

FAIR Guidelines and Data Regulatory Framework for Digital Health in Nigeria

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ABSTRACT

Adopting the FAIR Guidelines—that data should be Findable, Accessible, Interoperable and Reusable (FAIR)—in the health data system in Nigeria will help protect data against use by unauthorised parties, while also making data more accessible to legitimate users. However, little is known about the FAIR Guidelines and their compatibility with data and health laws and policies in Nigeria. This study assesses the governance framework for digital and health/eHealth policies in Nigeria and explores the possibility of a policy window opening for the FAIR Guidelines to be adopted and implemented in Nigeria’s eHealth sector. Ten Nigerian policy documents were examined for mention of the FAIR Guidelines (or FAIR Equivalent terminology) and the 15 sub-criteria or facets. The analysis found that although the FAIR Guidelines are not explicitly mentioned, 70% of the documents contain FAIR Equivalent terminology. The Nigeria Data Protection Regulation contained the most FAIR Equivalent principles (73%) and some of the remaining nine documents also contained some FAIR Equivalent principles (between 0–60%). Accordingly, it can be concluded that a policy window is open for the FAIR Guidelines to be adopted and implemented in Nigeria’s eHealth sector.

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ACRONYMS

DHIS	District Health Information Software
FAIR	Findable, Accessible, Interoperable, Reusable
FE-Score	FAIR Equivalency Score
ICT	information and communication technology
NIN	National Identity Number
VODAN	Virus Outbreak Data Network

1. INTRODUCTION

Data is ubiquitous and the Internet has made it widely available to global users and audiences. Although a significant amount of data stored is searchable using search engines, the data stored in repositories is not easily discoverable or accessible. Some data is fragmented and separated, making it difficult to make sense of the information that it portrays. Hence, the data held in most repositories is not easily interoperable, uniquely identifiable or machine readable, which constitute the basic requirements for research and development.

To this end, a set of guidelines called the FAIR Guidelines—that data should be Findable, Accessible, Interoperable and Reusable (FAIR)—were proposed to encourage good data management [1]. The FAIR Guidelines were developed in Europe by a group of interested stakeholders calling for data and services to be *FAIRified*. Since then, FAIR has rapidly gained attention from multilateral and national organisations, the European Union, as well as G7 and G20 nations. The European Commission has agreed that, from 2020 onwards, all publicly-funded scientific research will be expected to incorporate FAIR-based Guidelines in all research domains.

The FAIR Guidelines demand that both humans and machines can easily discover data and metadata. When data is not 'FAIR', it is difficult to perform the meaningful investigations and analyses that are typically needed to address research problems. By making the data contained in repositories Findable, Accessible, Interoperable and Reusable, users will be able to extract full value, saving time and money. While much progress has been made in FAIRifying data repositories in Europe, less has been achieved in Africa [2]. To address this, in 2020, the Virus Outbreak Data Network (VODAN) was established to facilitate the commencement of this process [3].

2. OBJECTIVES AND RESEARCH QUESTIONS

The main aim of this study was to examine the digital and health policy governance framework in Nigeria to assess to what extent it is aligned with the FAIR Guidelines in order to explore the possibility of a policy window opening for the adoption and implementation of the FAIR Guidelines in Nigeria's eHealth sector.

The specific objectives of this study were:

- To identify the relevant digital and health policy documents in Nigeria
- To evaluate the extent to which the FAIR Guidelines are mentioned in the digital and health policy documents in Nigeria
- To determine the extent of FAIR Equivalency in the policy documents examined
- To explore the possibility of a policy window opening for the FAIR Guidelines to be adopted and implemented in Nigeria’s eHealth sector

The research questions were:

- Q1. What are the data, digital and health policy documents in Nigeria?
- Q2. How are the FAIR Guidelines represented in these documents?
- Q3. What is the extent of FAIR Equivalency in the policy documents examined?
- Q4. Is there a policy window open for the adoption and implementation of the FAIR Guidelines in Nigeria eHealth sector?

3. HEALTH AND ICT POLICIES IN NIGERIA

3.1 Health Policies

The World Health Organization-International Telecommunication Union (WHO-ITU) Toolkit describes a framework for the stages of development of national information and communication technology (ICT) for a health enabling environment [1]. According to Wilkinson et al. [1], Nigeria could be considered as transitioning from ‘experimenters’ and early adopters to ‘developing and building up’ ICT in the health sector. Countries at the developing and building up stage are directed to:

- Strengthen existing systems
- Ensure that guidelines and policies are in place and enforced
- Establish funding and planning mechanisms for full transition to an enabling environment and long-term success

Table 1. Health related policies.

