

# WHERE'S MY DATA?

## HEALTH DATA GOVERNANCE MANIFESTO FOR THE UNITED REPUBLIC OF TANZANIA

This data governance manifesto sets out demands for stronger health data governance in The United Republic of Tanzania.

August 2023



## INTRODUCTION

In advocating for stronger health data governance, Imara Leadership Initiative Tanzania with support from Transform Health aims to engage people and politicians in the discussion on how we can build trust in the collection, use, management, sharing and disposal of our personal health data. My Data, Our Health driven by community-based organisations who are engaging individuals on questions of access, control and rights over their health data. Because health data is more than a technical issue, it is a personal, that's why we need to put individuals in the driving seat.

Imara Leadership Initiative in Tanzania and Transform Health are calling for a global health data governance framework, underpinned by **equity and human rights based principles**, to be developed and then adopted by governments, to establish an agreement between nations around a set of common regulatory standards for the governance of health data.

To ensure this, we need governments to support and adopt a global framework at the World Health Assembly mandating the WHO to develop, ensuring it is developed through an inclusive, multistakeholder process.

We are therefore calling on the Tanzanian with governments to ensure health data governance, and a resolution on a framework, is on the agenda at the 152nd WHO Executive Board meeting/EB152 (30 January - 7 February 2023) and at the 76th World Health Assembly/WHA 76 (21 - 30 May 2023).

Once adopted, we ultimately want to see a global framework domesticated into national regulation/legislation.

Strengthening the governance of health data necessitates specific and urgent attention by policymakers to protect people from the nefarious or discriminatory use of personal and sensitive information.

Effective governance of health data is required to maximise the enormous public health benefits that this data can generate whilst protecting the rights of individuals.

## OVERVIEW

The Ministry of Health (MOH) of the Government of Tanzania formed the Data Use Partnership (DUP) to support the implementation of Tanzania's Digital Health Investment Road Map (Tanzania Digital Health Investment Road Map 2017-2023 | PATH), which builds on the digital health strategy (Tanzania\_Digital\_Health\_Strategy\_2019\_-2024.pdf), in response to data use difficulties.

A work package to improve systems for management and oversight of health facility performance is included in the roadmap. The use of digital systems to streamline health facility supervision procedures before, during, and after the supervision visit and improve the utilisation of supervision of data is a crucial component of this endeavor.

We recognise the Government of Tanzania's commitments and efforts to improve the quality of health data for evidence-based decision making and to strengthen capacity to track progress towards the health-related Sustainable Development Goals. The United Republic of Tanzania has taken major steps and made significant progress towards improving availability, access, analysis and use of health data.

It recognizes the need for more coordinated and collaborative efforts from all stakeholders to unleash the full potential of its health information system. This will reduce fragmentation and duplication of efforts, improve the efficiency of investments and build confidence in the national health data system.

To realize this ambition in the United Republic of Tanzania, the Government launched the Tanzania Health Data Collaborative in Dar es Salaam on the 11th September 2017.

This is a collaboration of the Government of Tanzania, represented by the Ministry of Health, Community Development, Gender, Elderly and Children (MOHCDGEC) and the President's Office Regional Administration and Local Government (PORALG); Health Sector Stakeholders; and Global Partners. The Tanzania HDC also integrates the Digital Health Investment Roadmap supported by Bill and Melinda Gates Foundation (BMGF) and PATH.

Recognizing that the Tanzania Ministry of Health has in place a strategic request for collective action to rally all stakeholders behind a common monitoring and evaluation framework and the country's prioritized action plan. Identified priorities are as follows:

- Addressing fragmentation of M&E and data systems
- Alignment of indicators and data collection processes
- Alignment of health facility assessments and surveys
- Joint and aligned investment in digital health information systems
- Strengthening capacity for analysis and use of data
- Data dissemination and access

This manifesto calls on the government and all parties to strengthen health data governance in the United Republic of Tanzania so that people have more control over their electronic health data while ensuring that this data is kept both private and secure.

Stronger health data governance also needs to provide the regulatory framework to allow researchers, innovators, policy-makers and regulators to access relevant electronic health data for the public good, for example to promote better diagnosis, treatment and well-being of people, and to develop more responsive plans and policies.

The Manifesto also built upon the experiences of health workers / practitioners and citizens who have been actively engaged in the My Data Our Health campaign to call on :

#### **Endorsement of the Health Data Governance Principles**

The Health Data Governance Principles were launched in April 2022 and build on important initiatives, such as the WHO's data principles (which provide a framework for data governance for WHO) and their guidance on the ethics and governance of artificial intelligence for health; the Principles for Digital Development and Digital Investment Principles stewarded by the Digital Impact Alliance; the OECD's Recommendation on Health Data Governance and their Principles on Artificial Intelligence.

The Principles are being increasingly recognise as a set of normative standards to inform national are grounded in equity and universal health coverage (UHC) and support sustainable and resilient public health systems.

They have been developed and driven by civil society through an inclusive and consultative process to gather perspectives and expertise from across geographies, sectors and stakeholders. They target governments, developers and other stakeholders that collect health data and can eventually be used as a tool to hold them accountable to equity and human rights agendas.

#### **Support calls for a global framework on health data governance at the World Health Assembly**

More robust and effective governance of health data is needed to ensure the government we are fully harnessing the potential of data for public benefit and improved health outcomes, while also managing risks, protecting individual rights, and ensuring people's data is protected.

