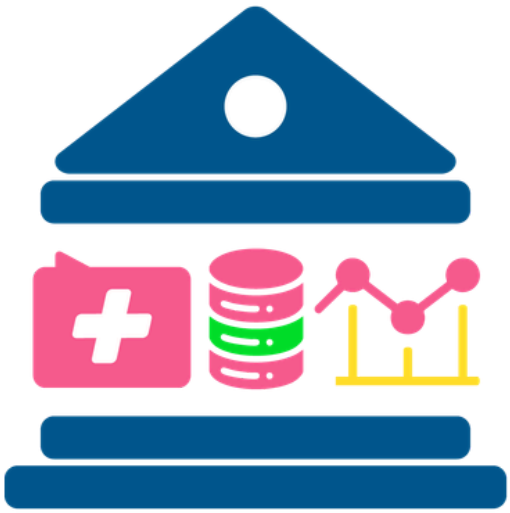
# Supporting stronger health data governance legislative frameworks

## *Uganda Case Study*



# Contents


*Background* 3

*Objectives and scope* 3

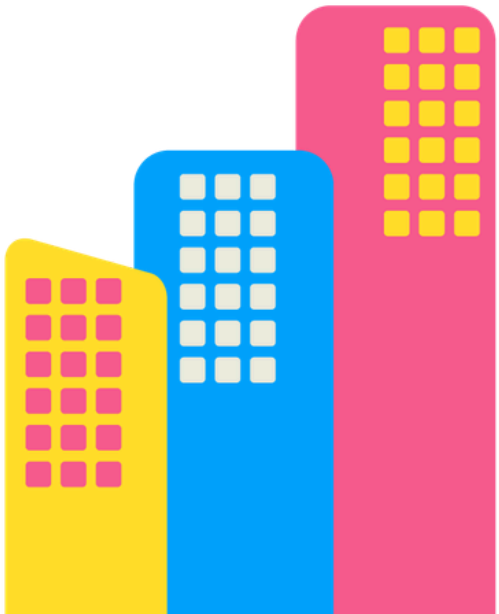
*Approach and process in Uganda* 4

*Key laws in Uganda relevant to health data governance* 4

*Legislative landscape review - key strengths, challenges and gaps* 5

*Recommendations to strengthen the health data governance legislative and regulatory environment in Uganda* 6

*Actionable implementation roadmap* 7

# Background

The digitalisation of health systems and the rapid development of digital tools and Artificial Intelligence (AI) for health has increased the amount of health data that is collected and used. As a result, the issue of how health data is governed is a rising concern amongst populations and growing on political agendas. Health data needs to be effectively and equitably governed to safeguard data privacy and rights, mitigate risks of data misuse, and support responsible data use for improved health outcomes and public benefit. Particularly important is the need to ensure robust legislative and regulatory frameworks are in place to establish the legal guardrails for this to happen and hold data stewards accountable.

Transform Health works with governments, national stakeholders and regional partners to strengthen national health data governance legislative and regulatory frameworks. This is supported through Transform Health's technical support approach and tools, including:

- Health Data Governance Principles, which provide equity and rights-based guidance for the governance of health data;
- National health data governance legislative and regulatory landscape assessment tool, which provides a framework to review the legal landscape;
- Health data governance Legislative blueprint (Model Law) and its Implementation Guide, which provide a legislative guide to support in strengthening national laws and frameworks.

