquisition of equipment for the effective functioning of the agency.	<p>Develop and advocate for a costed investment roadmap for digital health investments in DRC:</p> <ul style="list-style-type: none">• Support country ownership and leadership of digital transformation• The budgeted investment roadmap includes a detailed and budgeted planning tool to align stakeholders on a comprehensive strategy for implementing digital initiatives	<p>Support the MoH to develop the Enterprise Architecture components of a digitized health system:</p> <ul style="list-style-type: none">• Support the MoH to develop a vision and value of enterprise architecture and the process for developing one• Support training of trainers on TOGAF level 1 and 2• Change management and meetings to sensitize key stakeholders on how health systems operations will improve with deployment of enterprise architecture.

Key stakeholders

- **Government:** Presidency, Ministry of Health, Ministry of Digital, ANICNS
- **Partners:** USAID, MSP technical and financial partners, PATH, etc.



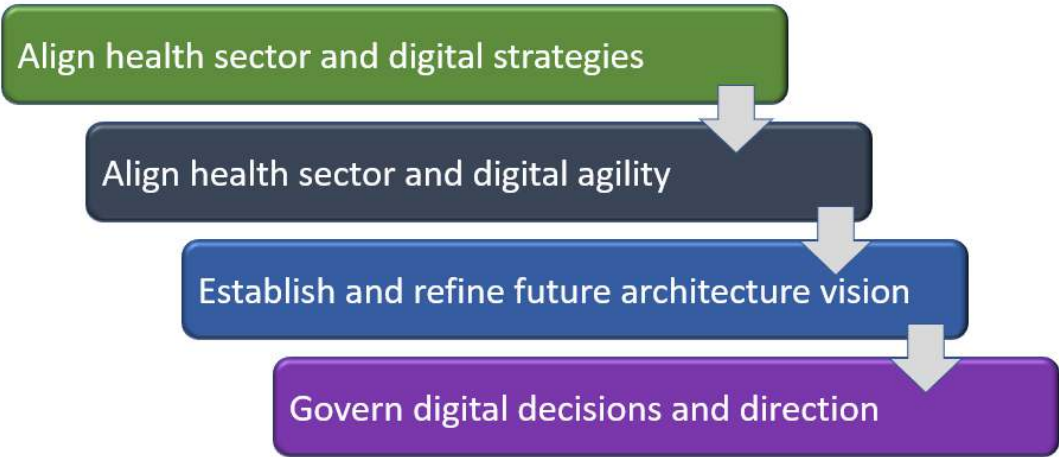
To support DRC's digital health transformation, the DRC government with support from PATH/Digital Square completed development of an investment roadmap for digital health transformation, which will serve as a basis for resource mobilization. 17 Key investments highlighted in the roadmap amount to a total budget of USD \$ **36,414,703**

Key strategic objectives	Investment roadmap
<div>1</div> <div>Objective 1: Coordination, standardization and interoperability of ICT solutions for the implementation of a single and reliable health information system in the DRC</div>	<ul style="list-style-type: none">▪ Total estimated budget: \$7,269,441▪ 9 priority investments including the operationalization of ANICNS, implementation of ICT norms and standards, development of a legal framework, enterprise architecture for digital health in the DRC, support to the national health observatory, establishment of a health data center, etc.
<div>2</div> <div>Objective 2: Health systems strengthening through digital health rollout</div>	<ul style="list-style-type: none">▪ Total estimated budget: \$23,753,214▪ 4 priority investments including interoperability between the various existing systems, optimization and rationalization of certain existing applications, development and deployment of central and cross-cutting applications and development of DRC's <i>Carte Sanitaire (health map)</i>.
<div>3</div> <div>Objective 3: Human Resources Capacity Building</div>	<ul style="list-style-type: none">▪ Total estimated budget : \$2,076,236▪ 4 priority investments including the operationalization of the Center of Excellence for Research and Training in Health Informatics (CERFIS), development of research in digital health, development of skills and knowledge in digital health and implementation of the Virtual Polyclinic of Congo

