Assessment of Stakeholder Perceptions and Attitudes towards Health Data Governance Principles in Botswana: Web-Based Survey

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Abstract

Background: Globally, healthcare organisations are demonstrating increased interest towards data driven decision making, necessitating health data governance. Transform Health has led the development of globally unifying human rights-based health data governance principles. Healthcare stakeholders in Botswana were engaged to solicit their perceptions about these principles.

Objective: To solicit Botswana health sector stakeholders' perceptions on the health data governance principles by Transform Health.

Methods: Purposive sampling of healthcare stakeholders in Botswana was done, and an online survey tool shared with them by email. The REDCap platform supported online data capture from 15 April until 20 May 2022. Twenty three participants completed the online survey and only 10 of them participated in a follow-up round-table discussion. Participants' responses were analysed using Microsoft Excel for descriptive statistics and Delve software for thematic analysis.

Results: Participants expressed the relevance and importance of the health data governance principles in the context of Botswana. However, modifications to the principles were also suggested as well as effective organisational governance for sustainable implementation of the principles.

Conclusions: This study highlights the necessity of data governance in healthcare. The findings could contribute towards next steps regarding revision or implementation of the health data governance principles by willing organisations. Clinical Trial: Not applicable

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Abstract

Background

The use of information and communication technologies for health – eHealth, is described as having potential to improve the quality of healthcare service delivery. Consequently, there is an increased

global trend towards adoption of eHealth interventions by healthcare systems worldwide. Despite the proliferation of eHealth solutions, many healthcare institutions especially in developing countries are struggling to attain effective data governance approaches. The Ministry of Health in Botswana is an exemplar institution continually seeking better approaches to strengthen health data governance approaches following the adoption eHealth solutions. Recognizing the need for a global health data governance framework, the Transform Health coalition conceptualized health data governance (HDG) principles that are structured around three interconnected objectives of protecting people, promoting the value of health and prioritizing equity.

Objectives

The aim of the study is to solicit and evaluate perceptions and attitudes of health sector workers in Botswana towards the Health Data Governance Principles by Transform Health, and derive any future guidance.

Methods

Purposive sampling was used to select participants. Twenty-three (23) participants from various healthcare organizations in Botswana completed an online survey and ten (10) participated in a follow up virtual round table discussions. The aim of the round table discussion was to gain further insight from participants' responses from the online survey. Participants were from the following healthcare cadres; nurses, doctors, information technology professionals as well as health informaticians. Both validity and reliability testing were done for the survey tool prior to sharing it with study participants. An analysis of participants' close ended responses from the survey was done using descriptive statistics. Thematic analysis of open-ended responses from the questionnaire and the round table discussion was achieved using Delve software and the widely accepted principles of thematic analysis.

Results

Although some participants highlighted having measures in place similar to the HDG principles, there were some who either did not know or disagreed that their organisations already had in place mechanisms similar to the proposed HDG principles. Participants further expressed relevance and importance of the health data governance principles in the context of Botswana. However, some modification to the principles were also suggested.

Conclusions

This study highlights the necessity of data governance in healthcare particularly towards meeting the requirements for Universal Health Coverage. Existence of other health data governance frameworks calls for a critical analysis to assess the most appropriate and applicable framework in the context of

Botswana and similar developing countries. An organizational centered approach may be most appropriate, as well as strengthening of existing organizations' HDG practices with the Transform Health principles.

Keywords: Health data, Governance, Botswana, Digital Health

Introduction

Efforts to improve the quality of healthcare service delivery using information and communication technologies (ICT), has resulted in health systems faced with challenges such as data overload, security, and privacy concerns [1]. Unforeseen access to health data by unauthorised parties also raise concerns with confidentiality and inappropriate data use, including results commercialisation and undisclosed surveillance [2]. In addition, the growing data volumes from diverse digital health sources, may cause data inconsistencies that need to be identified and addressed before decisions in a healthcare organisation are made based on incorrect data [3]. Notwithstanding these challenges, there is a growing appreciation of “data as an asset” by healthcare institutions as they face increasing pressure for reporting a "single version of the truth" [4]. The COVID-19 pandemic has further highlighted the importance of data quality for guiding decision making and practicing evidence based healthcare [5].