SN	Title	Year	Source of document	Website
1	HIV and AIDS Act	2006	Ministry of Health	https://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_127527.pdf
2	National Health Act	2014	Nigerian Health Watch	https://nigeriahealthwatch.com/wp-content/uploads/bsk-pdf-manager/2018/07/01_-Official-Gazette-of-the-National-Health-Act-FGN.pdf

The law establishing Nigeria's Federal Ministry of Health also establishes the National Council on Health and the National Planning Commission. The National Council on Health serves as an advisory board on health issues and is the highest policy-making body for healthcare in the country. In 2013, the National Council on Health issued a mandate for the routine reporting of data from all primary health facilities into the national data warehouse administered by the Department of Health Planning, Research and Statistics. The National Planning Commission, which reports directly to the president, is responsible for setting national priorities and goals and engendering consensus across government agencies [4].

While efforts have been made to strengthen the existing system in terms of adopting global models of health care delivery [4], not so much attention has been given to data management. Nigeria has virtually no robust electronic and interoperable health records for individuals, as most health facilities maintain their own records and make referrals using paper [5]. Patients' medical histories are still largely documented on paper and kept in files and cabinets. Over the years, however, some select health services have been supported by external funding to provide harmonised electronic aggregate data for use locally and globally. In 2006, Nigeria adopted the District Health Information Software 2 (DHIS2) as a platform for data management, deployed for HIV and other related services. It was referred to as the Nigeria National Response Information Management System [6]. This system enables participating facilities to enter and analyse patient data from their facilities. The data entered in the DHIS platform is aggregate data, not individual data, which inhibits deeper research on data available.

However, Nigeria's DHIS is yet to be integrated with other services. Until recently, the integration of the various information systems ('Interoperability') using the National Identity Number (NIN), which is aligned with international best practices on data reuse ('Reusability') was not prioritised, although stakeholders have continued to raise these issues [7, 8]. Only recently, the Federal Ministry of Communication and Digital Economy, through its agencies the Nigeria Communications Commission and Nigeria Identity Management Commission, mandated all mobile telephone subscribers to integrate their mobile phones with the NIN before the end of January 2021 or risk losing their phone number [9].

Kingdon [10] posits that policy change happens when three streams—the problem, political, and policy streams—converge. In this case, the 'problem stream' was the absence of a unified national record, which has resulted in lack of comprehensive information on citizens, which is necessary for planning and efficient service delivery across all sectors including health [8]. Compared to the past, when citizens had little trust in the process and the government showed indifference [7], recent regulations [9] and enforcement [11] in Nigeria have indicated a readiness of the 'political stream' [10] to effect a policy change and, hence, a National Identity Number is now recognised. With an overwhelming enrolment of over 54 million Nigerians [12], the general public are clearly desirous of using this as a means to access services, including in healthcare settings.

Hence, it appears that there is only a small divide between the opinions and beliefs of the stakeholders that need to be convinced to accept the FAIR Guidelines as part of the national healthcare system in Nigeria and the FAIR Guidelines. The difference between the FAIR Guidelines and the beliefs of stakeholders and practitioners who are expected to use these principles can be referred to as cultural entropy [13]. Van

Reisen [13] posits that if cultural entropy is big, it will usually affect the acceptance of the FAIR Guidelines. However, given the aforementioned developments in Nigeria, and leveraging the gains made by the NIN system, there appears to be a policy window open to include FAIR Guidelines in health systems data management in Nigeria.

3.2 ICT Policies

Established in 2011, the Federal Ministry of Communication Technology, now the Federal Ministry of Communication and Digital Economy [14], oversees ICT-related policy formation, implementation monitoring and evaluation, as well as the supervision and oversight of most government ICT-related projects and initiatives. The Ministry seeks to improve infrastructure, optimise the use of existing resources and build capacity. Similar to the Ministry of Health, the Ministry of Communication and Digital Economy exerts its operations through its departments and agencies [4].

Table 2. ICT related policies.