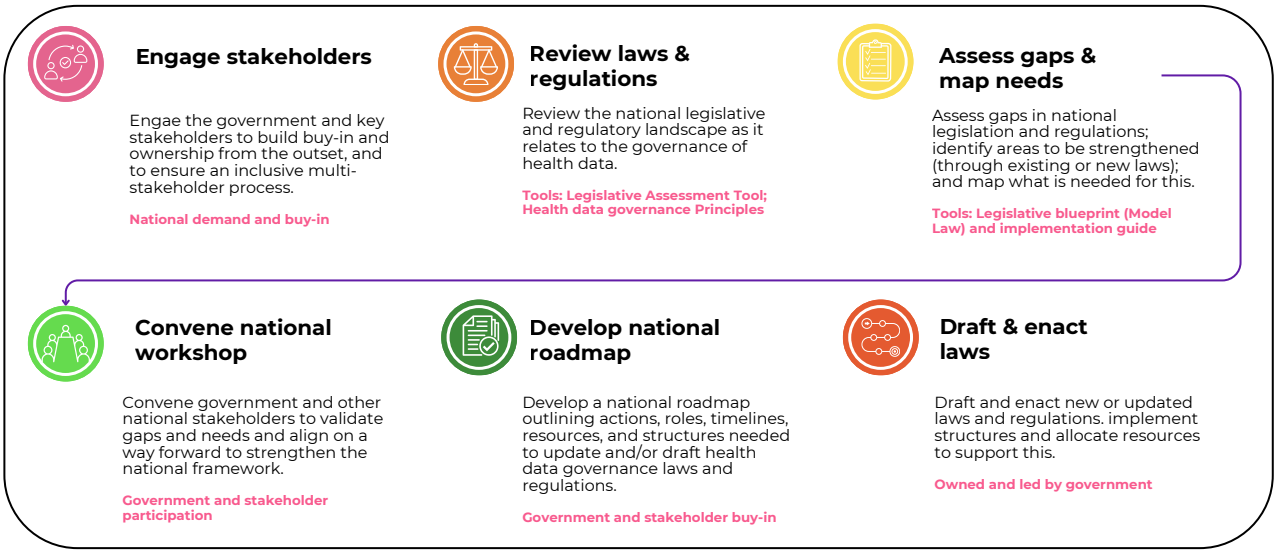
In Uganda, Transform Health worked with Health Informatics in Africa (HELINA) and the Uganda Health Informatics Association (UgHIA), together with government and national stakeholders to review and strengthen the health data governance legislative and regulatory environment.

# Objectives and scope

The primary objective was to work with and support the government to strengthen their national health data governance legislative and regulatory framework, through the development of a national actionable implementation roadmap that charts the way forward for this to happen. This entailed the following:

- **REVIEW AND ASSESS:** Reviewing the national legislative and regulatory landscape as it relates to the governance of health data to assess gaps and identify areas to be strengthened (through existing or new laws) and mapping how and what is needed.
- **CHART THE WAY FORWARD:** Developing a national roadmap to take forward the drafting and/or updating of national laws and regulations, setting out actions, roles and responsibilities, and timelines, as well as capacity, financial resources and other structures that would need to be established.
- **NATIONAL OWNERSHIP:** Ensuring national ownership and buy-in from both government and other stakeholders that need to be involved (Responsible, Accountable, Consulted, Informed) to update, draft, or enact legislation.
- **INCLUSIVE MULTI-STAKEHOLDER PROCESS:** Facilitating an inclusive multi-stakeholder process, including civil society and communities, to validate gaps and needs and to align on a way forward.

This work included the following key steps:



# Approach and process in Uganda

In Uganda, a multistakeholder consultative approach was adopted, involving 26 national and government stakeholders. This included representatives from the Ministry of ICT, the Ministry of Health, and the WHO and UNICEF country office, among others. The engagement aimed to build government ownership and stakeholder buy-in of the process and the resulting roadmap from the outset. It also ensured a broad range of perspectives were reflected.

A comprehensive landscape review was conducted to assess existing health data governance laws, regulations, and related frameworks, including strengths, gaps and needs. The review also sought to identify recommended actions to strengthen national legislation and regulations.

National workshops were then convened to bring together key stakeholders - government officials, healthcare practitioners, legal experts, data protection authorities, and civil society representatives - to discuss and validate the findings of the landscape review. These consultations also supported the development of an actionable roadmap outlining how Uganda could implement the recommendations in practice.

# Key laws in Uganda relevant to health data governance

2023
Anti-homosexuality Act

2021
The Data Protection and Privacy Regulations

2019
The Data Protection and Privacy Act

2015
HIV and AIDS Prevention and Control Act

2013
The Electronic Transactions Act, 2011 and Regulations

2013
The Electronic Signatures Act, 2011 and Regulations

2011
The Computer Misuse Act

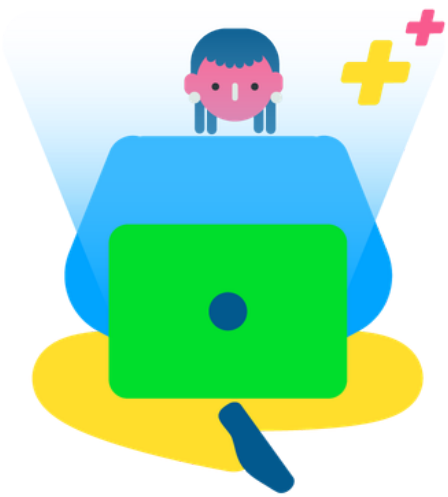
1995
The Constitution of the Republic of Uganda

This section provides a timeline and brief snapshot of the laws and regulations in Uganda relevant to health data governance.