Data quality - *the degree to which a given dataset meets a user's requirements* [6] is essential for use in patient care as well as for monitoring the performance of healthcare services and the health human resource [7]. Consequently the need for strengthening health data governance has arisen, as noted in pronouncements such as the Sustainable Development Goals (SDGs) [8] and Universal Health Coverage (UHC) [9]. The Data Governance Institute (DGI), defines data governance as *"a system of decision rights and accountabilities for information-related processes, executed according to agreed-upon models which describe who can take what actions with what information, and when, under what circumstances, using what methods"* [10]. In healthcare, data governance includes monitoring and enforcing security of critical health information, policies and procedures to guide, manage, protect, and govern electronic data under the control of a healthcare facility [11].

The benefits of strong data governance initiatives are many and diverse and so are the challenges. Some of the documented barriers in establishing data governance best practices in healthcare include; lack of executive support, inadequate resources, little trust in the data, lack of a strategy for educating, training, and supporting users on data governance practices, inconsistent data protections, resistance to change, digital data being perceived as a technology asset and not a corporate asset, complex nature of healthcare data (mostly unstructured), as well as non-interoperable data systems [12]. Inadequate data governance practices in any organisation, consequently results in challenges such as; loss of accountability, poor data quality, fragmented ownership with little authority and non-existent standards, policies, and procedures. This scenario could result in patients' data being exposed to exploitation and potentially resulting in bad decisions being made, financial wastage and opportunity loss [13].

The Ministry of Health (MOH) in Botswana is mandated with the overall oversight and delivery of healthcare services. Data at the point of generation is captured through hybrid systems involving a combination of paper based and electronic systems. Botswana's health sector still uses multiple data collection and reporting tools. Public and private health facilities in Botswana use separate health information management systems. Further, there are no established feedback mechanisms for ensuring that the data flow process is seamless between all the levels of the health system. There also exist challenges of health human resource capacity on data analytics, hindering the effective use of information for decision making. [14]

In Botswana, the continued proliferation of vertical health information systems (pre and post pandemic) has led to duplication of efforts in a scarcely resourced setting [15]. The Botswana National eHealth Strategy further highlights this by stating that, "There is duplication of efforts (EMR and DHIS2 data), data coming from the same source and some of the software are not in real

time. (Subsection 2.2.2)" [16]. As a result the meaningful use of health data becomes a tedious and complicated task.

As such a comprehensive health data governance framework is essential to address the afore-mentioned challenges as faced by many health systems worldwide. Upon this realization, Transform Health (a global coalition of organisations, based in Switzerland and dedicated to achieving health for all in today's digital era) led the development of globally unifying, human rights based Health Data Governance (HDG) principles [17]. Transform Health was set up to collectively respond to digital health challenges by bringing together local, regional, and global stakeholders from multiple sectors dedicated to achieving UHC in the digital age. It campaigns for and collaborates with individuals – particularly women and young people – and communities who would benefit most from the digital transformation of health systems, as well as the governments, organizations and institutions who recognize and support the fundamental role of digital technologies and data for improved health. The Transform Health coalition coordinated the development of the HDG Principles, under the leadership of its Policy Circle, whose members are from various organizations such as, Young Experts: Tech 4 Health, Central American Health Informatics Network/RECAINSA), Palladium Group/Health Data Collaborative Digital and Data Governance Working Group, Health Data Collaborative's Digital and Data Governance Working Group, Foundation Botnar, IT for Change, FIND, I-DAIR, Philips/ Digital Connected Care Coalition, Jhpiego, and Asia eHealth Information Network/AeHIN [18], all of which collectively developed the HDG principles. Protection of individuals is often embodied in general data protection laws. However, this is at the core of the HDG principles by Transform health which highlights that Health data governance must include special measures of protection against various kinds of individual and collective harm, including data-driven exploitation, harassment, discrimination, surveillance capitalism and neo-colonialism [18]. This dimension on data governance, complements other published healthcare data governance principles [19, 20].

