

FAIR Equivalency, Regulatory Framework and Adoption Potential of FAIR Guidelines in Health in Kenya

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ABSTRACT

This study explored the regulatory framework in Kenya that may facilitate the implementation of the FAIR Guidelines in health research, as well as the possibility of adopting the FAIR Guidelines at the national level. Fourteen key documents pivotal to the emerging digital health sector in Kenya were identified and analysed using a comprehensive coding and labelling approach based on a binary system for whether or not they mention the FAIR Guidelines or terms and vocabulary related to the FAIR Guidelines. The analysis revealed gaps in data stewardship that could be filled by the implementation of the FAIR Guidelines and, although the documents analysed do not explicitly mention the FAIR Guidelines, FAIR Equivalent terminology and practices are mentioned in varying detail. However, our analysis shows that there are still no provisions for the introduction and implementation of the FAIR Guidelines in health research in Kenya. Therefore, we recommend that the leadership be provided with a comprehensive introduction to the FAIR Guidelines, success stories about the FAIRification of data and research infrastructure in other parts of the world, and a demonstration of the steps needed for the FAIRification of health data in Kenya.

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ACRONYMS

DHIS2	District Health Information Software 2
FAIR	Findable, Accessible, Interoperable, Reusable
FE-Score	FAIR Equivalency Score
HIS	health information system
HIT	health information technology
ICT	information and communication technology
KP&TC	Kenya Posts and Telecommunications Corporation
SDG	Sustainable Development Goal
UHC	universal health coverage
VODAN	Virus Outbreak Data Network
WHO	World Health Organization

1. INTRODUCTION

Comprehensive clinical research data stewardship plays a critical part in facilitating high quality data and increased data sharing [1]. The FAIR Guidelines (also known as the FAIR Data Principles) for scientific management and data stewardship were first developed in 2014 to provide guidance on how to ensure data and metadata are Findable, Accessible, Interoperable and Reusable (FAIR) for humans and machines, both now and in the future [2]. Although the adoption of the FAIR Guidelines around the globe has been slow, the advent of the COVID-19 pandemic has provided a window of opportunity to speed up the uptake of the FAIR Guidelines. With the onset of the pandemic, the Virus Outbreak Data Network (VODAN) was established to make SARS CoV-2 virus data from different countries FAIR [3].

However, it is well known that there are more challenges with the implementation of these guidelines than with their formulation [4]. In most cases COVID-19-related data is sensitive and cannot leave the country where it was generated [3]. Among the first steps recommended for guideline implementation is a thorough understanding of the already existing infrastructure, practices and culture of the local users in a given context [5]. In our case, this includes the already existing policies, frameworks, recommendations and strategies that will influence the implementation of FAIR Guidelines in Kenya. This is an important step that informs stakeholders of the relevance and benefits of the implementation of the FAIR Guidelines for (meta)data management and stewardship within a framework that is, and will continue to be, of national relevance [6].

Mobile subscription, penetration and coverage in Kenya has been on the increase since the first mobile operators became active in the country in 1999 [7]. The Internet was promoted in Kenya in 1995, but was met with backlash by the Kenya Posts and Telecommunications Corporation (KP&TC), a monopoly state enterprise, which banned Internet services, citing that it amounted to the resale of products produced by the KP&TC and was, therefore, illegal [8]. This meant that what was being pushed through was the duplication of what KP&TC was supposed to be doing. However, the government thought that opening up

the same services to more bidders would create positive competition. In 1998, the government passed the Kenya Information and Communication Act, a new telecommunication law establishing a multi-operator environment [9]. This was followed by official recognition of the Internet by the Government of Kenya. However, it was not until 2005 that the Internet was officially recognised. Today, Kenya has fully embraced the Internet and information and communication technology (ICT) as drivers of socioeconomic growth and, in a bold move, established a high-level agency to mainstream e-government as a tool for governance. In the health sector, the government is in the process of digitising health services and integrating digital health in every sector to optimise service delivery. To harmonise the different aspects of ICT scattered in the different ministries, the Ministry of ICT was created in 2004 with the aim of bringing together all aspects of ICT scattered in different ministries [8].