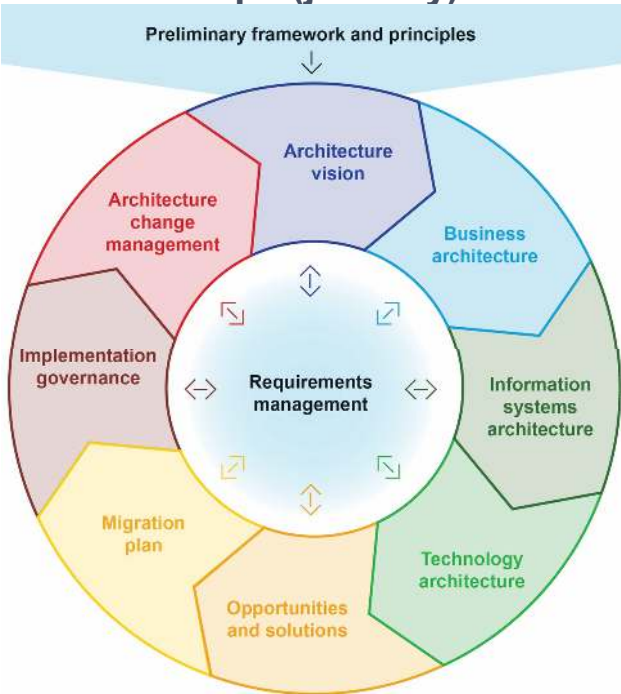
What is Enterprise Architecture?

Enterprise Architecture is a well-defined approach for **aligning management information systems** with an organization's **mission, goals, and objectives**. The intent of enterprise architecture is to determine how an organization can most effectively achieve its current and future objectives.

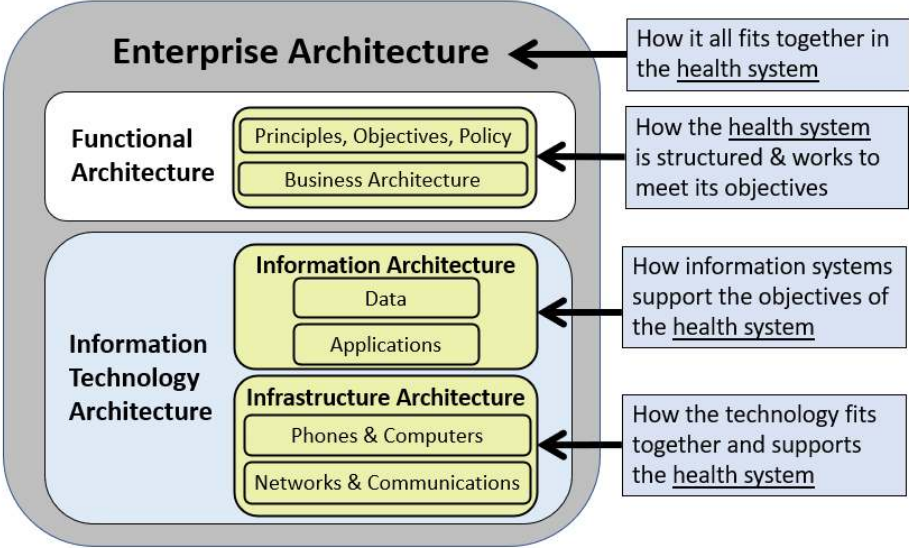
EA Objectives



EA steps (journey)



EA in the Health sector



How is the journey going to be like ?

1. Initiate the process (Scope, Team, Vision..)
2. Characterize baseline architecture (Business Process, Information systems, Policies...)
3. Develop target architecture (Gaps, Interoperability, standards, systems needs)
4. Establish EA governance structure (members of the EA governance identification and orientation)
5. Plan Architecture transition
6. Disseminate

Frameworks like TOGAF are used to develop Enterprise Architecture

Example of EA Vision in Senegal :

« Accelerate universal access to high quality health and social services through a robust digital system that produces reliable and secure data to support decision making »

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Enterprise Architecture for the Health Sector

Currently there is no documentation in DRC of standards and models on the high-level overview of the health sector's business processes, stakeholder engagement, IT systems and their interrelationships. Without this documentation, when new changes are implemented in the sector, their full effect may not be understood, and their desired outcomes may not be achieved. This may include the introduction of new technologies or changes to existing digital technologies. Since there is no official documentation of business processes there is no clear guidance to direct stakeholders in the health sector on how to manage these changes in business process which may impact how technological solutions are implemented.