The HDG principles by Transform Health are structured around three interconnected objectives: a) protecting people; b) promoting the value of health; and c) prioritising equity [18]. The principles are a result of an inclusive and consultative process including eight workshops, a public consultation and contributions from over 200 experts globally, as well as relevant sectors and stakeholders [18].

As part of an agenda towards establishing awareness as well as advocacy for the principles in Botswana, Transform Health engaged the authors to solicit and evaluate key health sector stakeholders' perceptions and attitudes towards the afore-mentioned Health Data Governance

Principles in Botswana, and derive any future guidance.

Methods

In this study, purposive sampling was used to select thirty participants (Nurses (5), Doctors (5), IT Officers or Technicians (5), IT Managers (5) System Analysts (5) and Health Informaticians (5). The inclusion criteria were as follows; being part of the healthcare system in Botswana as well as their availability and consent to participate in an online survey developed by the authors. Only 23 responded to the survey which had 8 close-ended questions (5 multiple choice and 3 Likert scale) and 2 open-ended questions. A 3-point Likert scale was used for the 3 closed-ended questions related to ranking the HDG principles according to priority (ordinal scale: Highest priority=1, Moderate priority=2, Lowest priority=3).

In order to ensure that the survey items addressed the objectives of the study and that the question items were not ambiguous, the electronic survey was first reviewed among five health sector representatives (two Nurses, two Medical Librarians and one Health Information Technology Manager) who were not part of the final study participants. The survey was pre-tested by two Health Information Technology Officers before being enhanced through improved branching logic. Feedback from the pilot test was considered and incorporated into the final survey distributed to study participants from 15 April - 20 May 2022. An analysis of participants' close ended responses from the survey was done using descriptive statistics in Microsoft Excel (version 2013; Microsoft Inc) in order to determine participants' perceptions regarding the HDG principles.

A follow up virtual round table discussion was conducted with some of the survey participants' who expressed willingness to elaborate on their survey responses. The intent of the round-table discussions was to gain further insight on participants' survey responses. This was done using Zoom as it was the common virtual platform that all participants had access to. The discussion was led by a moderator and loosely structured in order to gain an in-depth view and opinion of participants regarding the principles. Thematic analysis of open-ended responses from the questionnaire and the round table discussion was done. This was achieved via Delve software and using the widely accepted principles of thematic analysis [21]. Example quotes from participants were mapped to the identified themes.

Ethical Consideration

The study was approved by the Ethics Committee of the University of Botswana (Reference: UBR/RES/IRB/BIO/325). Initial contact with potential participants was done telephonically in order

to explain to them the objective of the exercise, as well as consent to participate in the study. The consent forms clearly explained the purpose of the study and provided assurance that data would be kept safe and de-identified. Participants were informed of their right to refuse to participate or withdraw from the study at any time. Those that consented to participate, were sent an electronic link of the questionnaire (developed by authors) for them to complete as well as web address (URL) to the Transform Health HDG Principles. The survey was hosted on the Research Electronic Data Capture (REDCap) system. REDCap is a secure (HIPAA and GDPR compliant) system for supporting electronic data capture for research and operational support projects [22]. No compensation was provided and participants included those beyond known to the authors.

Results

Study participants were representative of various healthcare stakeholders in Botswana (Figure 1).