The World Health Organization (WHO) has recognized the importance of data in eHealth as critical to achieving universal health coverage (UHC) [10]. Indeed the public health sector has grown due to the implementation of various health information systems (HISs), including the District Health Information Software 2 (DHIS2) and the use of electronic medical records (EMRs) [11–13]. The improved ICT infrastructure has made it possible for the Ministry of Health to coordinate the flow of information, ensure consistency in ICT implementation, and harmonise health sector systems [9]. Against this background, the present study is an attempt to explore the provisions made by the Government of Kenya that could facilitate the implementation of the FAIR Guidelines for scientific data stewardship, with special focus on health research.

2. METHOD

A desk review was conducted to identify documents published by the Government of Kenya to direct ICT and eHealth. The documents were accessed from the Ministry of Health archives, online libraries and Government of Kenya policy paper archives with government printers. Documents were selected based on their relevance to the study (see Table 1).

We then conducted an analysis of these documents, following Basajja et al. [14], to determine if they contain explicit mention of the FAIR Guidelines. If not, they were further examined to determine if they mentioned any of the 15 FAIR facets (sub-criteria) of the FAIR Guidelines. In order to measure the level of FAIR Equivalency in the policy documents, the analysis was extended to indicate whether or not similar terms and concepts to those used in the 15 facets of the FAIR Guidelines were mentioned in the documents. These FAIR facets comprise the following: Findability (F1, F2, F3, F4); Accessibility (A1, A1.1, A1.2, A2); Interoperability (I1, I2, I3) and Reusability (R1, R1.1, R1.2, R1.3) [15]. Whether or not a statement contained in the policy documents is considered similar to the FAIR data facets—or FAIR Equivalent—was based on whether or not it carries the same intent, purpose or meaning as the one provided by the first publication of the FAIR Data Principles by Wilkinson et al. in 2016 [2]. For example, where the document advocates for the prioritisation of data exchange, the specific statement was labelled as similar to the FAIR data principle of interoperability.

Using a coding-labelling approach, statements in the policy documents were labelled using the initials of the FAIR data principle that they represent (i.e., ‘F’, ‘A’, ‘I’, or ‘R’). The policy documents were arranged in rows and two columns, ‘FAIR mention’ and ‘FAIR Equivalent’, and annotations were tabulated using a binary code system. The number ‘1’ was assigned where the policy documents mentioned either the FAIR Guidelines or FAIR Equivalent and ‘0’ was assigned where neither were mentioned. From this data, the FAIR Equivalency Score (FE-Score) was calculated by aggregating the scores across all the 15 facets per document. Hence, the highest possible FE-Score for each policy document is 15. We based this analysis and interpretation on the detailed explanation of the FAIR Guidelines provided on the GO FAIR website [15]. Table 1 presents a summary of the FAIR Guidelines.

Table 1. Summary of the FAIR Guidelines [15].

<p>Findable:</p> <p>F1. (meta)data are assigned a globally unique and persistent identifier</p> <p>F2. data are described with rich metadata (defined by R1 below)</p> <p>F3. metadata clearly and explicitly include the identifier of the data it describes</p> <p>F4. (meta)data are registered or indexed in a searchable resource</p>	<p>Accessible:</p> <p>A1. (meta)data are retrievable by their identifier using a standardized communications protocol</p> <p>A1.1 the protocol is open, free, and universally implementable</p> <p>A1.2 the protocol allows for an authentication and authorization procedure, where necessary</p> <p>A2. metadata are accessible, even when the data are no longer available</p>
<p>Interoperable:</p> <p>I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.</p> <p>I2. (meta)data use vocabularies that follow FAIR principles</p> <p>I3. (meta)data include qualified references to other (meta)data</p>	<p>Reusable:</p> <p>R1. (meta)(data) are richly described with a plurality of accurate and relevant attributes</p> <p>R1.1. (meta)data are released with a clear and accessible data usage license</p> <p>R1.2. (meta)data are associated with detailed provenance</p> <p>R1.3. (meta)data meet domain-relevant community standards</p>