Uganda is not a signatory to the **African Union Convention on Cyber Security and Personal Data Protection**. This instrument enjoins states parties to establish robust legal frameworks for data protection and privacy (Article 8). Despite this status, Uganda enacted a relatively comprehensive law in the **Data Protection and Privacy Act, 2019** and operative Regulations in 2021 setting the institutional framework for health data governance in Uganda. The Act sets up a Data Governance framework that includes; Personal Data Protection Office (PDPO); The National Information Technology Authority-Uganda (NITA-U) and Data Protection Officers (DPOs) that are designated by Data Controllers and Data Processors.

In 2016, Uganda adopted the **Uganda National eHealth Policy**, and drafted the Uganda National eHealth Strategy (2017–2021), which continues to remain in draft form. The strategy recognised that Uganda's digital health landscape was characterised by fragmented, largely siloed and often pilot-driven information systems, with significant barriers to interoperability and data sharing. The Policy and Strategy sought to provide a coordinated national framework for the governance, standardisation and integration of digital health initiatives, promote interoperability and information sharing, and guide the effective use of information and communication technologies to strengthen health service delivery, health system management, and decision-making.

In May 2023, the health ministry launched the new **Uganda Health Information and Digital Health Strategic Plan 2020-2025** aimed at further strengthening the health information ecosystem in the country by promoting interoparability across digital health systems. The strategy seeks to enable seamless, secure, and standardised exchange of health information between health information systems, improve data quality and accessibility, reduce fragmentation and duplication, and support evidence-based decision-making and continuity of care across all levels of the health system.



# Legislative landscape review - key strengths, challenges and gaps

| | Strengths | Challenges and gaps |
|---|---|---|
| **Laws and policies** | With the enactment of the Data Protection and Privacy Act, 2019 and its Regulations, Uganda has made considerable progress in setting up a legislative framework for data protection and privacy. This law aligns with the African Union Data Framework in most aspects and provides a strong foundation for health data governance, especially with its focus on personal data consent, rights of individuals, as well as articulating obligations for data controllers and processors. | Uganda currently has no health-specific digital legislation, nor legal provisions addressing emerging technologies such as artificial intelligence (AI). While the personal data protection law offers broad protections, it does not provide sufficient focus on sensitivities of health data.<br><br>Uganda has limited health data protections for marginalised, minority and disadvantaged groups. Under section 14 of Uganda's Anti-homosexuality Act, 2023 any person (regardless of professional privilege) who knows or has reason to believe that anyone is engaged in homosexuality is duty-bound to report to the authorities. Similarly, Uganda's HIV and AIDS Prevention and Control Act, 2015 permits sharing of HIV results to, among others, intimate partners and other medical practitioners, without the consent of the tested.<br><br>Although the Anti-Homosexuality Act offers full Whistleblower protection to persons who may disclose any information to indicate that a person is homosexual;there are no frameworks for whistleblower protection, adjudication of data disputes, or open access to anonymised and non-identifiable health data. These gaps collectively limit transparency, accountability, and the ethical use of health information. |
| **Implementation & oversight** | The establishment of the Personal Data Protection Office (PDPO) under the Data Protection and Privacy Act, 2019 creates an opportunity for oversight and enforcement, though its capacity to address health-specific data issues remains underdeveloped. | There is currently no regulator tasked with the specific mandate of overseeing health data governance in Uganda. At the implementation level, consent processes remain weak in many health facilities, with insufficient safeguards to protect sensitive health data. The absence of a comprehensive health data governance framework also hinders consistent application of privacy and security standards across institutions. Despite progress at the policy level, and growing national attention around personal data, public awareness of data rights remains limited. |
| **Technical and infrastructure** | Uganda has established national digital health policies and strategies that provide a foundation for strengthening technical infrastructure and health information systems.<br><br>The Uganda National eHealth Policy, eHealth Strategy, and Digital Health Strategic Plan 2020-2025 prioritise interoperability, standardisation, and coordinated digital health implementation, while the Ministry of Health's eHealth Technical Working Group provides a platform for technical coordination. | Data security and encryption measures remain inadequate, exposing health data to potential risks. The lack of interoperability constrains seamless data exchange between systems and limits the Ministry of Health's ability to leverage data for decision-making.<br><br>In addition, many health facilities lack reliable electricity, internet, and modern hardware, constraining digital health adoption. This challenge is magnified by inconsistent data standards that are the result of variations in coding, formats, and collection methods. These eventually reduce data quality and comparability. |