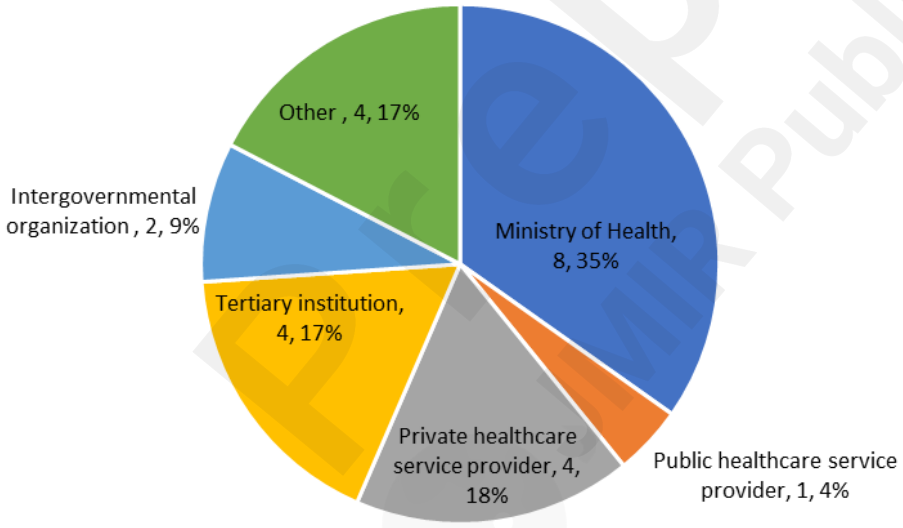

Figure 1: Representation of Stakeholders who participated in the HDG Principles survey

Survey participants shared their views on whether, 1) the HDG Principles are important in their industry, 2) their organisation could benefit from implementing the HDG principles; 3) their organisation already has in place mechanisms similar to the HDG principles and 4) whether the HDG principles in their current form are adequate to address issues related to health data governance in the context of Botswana.

Majority (17/23, 74%) of participants strongly agreed that the HDG Principles are important in their industries and that their organisations could benefit from their implementation. Whereas the majority of participants agreed that their organisations already had in place mechanisms similar to the HDG principles, it is worth noting that 17% (4/23) of participants disagreed that their organisations already had in place mechanisms similar to the HDG principles. Lastly, more than half (12/23, 52%) of participants also agreed that the HDG principles in their current form are adequate to address issues related to health data governance in the context of Botswana (Figure 2).