3. FINDINGS

The Constitution of Kenya (2010) and Vision 2030 development blueprint require the country to provide the highest attainable standard of healthcare through the adoption and use of ICT. To fulfil this mandate the Ministry of Health has developed the Kenya Health Policy (2016–2030) [16–18]. This comes at an important time when the health sector is implementing far reaching reforms to achieve UHC. This concept is anchored in the achievement of Vision 2030, the overall goal of which for health is to have an “equitable and affordable healthcare at the highest achievable standard” for the citizens of Kenya. This vision is informed by the strategies and results emanating from the implementation of the Kenya Health Policy Framework, 1994–2010, the health sector strategic plans, and the e-Government and Shared Services Strategies implemented by the e-Government Directorate and the ICT Board, respectively [16].

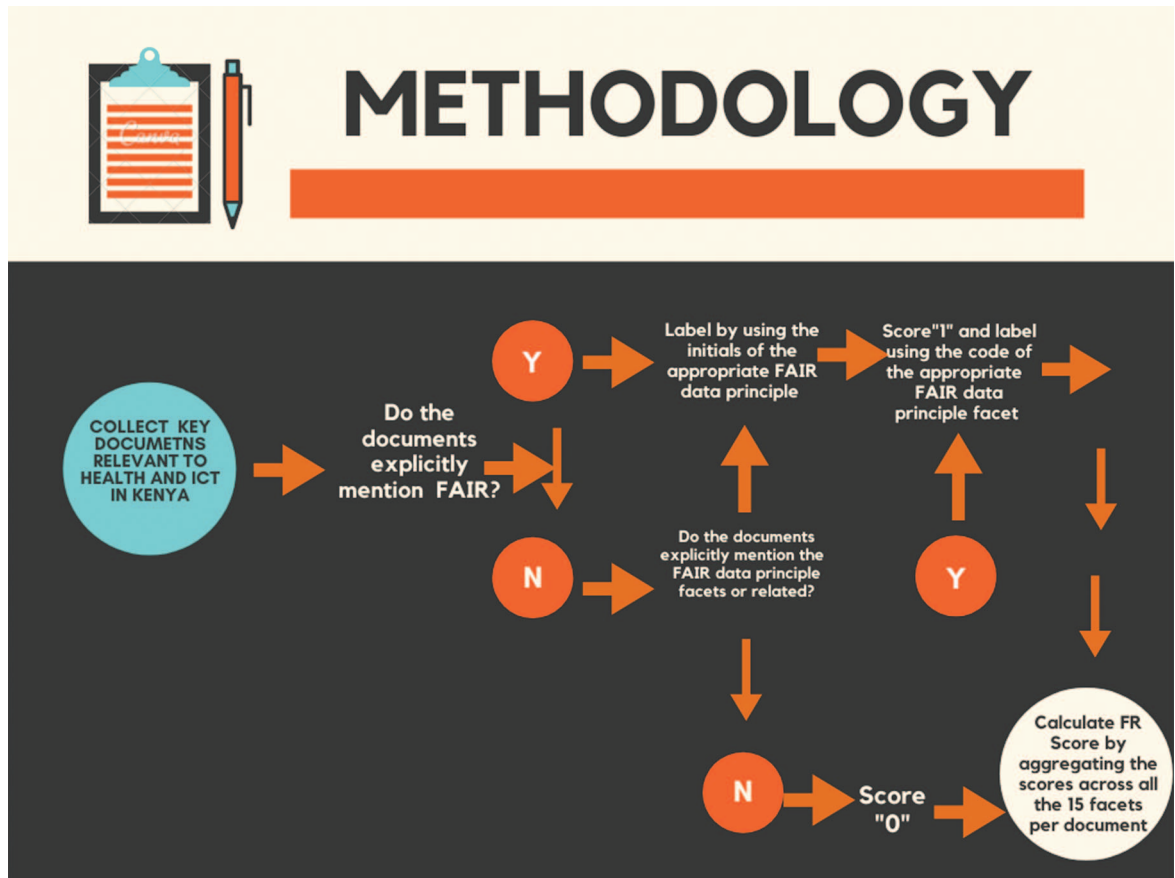


Figure 1. Methodology for ascertaining FAIR Equivalency. Source: Created by Esther Inau Thea

The legal and regulatory frameworks show that there have been many changes in the technological and competitive space since 2006, including the convergence of ICT, the transition from analogue to digital TV broadcasting and its effect on the broadcasting market and radio spectrum, and the advancement of mobile technology, which has enabled new services [19, 20]. Increased ICT-enabled services have come with increased demand for bandwidth and for better quality services, as well as changing consumer preferences [7].

Our analysis, as represented in Table 2, shows that although the FAIR Guidelines are not explicitly mentioned, similar concepts, such as the need for interoperability among heterogeneous silos, are described. For example, the Kenya Data Protection Act (2019) [21] outlines the right to data portability, under which the data subject has the right to receive personal data concerning them in a structured, commonly used and machine-readable format. The data subject also has the right to transmit this data obtained to another data controller or data processor without any hindrance, as well as to have the personal data transmitted