# Recommendations to strengthen the health data governance legislative and regulatory environment in Uganda

To strengthen Uganda's health data governance framework, coordinated action is required from the Government of Uganda, the Ministry of Health, the Ministry of ICT and National Guidance, the Uganda Communications Commission (UCC), and relevant regulatory bodies, in collaboration with civil society and the private sector.

## Laws and Policies

- The government should update existing legislation to close gaps in privacy, security, and consent, and to regulate the use of emerging technologies such as artificial intelligence (AI) in healthcare.

## Implementation and Oversight

- Dedicated oversight mechanisms should be established either through a new body or by expanding the mandate of existing institutions to ensure compliance and manage grievances.

## Technical and Infrastructure

- The government must prioritise digital health investment including technical infrastructure to support a national interoperability framework that enables seamless and secure data exchange across health systems. Targeted investments are needed to strengthen data security, including the adoption of standardised encryption protocols and consistent enforcement mechanisms.

## Capacity Building and Awareness

- Training programmes for healthcare professionals, policymakers, and IT specialists should be prioritised to enhance understanding of health data governance, risks, and responsibilities. In parallel, public awareness campaigns should empower citizens with knowledge of their health data rights and the importance of data protection.

# Actionable implementation roadmap

The following section sets out priority steps to update key national legislative instruments, which and conduct inclusive public consultations to ensure the revised legislation reflects stakeholder priorities and safeguards public trust. Subsequent steps entail the updated legal framework undergoing a formal legislative approval process. Parallel efforts will focus on establishing and strengthening institutional structures to support effective enforcement, alongside targeted capacity-building initiatives and ongoing monitoring to ensure the consistent adoption and implementation of the updated regulations.

## Step 1: Mobilise key stakeholder and establish technical working groups

| Actions | Lead actors |
|---|---|
| • Mobilise key institutional partners for the health data governance legislative strengthening process.<br>• Establish a national health data governance coordination mechanism and multi-sector technical working groups.<br>• Develop detailed legislative and regulatory workplans with clear timelines and assigned responsibilities. | Uganda Health Informatics Association(UgHIA) |

## Step 2: Drafting and technical review

| Actions | Lead actors |
|---|---|
| • Update the **Health Data Governance and Management Regulations (Proposed)**<br>  ◦ A new set of sector-specific regulations to operationalise health data governance principles within the health sector. These regulations will define institutional roles and responsibilities and establish enforceable rules for health data collection, access, sharing, retention, accountability, and oversight across public and private health systems. | Ministry of Health |
| • Update the **Data Protection and Privacy Act, 2019 - Health Sector Operationalization**<br>  ◦ Updates to digital health and health information system regulations and guidelines to strengthen interoperability, cybersecurity, certification of digital health solutions, and governance of health information exchange, aligned with national ICT standards | Ministry of Health |
| • Update the **Ethical Governance Framework for Advanced Analytics and Artificial Intelligence in Health (Proposed)**<br>  ◦ A new ethical and governance framework to guide the responsible, transparent, and accountable use of artificial intelligence, machine learning, and advanced analytics in health research, service delivery, and decision-making. | Ministry of Health |

## Step 3: Public and stakeholder consultation

| Actions | Lead actors and partners |
|---|---|
| • Carry out public consultation on updated draft legislation, including consulting key stakeholders | Lead: Ministry of Health<br>_____<br>Partners: Universities, professional councils, and civil society organizations |