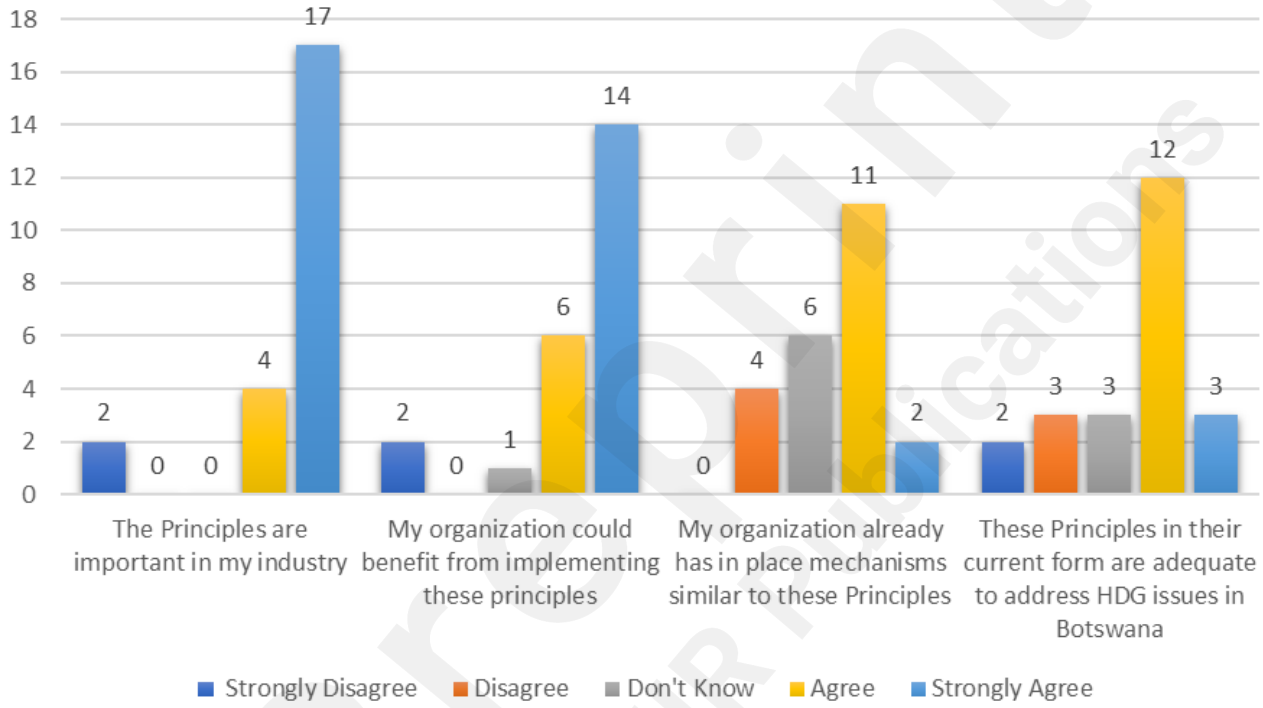

Figure 2: Participants' perceptions of the importance, benefits and adequacy of HDG Principles in their industry

Participants' also responded to a question that asked them to rank the HDG principles, in order of importance (Figure 3) and none ranked the principle of "protecting people" as being of lowest priority.

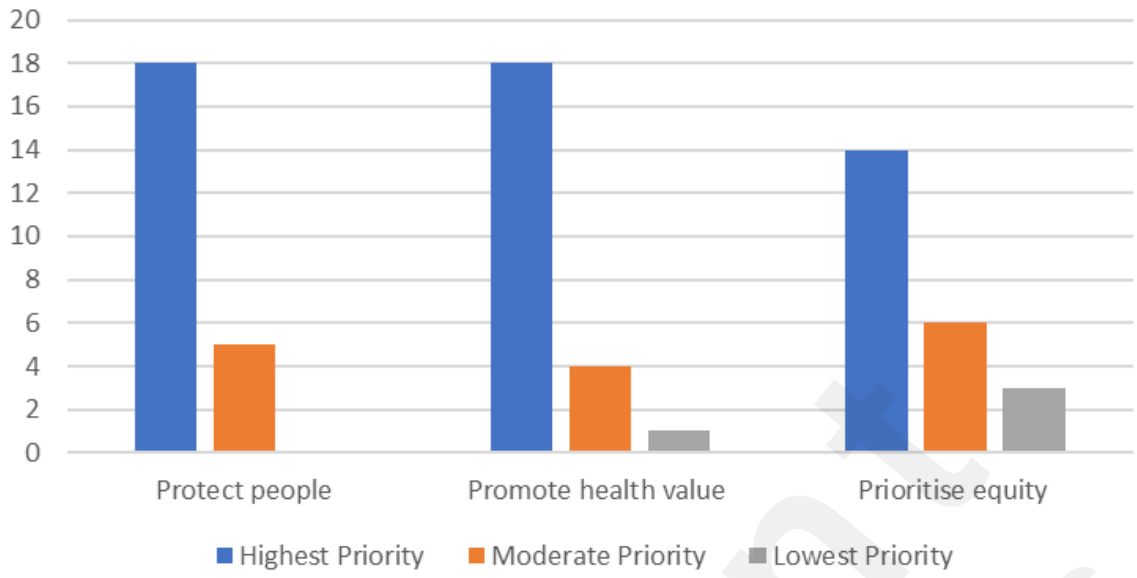

Figure 3: Participants' ranking of the HDG principles (Lowest to Highest priority)

A thematic analysis of open ended responses from the online survey as well as participants' responses from the round table discussion regarding the HDG principles are presented in Tables 1 and 2. Table 1 is a presentation of participants' opinion on modifications required on the existing HDG principles so they could better align with the context of Botswana. Table 2 is a thematic presentation of participants' opinion on factors to be considered by an organisation willing to implement the HDG principles.

Table 1: Participants' suggested revisions to the HDG principles.

