HEALTH DATA GOVERNANCE (HDG) TECHNICAL WORKING GROUP LAUNCH

REPORT

Rwanda National Consultation

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Abstract

The launch of the Health Data Governance (HDG) Technical Working Group on August 23, 2024, represents a critical milestone in advancing Rwanda's health data management landscape. This report captures the key insights, discussions, and outcomes from the event, offering a comprehensive overview of the principles, roles, and responsibilities established to guide health data governance in Rwanda. It outlines the collaborative efforts of various stakeholders, the strategic importance of data security and legal frameworks, and the steps forward in ensuring ethical, secure, and equitable use of health data. The report serves as a foundational document that will inform the HDG Technical Working Group's future activities and policy developments.

Health Data Governance (HDG) Technical Working Group Launch

1. Introduction

The Health Data Governance (HDG) Technical Working Group was officially launched on August 23, 2024, during a highly anticipated online event attended by key stakeholders from Rwanda's health sector, including representatives from government agencies, healthcare providers, and the private sector. This launch represents a crucial milestone in Rwanda's journey toward strengthening the governance of health data, ensuring that it is managed transparently, ethically, and securely. This report captures the key discussions, insights, and recommendations from the event, serving as a guiding document for the HDG Technical Working Group's future activities.

2. Presentations Overview

The launch event featured a series of insightful presentations from distinguished speakers, each focusing on critical aspects of health data governance in Rwanda. **Mr. Sylver MUGUMYA** from the Ministry of Health kicked off the session with an introduction to the significance of the Health Data Governance (HDG) Technical Working Group, emphasizing its anticipated impact on strengthening Rwanda's health sector. This was followed by **Mr. Augustin MANIRAKIZA**, a pharmacist, who reflected on the outcomes of the March 2024 consultation, highlighting key takeaways and their implications for the future of health data governance in the country.

Dr. Emile NGABO then delivered a compelling presentation on how robust health data governance can revolutionize Rwanda's health system, focusing on the integration of data to improve patient care and inform smarter policy decisions. **Mr. NTAGANDA Alfred** from the Rwanda Information Society Authority (RISA) provided an in-depth discussion on Rwanda's current data protection and privacy laws, offering insights on how the HDG Technical Working Group can enhance compliance and safeguard patient data. Additionally, **Munyaradzi Madziwa** presented on the core principles of health data governance, outlining the essential guidelines that will drive the group's future efforts in ensuring data is managed ethically and effectively.

3. Presentation Highlights

Introduction to the HDG Technical Working Group

Presenter: Mr. Sylver MUGUMYA (Ministry of Health)

Mr. Sylver MUGUMYA opened the session by introducing the significance of the Health Data Governance (HDG) Technical Working Group. He emphasized the group's crucial role in strengthening Rwanda's health sector by ensuring that health data is managed transparently, ethically, and securely. His presentation set the tone for the event, highlighting the anticipated impact of the Working Group on improving health outcomes and data-driven decision-making in Rwanda.

3.1. Reflections on Past Consultation

Presenter: Mr. Augustin MANIRAKIZA (Pharmacist)

Mr. MANIRAKIZA reviewed the outcomes of the March 2024 consultation, focusing on key takeaways that are critical for the future of health data governance in Rwanda. He highlighted the importance of stakeholder engagement, the challenges of data fragmentation, and the opportunities for improving collaboration and infrastructure to support robust health data governance.

3.2. Revolutionizing Rwanda's Health System with Better Data Governance

Presenter: Dr. Emile NGABO

Dr. NGABO explored the transformative potential of strong health data governance in Rwanda's health system. He emphasized how data integration and governance can enhance patient care, support smarter policy decisions, and contribute to the sustainability of the health system. His presentation linked data governance directly to improved health outcomes and more effective resource allocation.

3.3. Rwanda Data Protection and Privacy Law

Presenter: Mr. NTAGANDA Alfred (RISA)

Mr. NTAGANDA discussed Rwanda's current legal frameworks for data protection, focusing on the Data Protection and Privacy Law. He provided insights into how the HDG Technical Working Group can enhance compliance with these laws and safeguard sensitive health data through robust cybersecurity measures and strengthened legal frameworks.

3.4. Health Data Governance Principles

Presenter: Munyaradzi Madziwa

Munyaradzi's presentation delved into the practical application of the HDG principles, emphasizing ethical data management, security, and privacy. He highlighted the role of these principles in driving Rwanda's health system transformation and their alignment with global best practices, ensuring that health data governance supports both public health outcomes and individual rights.

4. HDG Technical Working Group Roles and Responsibilities

The Launch detailed the roles and responsibilities of the HDG Technical Working Group. The group is tasked with consulting key government bodies, engaging stakeholders, and contributing to the development of a global health data governance framework. The group will convene bi-monthly and produce quarterly reports to monitor the implementation of HDG principles, ensuring adherence to both global standards and local requirements.

- **Key Points and Highlights:**

    o **Roles of the HDG Technical Working Group:** Policy formulation, oversight, and capacity building.

    o **Stakeholder Engagement:** Continuous and active engagement with stakeholders across the health sector is critical.

- o **Monitoring and Evaluation:** Importance of tracking the implementation and impact of data governance policies.

- o **Collaboration and Coordination:** Ensuring seamless coordination among stakeholders to achieve unified health data governance.

- **Implications for the HDG Technical Working Group:** The defined roles will shape the operations of the Working Group, ensuring effective oversight and governance of health data in Rwanda.