Table 2. Summary of FE-Scores including percentages of how many times each principle is discussed in the policy papers from 2006 to 2019.

Document	F1	F2	F3	F4	A1	A1.1	A1.2	A2	I1	I2	I3	R1	R1.1	R1.2	R1.3	FR Score	%
Kenya Data Protection Act, 2019 [21]	1	1	1	1	1	1	1	0	1	1	1	1	1	1	1	14	86.7
National ICT Policy 2019 [9]	0	0	1	0	1	1	1	0	1	1	0	1	1	1	0	9	60
Medical Practitioners and Dentists Act 2019 [22]	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0.00
Kenya eHealth Policy 2016–2030 [23]	1	1	1	1	1	0	1	0	1	1	1	0	1	1	0	11	73.3
The Health Act, 2017 [24]	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	6.67
Kenya Standards and Guidelines for mHealth Systems [25]	1	0	1	0	0	1	1	0	1	0	1	0	0	0	0	0	40.0
Kenya National eHealth Strategy 2011 [26]	1	1	0	0	1	1	1	0	1	1	1	0	0	0	0	8	53.3
The Nurses Act 2012 [27]	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0.00
Kenya Health Sector Strategic & Investment Plan, July 2013–June 2017 [28]	1	0	0	1	1	1	1	1	1	0	1	0	0	0	1	9	60.0
Kenya Medical Laboratory Technicians and Technologists Act 2012 [29]	1	0	1	0	1	1	1	0	1	0	0	1	0	0	1	8	53.3
Pharmacy and Poisons Board Act 2012 [30]	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0.00
Kenya Health Information Systems Interoperability Framework [31]	1	1	1	1	1	1	0	0	1	0	0	0	0	0	1	8	53.3
The e-Government Strategy: The Strategic Framework, Administrative Structure, Training Requirements and Standardization Framework [32]	1	1	1	1	1	1	1	1	1	1	0	1	1	0	1	13	80.0
Health Sector ICT Standards and Guidelines [33]	1	0	1	0	1	0	0	0	1	0	0	1	0	0	0	5	33.3

directly from one data controller or processor to another. A data controller or data processor shall comply with data portability requests, at a reasonable cost and within a period of 30 days. It is, however, possible to request an extension of this period. Although not explicitly stated in the Act, the interoperability of data and databases is a key factor in ensuring the timeliness of the data transmission. The implementation of the FAIR Guidelines also play a role in facilitating the data controller or data processor in the implementation of appropriate technical and organisational measures for ensuring that an authentication and authorisation procedure is in place to determine data access. The scores per document show a great variation from 0 to 14 (out of total score of 15).