Type of change suggested	**Participants' suggestion**
Elaboration	*"Detailed clarification of what constitutes health data is required."*
Remodelling	*"Emphasis on aspects relating to health data accountability and ownership needs to be reflected by the principles."*

Participants' proposed revisions to the HDG principles included an elaboration as well as a suggestion relating to remodelling of the HDG principles (Table 1). Participants' thoughts on factors necessary for successful implementation of the HDG principles by a willing organisation

resulted in the emergence of four themes; Needs assessment, Data protection, Health workforce capacity development, and Interoperability (Table 2).

Table 2: Survey participants' suggestions regarding implementation of HDG principles

Theme	Example Quotes
Needs Assessment *(organizational needs prior to implementation of HDG principles).*	"To start, an evaluation of a given environment to determine the scale at which the principles are needed looking at the current governance values and its impact to this day." "Need analysis would be relevant" "Private health providers must be engaged" "The health system in Botswana is open to innovation. Perhaps a process for new innovations to go through would be useful, in order to be ratified by the ministry of health. This would fast track innovation while ensuring compliance." "HDG principles should be treated as equally important." "A deliberate decision to transition from paper data to paperless data capture across the country."
Data Protection *(organizational data protection considerations prior to implementation of HDG principles).*	"Health data must be kept within the country and data sharing with other facilities for quick diagnosis and fast treatment of the patient." "Data protection is only observed within the private sector and there is no implementation of the data protection act." "Protecting people could be strengthened, in terms of confidentiality and protecting info on individual patients, using 'Omang number (national identity number for citizens) for everything may pose just that risk of one being able to access all confidential info, including health data."
	"Stakeholder awareness campaign workshops are

Health Workforce Capacity Development *(Human resource capacity development requirements prior to implementation of the HDG principles).*	essential” “Through workshops, and inclusion of these principles in internal assessments of members.” “Best would be to educate on international standards, develop procedures and generic templates, legal education around health data and data governance” “Capacity needed for Sector leadership on optimal implementation - need for dissemination to implementers” “Data managers to be research-centric. This will improve data capture, management and utilisation. ”
Interoperability *(Health data sharing considerations prior to implementation of HDG principles).*	“There should also be a system that is able to collect health data from the private sector if it is not in place already. I am not aware that there is one. As far as I know clinics keep their own data.” “Although the ministry of health promotes data sharing through the Health Data Collaborative initiative, there is minimal guidance on how to do that” “Enforcing data sharing, intellectual property and data sharing agreements.” “Implementing health data sharing to avoid duplication.”

Discussion

Overall, participants agreed that the HDG Principles are important in their industries and that healthcare institutions could benefit from their implementation. Although some participants highlighted having measures in place similar to the HDG principles, there were some who either did not know or disagreed that their organisations already had in place mechanisms similar to the proposed HDG principles. Participants further agreed that HDG principles in their current form are adequate to address issues related to health data governance in the context of Botswana. Each

principle was considered to be of high priority by the majority of participants and none of the participants perceived the principle of “Protecting People " as being of lowest priority. The need to provide a clear definition of what constitutes health data as well as an emphasis on issues relating to health data accountability, emerged from the round-table discussions. Participants' responses on considerations for successful implementation of the HDG principles by a willing organisation in Botswana were categorised into four themes (needs assessment, data protection, health workforce capacity development, and interoperability).

One participant expressed that *“landscape analysis will help to determine the scale at which the principles are needed looking at the current governance values and its impact to this day.”* Consequently, the needs assessment process will guide decision-making, justify decisions before they are made, result in flexible processes and offer solutions to complex problem scenarios [23].