National legislation needs to be based on common standards to enable governments and health service providers to exchange information across borders while ensuring the same protective measures for citizens everywhere.

To achieve this the government of Tanzania needs to support a resolution on health data governance at the 77th World Health Assembly in Geneva in May 2024.

## **HEALTH DATA GOVERNANCE DEMANDS**

### **1: Formulation of a New Tanzania Digital Health Investment Road Map Demand**

Revision, amendment or evaluation of the current Tanzania Digital Health Investment Road map 2017-2023 key progress, successes and gaps impeding health data use in The United Republic of Tanzania and open multi stakeholders or public inputs on the formulation of a new Tanzania Digital Health Investment Plan roadmap.

- Expedite the processes of the new Tanzania Digital Health Investment Roadmap through the existing eHealth Steering Committee's (eHSC) under the Ministry of Health mandated to perform governance functions for the eHealth strategy through the task teams in conjunction with the Enterprise Architecture technical working group to advance the digitalization of (i) Care Delivery task team that focus on standards for client-level data and electronic medical records, and a way forward for the client registry, (ii) Decision Support task team to increase the development initial requirements for a data warehouse (iii) Health Information Access task team for the development initial requirements for a health information mediator and the (iv) Healthcare Resources

- Recognizing the current digital transformation from the use of Artificial Intelligence (AI) tools to advance health systems and high-quality health services, the new Tanzania Digital Health Investment roadmap needs to meet the existing digital transformation with stronger transformation and call for electronic systems and less paper based systems of records.



## 2. Country-wide use and dissemination of the Government of Tanzania, Hospital Management Information System (GoTHoMIS) in Health Facilities Demand

- Acknowledgement of the contribution of the GoTHoMIS an electronic information system intended to collect and report facility level clinical information (basic patient level clinical dataset), and support health facilities in service delivery management. The system incorporates various valuable functionalities that play vital roles in line with Health Sector needs and the Government at large.
- The Electronic Medical Record of the GoTHoMIS allows patient profile to be available across facilities through the use of centralized database and have an inventory and tracking of medical supplies as they trickle down to the final consumer.

- The need to increase integration with other systems in the Health Sector - GoT-HoMIS => District Health Information System (DHIS) integration for Health Management Information System (HMIS) statistics this shall advance the electronic copy of medical records accessibility.



## 3. Popularization of the Afya Supportive Supervision System (AfyaSS) Demand

- Data Use Partnership (DUP) chose 6 of Tanzania's 26 regions to examine the rollout and use of AfyaSS, and the effects AfyaSS has had on the use of data for planning, conducting, and following up on supervision visit and yet more regions still have not been reached this needs to change.
- Provision of universal access to AfyaSS system education and usage to the public as a digital system that was developed through the collaboration between Ministry of Health (MOH), President Office - Regional Administration and Local Government (PO-RALG), PATH and other stakeholders. The AfyaSS system aimed to improve the management and use of health facility supervision data for better health service delivery in Tanzania. It also supports continuity in tracking performance and ensures that better quality data is available and used in managing supervisions.



- The digital supportive supervision system, known as AfyaSS was launched by the MOH and other partners in September 2021. The AfyaSS aimed to improve systems to monitor the performance and track progress of healthcare facilities. The specific goal for AfyaSS is to enhance and facilitate supportive supervisory activities in Tanzania's planning, coordination, implementation, and follow-up processes, however few citizens are aware of AfyaSS and the usage modalities to be able to access their health data information.

#### AfyaSS Education Publicized



#### Stronger Health Data Governance



### 5. Strengthen the Quality Health Data Assurance and Privacy Demand

- Advocate for quality health information with allocation of adequate funding for data quality assessment and privacy activities.
- Monitor the quality of health data collected through DHIS2 and Strengthen mechanisms for meaningful multistakeholder engagement at all levels of planning, strategy, execution and monitoring to ensure the digital transformation is effective in improving health outcomes and accelerating UHC progress.
- Inclusion of meaningful engagement of civil society, youth, women and marginalised and hard-to-reach communities to support and champion for Council Health Management Teams (CHMTs) in improving data quality information.

#### Quality Health Data and Privacy Rights



### 4. Parliamentarians Championing the need for stronger Health Data Governance Demand

- Introduction of national parliamentary groups on digital health/health data governance, or ensure this issue is included within the mandate of existing health . digital and data parliamentary groups (as relevant).
- Raise at least one parliamentary question or debate on health data governance, including calling for the government's endorsement of the Health Data Governance Principles and support for a global framework at EB176/WHA76.
- Engage in/speak at at least one national/regional/global meetings to champion the health data governance agenda with real-time examples from stories collected at constituency visits presented to parliament.

## 6. Targeted funding for digital health in Tanzania Demand

- Increased national and international budget allocation for financing digital health in Tanzania to support the equitable, inclusive, sustainable digital transformation of health systems, as part of the wider health system investment to deliver Universal Health Coverage.
- Prioritize digital funding allocation to rural communities in Tanzania to close the divide in digital access with strategic targets and coordinated actions to ensure this happens. This is a prerequisite for equitable access to technology-enabled health services, confronting coverage gaps, affordability and digital literacy
- Ensure funding is coordinated and aligned with national priorities by developing national costed digital health strategies ( with coverages from council / ward levels ) as an integral component of universality that shall advance coordination - enhance the capacity and capability to manage and coordinate M&E activities at levels (central, regional, council) and promote data supply and demand.

### Financing Digital Health



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