4. DISCUSSION

Although the East Africa Health Research Commission has recognised the relevance of the FAIR Guidelines for health policy in the region [34], there is no reference to FAIR Guidelines in the policy documents in Kenya. The Kenya Data Protection Act (2019) defines a ‘data subject’ as an identified or identifiable natural person who is the subject of personal data. The Act also defines ‘health data’ as data related to the state of physical or mental health of the data subject and includes records regarding the past, present or future state of the health, data collected in the course of registration for, or provision of, health services, or data which associates the data subject to the provision of specific health services [21]. We shall use these definitions for this discussion.

The Constitution of Kenya of 2010 states that the right to health is a fundamental human right and provides that every person has the right to the highest attainable standard of health, including the right to healthcare services [35]. This is reflective of Sustainable Development Goal 3 (SDG 3), which aims to ensure healthy lives and wellbeing for all across all stages of life [36]. The Government of Kenya has identified ICT as a catalyst for improving efficiency in healthcare service delivery as well as improving the quality of healthcare services [28].

The Kenya Health Sector Strategic & Investment Plan 2018–2023 is guided by the Constitution of 2010, the Kenya Vision 2030 and the Kenya Health Policy 2016–2030 [28]. It is focused on UHC and provides a framework for investing in primary healthcare, following the Astana Declaration on primary healthcare and other commitments [37–41]. This strategy highlights the need for data findability in data information systems. It also stipulates that modern data systems be installed in 98 hospitals across the country (2 per county). With regards to health information monitoring and evaluation, the Government of Kenya has highlighted key challenges that need to be addressed in the present strategy. They include: an inadequate capacity for data analysis, slow development of targeted dissemination products, lack of quality data for decision making, the existence of multiple unlinked data silos, inadequate use of ICT, poor investment in health information technology (HIT) and inadequate resources to support use of HIT [28]. The Kenya eHealth Policy (2016–2030) further highlights other challenges faced in achieving the 2030 goal of better health delivery and service to all. These challenges are low level of capacity in terms of ICT, the centralisation of ICT at the national level, the lack of information systems integration, and poor ICT infrastructure at government health facilities [42, 43]. The Government of Kenya has emphasised the need for standardised

health information exchange through interoperability frameworks, as well as the need for a comprehensive integrated HIS [23].

The National ICT Policy 2019 shows that Kenya has advanced in terms of IT-enabled services, which has resulted in an improvement in the quality of services rendered. It also acknowledges challenges to cyber security and the need for the integration of projects and harmonisation of ICT policies regionally and internationally [9]. The policy also highlights the need to create conditions under which high speed wireless technology can be used across the country as well as the need to enable secure infrastructure and frameworks that support the growth of data centres, pervasive instrumentation (Internet of Things) and machine learning [9].

The Government of Kenya, through the National ICT Policy 2019, requires all arms of the government to build, deploy, operate and manage locally built back-end and front-end systems to deliver services [25, 32]. However, while the policy establishes that back-end and front-end systems to deliver services be built, deployed, operated and managed locally, the need for interoperability among the involved systems is not described [9]. Interoperability is required, as shown by previous attempts to exchange data elements in an integrated system (comprised of a Master Facility List [MFL], DHIS2, and human resources information systems through application programming interfaces [APIs]), which resulted in data transmission errors caused by wrong MFL codes, data type mismatches and hyphens in legacy data. Lack of information exchange standards for aggregate data in this instance made programming time-consuming [44].