According to the DGI [10], four major factors that may influence an organisation's need to adopt formal data governance include, 1) an organisation’s expansion such that traditional management is not able to address data-related cross-functional activities; 2) complex data systems making it tedious for traditional management methods to address data-related cross-functional activities; 3) the need for organisational units to interoperate and share data; and 4) Regulation, compliance, or contractual requirements for formal Data Governance. The World Health Organization (WHO) further recognises the ongoing accelerated trends towards digitisation in health, persistent data gaps and fragmented approaches to governing health data in different contexts, and calls for a global consensus on health data governance [24]. The above cited reasons by both DGI and WHO could justify one of the findings in the current study whereby the majority of participants ‘strongly agreed’ that the HDG Principles are important in their industries and that their organisations could benefit from implementing these principles. Furthermore, regulatory obligations such as complying with the Botswana Data protection act of 2018 [25] as well as the guiding principles outlined within the Botswana National eHealth strategy (2020-2024) [16] may have contributed to participants appreciating the importance and the benefit of the HDG principles in their organisations. Compliance to the DPA can be strengthened by making sure that it informs all health data management practices in healthcare organizations.

It is worth noting that in most organisations, data related roles exist such as operational, tactical, strategic and support roles [26]. Consequently, most organisations may be already governing data, but in an informal manner [26]. Therefore depending on how well an individual is informed with regards to issues of data governance, one may or may not be aware of their organisations’ data

governance status or their expected roles and responsibilities regarding data governance in their organisation. This may explain participants' varying views regarding their organisation's health data governance status. Therefore health workforce capacity development is essential as it would make implementation of the principles smooth since employees would understand its purpose, hence become less resistant to change. Moreover, continuous training helps organisations to evolve as new challenges and complex scenarios will emerge over time requiring different resolution approaches [27, 28]. Train-the-trainer model is documented as an example of a sustainable training model [27]. Moreover, training which is tailor-made to a country's experiences could inform sustainable approaches to health human resource capacity development. For example, a recent study conducted in Tanzania, reported that the Ministry of Health successfully coordinated a hands-on training which utilised a structured methodology and standardised training materials for different groups of users, with participants given access to materials, facilitator-led demonstrations, presentations, group assignments, pre-tests, and post-tests to enhance trainees' understanding and assimilation of issues [28].

Globally, the increasing number of heterogeneous non-interoperable digital health systems have resulted in data silos across health sectors. In the developing world, this is often due to ad hoc, donor driven, initiatives [29]. Guidance for achieving interoperable health information systems in Botswana should align with the National eHealth Strategy pillar on 'Standards and Interoperability' [16]. The Strategy seeks to strengthen health information availability and sharing by "*Establishing an interoperability architecture*" with specific strategic interventions of *"Establish[ing] a standards and interoperability framework", "Design[ing] the interoperability platform"* and *"Implement[ing] the interoperability platform"* with key stakeholder involvement (subsection 3.5.4, Table 5 of the National eHealth Strategy [16].

"Non nocere!" (do no harm) is the indispensable principle of the healthcare profession, meant to encourage healthcare practitioners to desist from actions that may result in causing more harm than good [30]. In the age of digital health, the new definition of "do no harm" may include that digital health technologies should "do no harm". This could be a possible explanation why the HDG principle of "Protect People" may have resonated more with the participants resulting in none of them ranking it as being of lowest priority.

The HDG principles align with consideration for health data governance by the WHO Global Strategy on Digital Health [19] and the Africa Health Strategy (2016-2030) by the African Union

Commission [20]. Thus a possible reason why the majority of participants also agreed that the principles in their current form are also adequate in the context of Botswana.

Globally, stakeholders in the health sector are guided and motivated by instruments such as the Universal Health Coverage [9] as well as the WHO Global strategy on digital health (2020-2025) [19], both of which align with the HDG principles. Consequently, this might have influenced participants' view of the HDG principles as being of equal importance and priority.