SN	Title	Year	Source of document	Website
1	Nigeria Communication Commission Act	2003	Nigeria Communication Commission	https://www.ncc.gov.ng/accessible/documents/128-nigerian-communications-act-2003/file
2	Nigeria Identity Management Commission Act	2007	Nigeria Identity Management Commission	https://www.lawyard.ng/wp-content/uploads/2016/01/NATIONAL-IDENTITY-MANAGEMENT-COMMISSION-ACT.pdf
3	Cyber Crime Act	2015	Nigeria Identity Management Commission	https://www.cert.gov.ng/ngcert/resources/CyberCrime_Prohibition_Prevention_etc_Act_2015.pdf
4	Consumer Code of Practice Regulation	2018	Nigeria Communication Commission	https://www.ncc.gov.ng/docman-main/legal-regulatory/regulations/102-consumer-code-of-practice-regulations-1/file
5	Registration of Telephone Subscribers	2011	Nigeria Communication Commission	https://www.ncc.gov.ng/docman-main/legal-regulatory/regulations/201-regulations-on-the-registration-of-telecoms-subscribers/file
6	Nigeria Data Protection Regulation	2019	National Information Technology Development Agency	https://ictpolicyafrica.org/api/documents/download?_id=5eb9686c7c7814001bc4ca8b

In part due to the number of relevant government departments and agencies, ICT for health is decentralised and roles are not clearly defined. Competing programmes and priorities within the government further complicate the development of a coordinated cross-ministerial ICT for health strategy [4]. The establishment of an inter-ministerial governing body for ICT for health with representation from all levels of the health system was supposed to provide a platform for the strategic alignment of health informatics activities [4]. Such a platform would also serve to improve cross-sector communication and collaboration by facilitating shared learning, promoting transparency and partnerships, and encouraging the adoption of best practices. However, it is still not clear how this will be possible under the current federal structure.

4. MATERIAL AND METHODS

This study is basically a literature review that involved analysing health-related policy documents published by the government of Nigeria and identifying the mention of the FAIR Guidelines or FAIR Equivalent terminology in the documents. According to Basajja et al. [15] and Mutatina et al. [16], who studied the regulatory framework in Uganda, five steps are involved in the analysis of policy documents. These steps include identification of the research question; identification of the relevant documents; screening and selection of the documents; charting of the data; and collating, summarising and reporting the results [16]. The same steps are followed here.

4.1 Identification of Relevant Documents

The first research question asks: What are the data, digital and health policy documents in Nigeria? A total of 10 documents, including policies/policy frameworks, acts (of parliament), strategies and programmes (hereafter, referred to as 'policy documents'), were identified as relevant to the research questions in this study (see Table 3). These documents are ICT or health related and published by the government of Nigeria. All of the documents were obtained from the websites of the relevant government institutions. The 10 documents included in the analysis were published between 1999 and 2019.

4.2 Mention of FAIR Guidelines in Policy Documents

The second research question is concerned with the extent to which the FAIR Guidelines are mentioned in the policy documents that establish the health regulatory framework in Nigeria. The policy documents that were selected as relevant to the eHealth sector (Table 3) were carefully analysed by coding and labelling [15, 17] to verify whether or not they mentioned the FAIR Guidelines, using a binary system: '1' corresponded to cases where the policy documents mentioned the FAIR Guidelines (FAIR Mention) and '0' to cases where the FAIR Guidelines were not mentioned (see Table 4).

4.3 FAIR Equivalency in the Policy Documents

Research question three is concerned with establishing the degree of FAIR Equivalency in the policy documents analysed. The policy documents were analysed with regard to whether or not they mention the equivalent of the 15 sub-criteria of the FAIR Guidelines (also known as 'FAIR facets'), as set out in the foundational FAIR article [1] (see Appendix 1 for an explanation of each facet). 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') [1]. A detailed and comprehensive analysis of the mention of the equivalent of the 15 FAIR facets in each of the policy documents was carried out using the coding-labelling approach [15]. In this analysis, the mention of the equivalent of the FAIR facets in the policy documents was labelled by appending the code for the appropriate FAIR facet (i.e., 'F1', 'F2', 'F3', 'F4'; 'A1', 'A1.1', 'A1.2', 'A2'; 'I1', 'I2', 'I3'; 'R1', 'R1.1', 'R1.2', 'R1.3') to the corresponding statement [15]. Policy documents were arranged in rows, while the FAIR facets were arranged in columns. For each policy

Table 3. Policy documents analysed.