The Government of Kenya is determined to improve access to, and the equity of, quality essential healthcare services, as well as ensure the attainment of the SDGs through the implementation of UHC. To fulfil this mandate, the Ministry of Health developed the Kenya eHealth Policy (2016–2030) with the objective to plan, design, and install ICT infrastructure and a HIS for the management and delivery of essential healthcare [16]. An important contributor to the achievement of quality health and health services is high quality data and data infrastructure [45]. However, data quality deficiencies are more pronounced in low and middle-income countries [46]. Further compounding this, there is not much emphasis on policies that direct data collection, handling and storage by frontline healthcare workers in Kenya. The updated Medical Practitioners and Dentists Act (Amendments 2019), Kenya Medical Laboratory Technicians and Technologists Act 2012, and Pharmacy and Poisons Board Act 2012 are silent on use of data collection, handling and storage, as well as the use of data for secondary purposes [22, 29, 30]. Similarly, the Nurses Act 2012 stipulates that nurses should have knowledge about data management and interoperability, but does not set out the specific knowledge and skills required, nor the purposes for which the knowledge is to be obtained [27]. This indicates that there is still a long way to go before FAIR health data and supportive infrastructure can be established in Kenya.

It is interesting to note that the Kenya eHealth Policy (2016–2030) encourages access, exchange, storage and reuse of eHealth data in a more responsible manner [23]. This policy draws its strength from various legislative and regulatory instruments [18, 47, 48]. Among these instruments is the Draft Health Bill 2016, which is yet to be enacted [47]. Once enacted, it promises to protect and regulate the use of eHealth in

terms of the collection, retrieval, processing, storage, use and disclosure of personal health information, as well as promote the use of the standards that have been developed to ensure interoperability, security, quality and the meaningful use of ICT in healthcare. The need to convert health information systems into interoperable data gadgets has been highlighted in the plans to establish the Kenya Health Enterprise Architecture (2016) [49]. However, no roadmap to achieve this has been outlined. This opens a window of opportunity for the introduction of the FAIR Guidelines in Kenya.

However, there still remains a lot to be done with regards to the uptake of the FAIR Guidelines in the health domain in Kenya. Although the documents analysed do not cite the FAIR Guidelines explicitly even once, there are a number of activities that have been proposed that may create the foundation for the FAIRification of data. For example, the operationalisation of health information systems designed to provide computer aided hospital management operations that will facilitate the recording of various hospital operations and connect to the Ministry of Health has been suggested as an important step to provide a central repository of health data and statistics [32]. In an effort to modernise operations to improve efficiency and service delivery, government ministries and departments have introduced and implemented systems intended to meet their specific objectives. However, these systems remain disparate and unlinked, leading to the duplication of effort and resource wastage. Some of the documents analysed do cite data interoperability (which facilitates data exchange and data communication), as a prerequisite for the successful implementation of e-government standards and guidelines. These documents go on to describe the need to prioritise explicit definitions for the kind of data that must be standardised, the standards to be used, the extent to which data can be accessed by the different parties, the recommended standards protocols for the various telecommunications and who the data owner/manager is. The outcomes for e-government ICT standards have been set up with that aim of enhancing data integrity and security within databases, as well as defining and exchanging data within operating systems.

The documents analysed recognise reusability as a route to reduce the duplication of work among health systems developers and implementers [31]. The Kenya Health Information Systems Interoperability Framework of 2015 highlights reusability as a core interoperability principle, which can be achieved by adopting solutions that have proven their value in the past in addressing current problems. This principle, as described in the Framework, requires health systems developers and implementers to openly share their interoperability solutions, concepts, frameworks, specifications, tools, and components with others. The stated benefit of this is that the reusability of IT solutions, information, and data enables interoperability and improves quality, because it extends operational use and saves money and time [31].

Activities that have been proposed to make e-government standards a reality include the formulation of website guidelines that direct government departments to make data open, except where reasons preclude such availability as specified in legislation. Another proposed activity is the establishment of metadata standards to give descriptions of all web resources. It is also proposed that metadata standards conform to the Dublin Core Metadata initiative, which has been adopted by many governments and across many industries worldwide [50].