5. Key Takeaways

- **Collaboration is Key:** The success of health data governance in Rwanda hinges on active collaboration among all stakeholders, including government agencies, healthcare providers, and the private sector.

- **Principles and Legal Frameworks:** Strict adherence to core health data governance principles and compliance with existing legal frameworks are essential for the ethical and secure use of health data.

- **Ongoing Engagement:** Continuous engagement with stakeholders is necessary to adapt to the rapidly evolving landscape of health data governance.

6. Next Steps

Action Items for the HDG Technical Working Group:

1. **Finalize Governance Framework:**

   - o Develop and finalize a comprehensive health data governance framework, incorporating stakeholder feedback from in-country consultations. Ensure the framework aligns with the HDG principles discussed during the launch.

2. **Stakeholder Engagement and Mobilization:**

   o   Convene meetings with government officials and the World Health Organization (WHO) to discuss and refine the draft Model Law on Health Data Governance.

   o   Gather valuable feedback from stakeholders to strengthen and validate the draft model law through inclusive consultations.

3. **Advocacy and Collaboration:**

   o   Collaborate with regional stakeholders to build political support for the HDG agenda at the World Health Assembly (WHA) and African Union (AU) levels.

   o   Enhance awareness and foster collaboration among key stakeholders to advance the HDG framework and support robust health data governance legislation.

4. **Monitoring and Reporting:**

   o   Establish a robust monitoring plan to track the implementation and impact of the health data governance policies.

   o   Prepare and submit country-specific feedback reports, integrating consultation feedback into the draft Model Law. Document and share progress with RHIA, HELINA, and Transform Health Alliance (THA).

5. **Follow-Up Meeting:**

   o   Schedule a Technical Working Group meeting to review progress, address emerging challenges, and ensure continued alignment with the HDG principles and objectives.

7. Conclusion

The launch of the Health Data Governance Technical Working Group marks a pivotal moment in Rwanda's efforts to enhance health data management. By adhering to the principles discussed and

actively engaging with all relevant stakeholders, the Working Group is poised to play a critical role in ensuring that health data is managed ethically, securely, and effectively.

8. Participation Overview

The launch of the Health Data Governance (HDG) Technical Working Group was attended by a diverse group of 38 participants, representing a wide range of organizations from across the health, government, and academic sectors. The attendees included key stakeholders from government bodies such as the Ministry of Health and Rwanda Information Society Authority, health informatics professionals from Rwanda Health Informatics Alliance, healthcare providers, researchers, and representatives from international organizations. This broad participation underscores the collective commitment to strengthening health data governance in Rwanda and highlights the importance of collaboration among various sectors to achieve common goals.

6.1. Participants and Organizations

No.	Name	Organization
1	NTAGANZWA Roger	Rwanda Health Informatics Alliance (RHIA)
2	Augustin MANIRAKIZA	Nyamata Level Two Teaching Hospital
3	BAGARAGAZA Aimable	Kiziguro Hospital
4	KAZUMUHIRE Consolee	Rwanda Health Informatics Alliance (RHIA)
5	Umutoni Fanny Shadia	Rwanda Health Informatics Alliance (RHIA)
6	Richard ABAYIZERA	Health Informatics
7	Josue MUTABAZI	Resolve To Save Lives
8	Idukunda Kayihura Emma Sabine	IGIHE

9	IMANISHIMWE Diane	Alight Rwanda (Mugombwa Refugee Camp)
10	Fabien HAGENIMANA	Rwanda Health Informatics Alliance (RHIA)
11	RUKUNDO PRINCE	African Quantitative Sciences
12	Oda Munyura	University of Global Health Equity
13	Obard IRANKUNDA	University of Rwanda
14	Bienvenu NKURIYINGOMA	Lancet Laboratories Rwanda
15	Victor Mithi	University of Global Health Equity (UGHE)
16	Karemera Joseph	Lifesten Health
17	Mireille Rugwizangoga Umwali	WYS Ltd
18	Dr. Emile NGABO	OAZIS Health
19	IRAMBONA Alain Dany	King Faisal Hospital Rwanda
20	Oumar Adam Mahamat Maina	Light Choice Health
21	HAGUMIMANA Didier	University of Rwanda
22	IRAGENA Marie Isabelle Zuzu	Rwanda Health Informatics Alliance (RHIA)
23	UWAMAHAORO Jeannette	Rwanda Health Informatics Alliance (RHIA)
24	Umurerwa Anabelle Clementine	Rwanda Health Informatics Alliance (RHIA)
25	Ursule Aurore KWIZERA	ALIGHT
26	Mr. Sylvere MUGUMYA	Ministry of Health (MOH)
27	BIKORIMANA Peter	Ministry of Health (MOH)
28	RUTEBUKA HERVE	SFH Rwanda

29	Daniel Ndamukunda	Rwanda Health Informatics Alliance (RHIA)
30	Seminali Theoneste	University of Rwanda
31	Kwame Norvixoxo	African Leadership University
32	Moses Gasana	Rwanda Information Society Authority (RISA)
33	Alfred NTAGANDA	Rwanda Information Society Authority (RISA)
34	NIYOYITA Jean Paul	University of Rwanda
35	Sebaganwa Claudel	Tony Blair Institute
36	Jerome NSHIMIYIMANA	JoCare
37	KAYIGANWA Michele	Rwanda Ministry of Health
38	DUSHIME	Nyamata Level II Hospital
39	Munyaradzi Madziwa	HELINA