## Step 4: Legislative approval

| Actions | Lead actors and partners |
|---|---|
| • Seek legislative approval of the updated legislation through the national legislative process, including:<br>  ◦ Obtain final technical clearance and endorsement from the Ministry of Health and relevant government agencies.<br>  ◦ Submit the draft legislation to the Ministry of Justice and Constitutional Affairs for legal review and drafting support.<br>  ◦ Secure Cabinet approval, where required, before submission to Parliament.<br>  ◦ Table the Bill or statutory instrument before Parliament in accordance with the applicable legislative procedures.<br>  ◦ Facilitate review by the relevant Parliamentary Committee(s), including stakeholder hearings and incorporation of recommended amendments.<br>  ◦ Obtain Parliamentary approval and passage of the legislation.<br>  ◦ Secure Presidential assent, where required, for Acts of Parliament.<br>  ◦ Publish the approved legislation or regulations in the Uganda Gazette and communicate their commencement and effective date.<br>  ◦ Disseminate the new legal framework and implementation guidance to all relevant institutions and stakeholders. | Lead: Ministry of Health<br><br>Partners: Ministry of Justice |

## Step 5: Institutional preparation

| Actions | Lead actors and partners |
|---|---|
| • Develop implementation guidelines and standard operating procedures in collaboration with the Personal Data Protection Office, National Information Technology Authority–Uganda, district health authorities, and professional councils to support consistent implementation of the legislation across the health sector.<br>• Strengthen institutional and enforcement capacity at national and sub-national levels at national and sub-national levels by defining institutional roles, training implementers and regulators, and establishing compliance, monitoring, and enforcement mechanisms to ensure effective implementation and oversight of the legislation. | Lead: Ministry of Health and HIAM<br><br>Partners: Personal Data Protection Office (PDPO), National Information Technology Authority–Uganda (NITA-U), district health authorities, and professional councils |

## Step 6: Early implementation and monitoring

| Actions | Lead actors |
|---|---|
| Roll out the updated legislation, implementation guidelines, and standard operating procedures across national and sub-national health institutions. | Ministry of Health |
| Conduct training and capacity-building for health workers, data protection officers, regulators, and digital health implementers on the new legal and regulatory requirements. | Ministry of Health; Personal Data Protection Office; Health training institutions |
| Establish routine monitoring and compliance mechanisms, including audits, reporting systems, and compliance assessments to evaluate implementation of the legislation. | Personal Data Protection Office; Ministry of Health |
| Monitor implementation of interoperability, cybersecurity, and health data protection requirements across digital health systems and health facilities. | Ministry of Health; National Information Technology Authority–Uganda |

**Step 6: Early implementation and monitoring (contd.)**

| Actions | Lead actors |
|---|---|
| Conduct public awareness and stakeholder engagement activities to improve understanding of health data rights, responsibilities, and complaint mechanisms. | Ministry of Health; Personal Data Protection Office; Civil society organizations |
| Collect implementation data and stakeholder feedback to identify challenges, document lessons learned, and inform continuous improvement of the legislative and regulatory framework. | Ministry of Health; Personal Data Protection Office; Technical Working Group |
| Produce periodic implementation and compliance reports and recommend updates to legislation, regulations, and implementation guidance where necessary. | Ministry of Health; Personal Data Protection Office |

## Overview and acknowledgements

**This case study highlights Uganda's efforts to strengthen the health data governance legislative and regulatory framework through a collaborative, country-led process. It outlines the approach taken to review the national legislative landscape, identify strengths and gaps, engage stakeholders from across national and district government, academia, civil society and health service delivery, and develop a practical roadmap for strengthening health data governance. It also shares lessons and recommendations that can inform similar reform efforts in other countries.**

**The case study was developed by Transform Health with the Pan African Health Informatics Association (HELINA) and the Uganda Health Informatics Association (UgHIA), who led the process in Uganda. We are grateful to the organisations that have been engaged in the process, including the national stakeholder workshops, where the findings of the landscape review were validated and the priorities and actions set out in the Roadmap were shaped.**

**Stakeholders engaged in the process include: Uganda Ministry of Health · Buikwe District Local Government Uganda · Rubiriizi District Local Government Uganda · Makerere University School of Public Health · Uganda Health Informatics Association (UgHIA) · Afya na Haki · Living Goods · BRAC International · Medic.**

Transform Health is a global coalition of organisations that work to harness the potential of digital technology and the use of data to achieve universal health coverage (UHC) by 2030. To learn more about Transform Health visit: www.transformhealthcoalition.org.

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All of Transform Health's health data governance tools and resources - including the Health Data Governance Principles, the Legislative Blueprint, national landscape reports, and the assessment tool - are publicly available on our dedicated health data governance website. This website was established as an indepedent platform, to foster collaboration and ownership of this agenda across the sector.

Transform Health