It has also been proposed that the Government of Kenya formulate standards and related guidelines for domain name registration and the documentation of directory services for all government entities to follow [32]. As healthcare is a service offered by the Government of Kenya, we expect to see the government establish this under the Ministry of Health. Another proposal is that access standards be established covering things that need to be in place to obtain access to information, such as security (authentication), expected features of defined access methods (including presentation for disabled clients), and the range of expected transactions, e.g., peer-to-peer (relying on data integration).

It has also been proposed that a common framework be put in place for cost-effective delivery of e-government services across different government agencies and levels by implementing interoperability guidelines and standards that allow for electronic sharing of data [32], including:

- data integration covering matters needed to allow for the recognition of data, including codes, recognition methods, interpretation, including formats used (relying on interconnection elements)
- matters related to data exchange including transmission mechanisms, transfer mechanisms that link the transfer medium and an end party, and security and protocols for managing the connection.

The Kenyan legislation does not provide specific legal or regulatory text defining or dealing directly with ICT related matters [21]. Accordingly, electronic legal transactions, electronic contracts, electronic evidence and crime issues are not currently subject to any specific legislation. Hence, the following actions are needed:

- The legal environment relative to ICT matters needs to be examined, together with the related opportunities and constraints.
- Legal steps need to be taken to facilitate the introduction and implementation of ICT standards and guidelines, as part of the process leading to enhanced eHealth. This will also enable the examination of issues related to e-signatures and e-transactions in that context.
- The ICT standards and guidelines should be reviewed in conjunction with the Global Policy Document, which presents related policies and recommendations. It is imperative to note that no constitutional, legal or regulatory provision forbids the introduction of ICT standards and guidelines in Kenya, whether at the government level or any other level.
- The proper authority to introduce, set-up and monitor the implementation of ICT standards and guidelines applicable in eHealth needs to be identified.

While this article presents the specific alignment of the FAIR Guidelines to the policy direction given in Kenya, the overall finding is that no obstacles were identified to the adoption of the FAIR Guidelines in digital health data curation. On the contrary, the direction in which the regulatory framework is developing is consistent with the FAIR Guidelines. The situation in Kenya is similar to other countries where FAIR Equivalency was researched, notably in Uganda [14], Nigeria [52], Ethiopia [53], Zimbabwe [54], as compared and reported in Van Reisen et al. [34].

5. CONCLUSION

The digital health community in Kenya and the region continues to develop rapidly [51]. Our analysis of the documents has shown that there is a gap in health data stewardship in Kenya, which could be understood as a window of opportunity to introduce and implement the FAIR Guidelines. The FAIR Guidelines are not explicitly mentioned in any of the policy documents that are relevant to Kenya's digital health sector. However, a lot of FAIR Equivalent terms and concepts are mentioned, in particular the need for interoperability among heterogeneous systems has been comprehensively described.

Among the prerequisites for the successful implementation of FAIR in health data is a thorough understanding among the scientists and stakeholders who are in positions of leadership of the FAIR concept and the steps needed to make data FAIR [55]. The documents analysed in this study were authored by institutions with a nationwide mandate to provide leadership, guidance, and support for digital health efforts in Kenya. However, our analysis has shown that the leadership is yet to make any provisions for the introduction and implementation of the FAIR Guidelines in Kenya. We recommend that the leadership be provided with a comprehensive introduction to the FAIR Guidelines, including a demonstration of the steps needed to make health data FAIR in a way that is aligned with the local infrastructure and context, as well as a demonstration of what has been achieved in other parts of the world as a result of FAIRification of health data and health research infrastructure. It would also be interesting to conduct further research into the readiness of the already existing local infrastructure, context and legal environment to adopt the FAIR Guidelines.

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CONFLICT OF INTEREST

All of the authors declare that they have no competing interests.

ETHICS STATEMENT

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