Without sector-wide standards and models it is difficult to manage the current state of affairs, model future states, and develop effective and sustainable implementation road maps. These standards and models will provide guidance on business processes, use of information and data, applications, infrastructure and stakeholder engagement (roles and responsibilities, involvement, concerns, needs, etc.).

Why do we need the DRC Health Enterprise Architecture?

The DRC EA will be driven by the need to:

1. **Eliminate duplication of efforts:** This includes functionality, using a unified framework for developing and documenting digital solutions that address mission-specific requirements and adhering to government standards and reporting needs.
2. **Establish a common frame of reference:** This will enable the government to contract service providers or steer the development of digital health solutions in a cohesive manner.
3. **Achieve cost savings in technology investment:** Increased cost savings and redirecting resources will help ensure the sustainability of integrated digital health initiatives.
4. **Increase business and IT alignment:** IT investments will be better aligned to contribute to the mission, vision, goals and objectives of the health sector in DRC.
5. **Provide holistic vision:** DRC requires a holistic vision of the relationship between the health sector business operations and digital health investments. It also requires a holistic vision of the systems for enabling integrated digital health services and evidence-based decision making in the health sector.
6. **Enable integration of existing siloed systems:** There are many instances of more than one software application providing the same functionality and not exchanging data. The DRC EA will help identify use cases for integration of systems and interoperability and define a road map for its implementation, governance, and standards.

DRC EA Development Approach

The design and development of the DRC EA will be client-centered to ensure the DRC health system is set up to provide quality health care to its clients. DRC EA will be developed in a focus that the health information systems play a role in provision of safe, effective, timely, efficient, equitable and client-centered health care.

DRC EA will be comprised of the following components:

- 1. Business architecture:** This will involve mapping the existing business processes of the health sector (“as-is”) and how they can be improved (“to-be”). This component will answer key questions on what services are being provided, the health sector’s current processes, and how these processes could they be improved.
- 2. Data architecture:** This will involve mapping data flows throughout the health sector and how they can be improved to ensure availability and quality of services for clients. This component will answer questions like how information is structured, how it flows, and how it’s shared. It will also determine how information flow can be improved.
- 3. Applications architecture:** This will involve mapping how different software applications will interact within the health sector. This component will seek to answer questions about the use of different user-facing software applications. It will determine if there are use cases for how these applications could interact better or exchange data, and if it’s possible for services to be provided within a single application, and shared across the sector.
- 4. Technology architecture:** This will involve mapping how technology will facilitate interactions between health sector functions, services, processes and applications. This component will seek to answer questions about how the underlying technology can support multiple user-facing software applications, including software platforms, networks, communications infrastructure, and hardware. It will also determine if there are ways technology could better serve multiple applications.

DRC Expected Benefits

Process improvement - Modelling of health functions, services and processes will result in better alignment with priorities of the health sector policies and strategies. This will result in better efficiency and quality of health sector services.

Cost reduction and standardization - Implementation of target architecture will ensure it improves the quality of the health services provided and results in cost savings over time, With standards in place it will be more affordable to integrate systems, because less work will be required to develop data definitions.

Achieving strategic plans - The DRC EA development process will help realize DR Congolese’s vision for a better, more effective health sector through alignment of business functions with IT. The development of the DRC EA will align with the National Health Policy, health sector strategies, digital health investments, and Digital Health Strategy.

Improving collaboration between stakeholders - The architecture will identify existing health sector stakeholders, outline their services and processes and potential areas for integration and collaboration.



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