Suggested modifications to the HDG principles by participants were that a clear definition of health data as well as emphasis on aspects relating to health data accountability and ownership be provided for in the principles (Table 1). Health data can be explained as data concerning health [31]. As such health data not only covers specific details of medical conditions, tests or treatment, but includes any related data which reveals anything about an individuals' past, current or future health status [32]. This includes both "ill health" data as well as "healthy health" data [31]. With such a broad definition, it is therefore justifiable that the HDG principles should outline what they deem as health data so as to guide any organisation willing to implement the principles. While the HDG principles cite issues relating to health data accountability and ownership, some participants' sentiments were that such coverage was inadequate and almost suggesting that the HDG principles should be remodelled such that health data accountability and ownership should appear as an additional principle. Other than medical and health records, generation of health data is also increasingly occurring through the internet, social media, health apps and wearable monitors [33]. This health data ecosystem creates a problem that complicates issues related to health data accountability and ownership. Mirchev et al. [34], describes this as an under researched interdisciplinary problem, incorporating legal, ethical, medical and aspects of information and communication technologies. As such further emphasis by the HDG principles on issues relating to health data ownership and accountability, may be a worthy consideration.

Themes emerging from Table 2 suggest that successful implementation of the HDG principles will result in a change process within the implementing organisation, necessitating organisational readiness and change management strategies [35]. Nilsen et al. [36], notes that characteristics of successful changes in a healthcare organisation are; having the opportunity to influence the change; being prepared for the change and valuing the change. This highlights that implementation of the HDG principles may also require organisational collective motivation [37].

Future Guidance

Data is an important corporate financial asset [38]. According to Alofaysan et al. [39],

"organisations should understand that data can lead to better healthcare decisions, which ultimately lead to better business, shifts organisations to a new era of consuming patients' data rather than only producing it". It is therefore essential for organisations to implement HDG principles while being guided by organisational governance structures. The Pan American Health Organization in collaboration with WHO notes that effective governance will give the individuals in an organisation an understanding of the strategic view and the reasoning behind what is being done and why [40]. In essence, giving organisational members an understanding of the project aim, direction and tasks involved in the execution, reducing confusion that might otherwise lead to resistance towards the implementation [40].

Based upon these and current study findings, the following guidance for implementing HDG Principles in Botswana is proffered.

- A comprehensive health sector needs assessment is an important first step towards implementation of the HDG Principles.
- Considering the sensitive nature of health data, issues of health data security and protection in Botswana should be prioritised and aligned with the Data Protection Act (2018) [24]..
- Botswana healthcare sector should engage in relevant and continuous health workforce capacity development to ensure effective and sustainable implementation of the HDG principles.
- The current digital health landscape of Botswana calls for consideration regarding adoption of eHealth interoperability standards as a cornerstone to implementation of the HDG principles.

Limitations

The health sector in Botswana is primarily government-led, therefore fewer private stakeholders were included in the study compared to public sector stakeholders. Similarly, understanding of health data governance principles was not the same across public and private sectors, therefore comparing the two was limited. The views presented on this study might not necessarily be generalizable to the Botswana landscape based on the number of participating organisations. It is also worth noting that some participants might not have been aware or previously exposed to the concept of HDG.

Conclusion

Health data governance is an essential part of meeting requirements for Universal Health Coverage. The health sector stakeholders' who participated in the study acknowledge the relevance and applicability of the health data governance principles by Transform Health in the context of

Botswana, but also suggested some improvements. Existence of other health data governance frameworks calls for their critical analysis in order to assess the most appropriate and applicable framework in the context of Botswana and similar developing countries. An organizational centred approach may be most appropriate, as well as strengthening of existing organizations' HDG practices with the Transform Health principles.

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Competing interests

This research is sponsored by Transform Health and the findings may assist Transform Health to revise their health data governance (HDG) principles as well as informing them towards their HDG framework development.

Author contributions

All authors jointly conceived the study, and jointly contributed to its design, and development of the survey tool and round-table discussion guide. KN, KLM and SC performed the surveys and round-table discussions, completed initial data analysis, and wrote the first draft of the manuscript. SW and TO made substantial editorial and intellectual input, and all authors contributed to subsequent revisions. All authors approved the final manuscript.

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Data availability statement

The datasets used and/or analysed during the study is available from the corresponding author on reasonable request.

Disclaimer

The views expressed in the submitted manuscript are solely those of the authors and not an official position of their institutions or the Transform Health consortium.

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