SN	Title	Year	Source of document	Website
1	Constitution of Federal Government of Nigeria	1999	Nigeria Identity Management Commission	https://lawsfnigeria.placng.org/laws/C23.pdf
2	Freedom of Information Act	2011	Ministry of Information	https://www.cbn.gov.ng/FOI/Freedom%20Of%20Information%20Act.pdf
3	Nigeria Communication Commission Act	2003	Nigeria Communication Commission	https://www.ncc.gov.ng/accessible/documents/128-nigerian-communications-act-2003/file
4	Nigeria Identity Management Commission Act	2007	Nigeria Identity Management Commission	https://www.lawyard.ng/wp-content/uploads/2016/01/NATIONAL-IDENTITY-MANAGEMENT-COMMISSION-ACT.pdf
5	Cyber Crime Act	2015	Nigeria Identity Management Commission	https://www.cert.gov.ng/ngcert/resources/CyberCrime__Prohibition_Prevention_etc__Act__2015.pdf -
6	HIV and AIDS Act	2006	Ministry of Health	https://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_127527.pdf
7	National Health Act	2014	Nigerian Health Watch	https://nigeriahealthwatch.com/wp-content/uploads/bsk-pdf-manager/2018/07/01_-_Official-Gazette-of-the-National-Health-Act-FGN.pdf
8	Credit Reporting Act	2017	Credit Bureau of Nigeria	https://www.crccreditbureau.com/uploads/files/Credit-Reporting-Act-2017.pdf
9	Registration of Telephone Subscribers	2011	Nigeria Communication Commission	https://www.ncc.gov.ng/docman-main/legal-regulatory/regulations/201-regulations-on-the-registration-of-telecoms-subscribers/file
10	Nigeria Data Protection Regulation	2019	National Information Technology Development Agency	https://ictpolicyafrica.org/api/documents/download?_id=5eb9686c7c7814001bc4ca8b

document, the mention of the equivalent of the FAIR facet was labelled with a '1' and the lack of mention was labelled '0' in the corresponding data cell (see Table 4). This analysis using a spreadsheet is similar to the framework approach, an increasingly popular approach to the management and analysis of qualitative data in health research [18]. The objective was to establish what the limitations are, if any, in getting clinical health data FAIR under the Nigerian regulatory framework [cf. 17].

5. RESULTS AND DISCUSSION

5.1 Mention of the FAIR Guidelines in the Policy Documents

The analysis of whether or not the policy documents mention the FAIR Guidelines found that although none (0%) of the documents explicitly mention the FAIR Guidelines, 7 out of the 10 documents (70%) mention the equivalent of the FAIR Guidelines (or FAIR Equivalent) (see Table 4).

Table 4. Coding and labelling of whether FAIR Guidelines or FAIR Equivalent were mentioned ('1') or not mentioned ('0') in the policy documents analysed.

SN	Title	Year	Fair mention	Fair Equivalent
1	Constitution of Federal Government of Nigeria	1999	0	0
2	Freedom of Information Act	2011	0	1
3	Nigeria Communication Commission Act	2003	0	0
4	Nigeria Identity Management Commission Act	2007	0	1
5	Cyber Crime Act	2015	0	0
6	HIV and AIDS Act	2006	0	1
7	National Health Act	2014	0	1
8	Consumer Code of Practice Regulation	2018	0	1
9	Registration of Telephone Subscribers	2011	0	1
10	Nigeria Data Protection Regulation	2019	0	1
	Total number of documents			7

5.2 FAIR Equivalency in the Policy Documents

The FAIR Guidelines comprise 15 facets. These 15 facets, as defined by Wilkinson et al. [1], are the 15 FAIR sub-criteria of 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 (see A 1). Table 5 highlights how these facets are reflected in the policy documents analysed.

The policy documents were carefully reviewed for mention of the equivalent of the FAIR sub-criteria. Each mention of any of the 15 sub-criteria was scored '1' while no mention of the sub-criteria was scored a '0' across all documents. A FAIR Equivalency Score (FE-Score) was obtained by aggregating the scores for all the 15 sub-criteria per policy document, with the highest possible score being 15.

From Table 5, we can see that the Cyber Crime Act contained no mention of the FAIR Guidelines or FAIR facets (and, therefore, scored 0). This means that the document does not conform with any of the FAIR Guidelines. In contrast, the Nigeria Data Protection Regulation had the highest mention of FAIR Equivalent principles and FAIR facets, with a score of 11 out of 15. This means that the Nigeria Data Protection Regulation policy conforms the most with the FAIR Guidelines.

It is important to highlight the fact that although some policies reflect some of the FAIR Guidelines, most do not contain the complete set of FAIR facets for each principle or element. For instance, although the Nigeria Identity Management Commission Act recognises 'Findability' (F1) (i.e., that data and metadata can be assigned a globally unique and persistent identifier), it does not require data to be described with rich metadata (F2) or for metadata to be clearly and explicitly included in the identifier of the data it describes (F3).

The findings reveal that the regulatory framework does not place any restrictions on the implementation of the FAIR Guidelines in Nigeria and, in principle, most regulations appear to support FAIR Guidelines by application or implication, as highlighted above. These findings reflect the conclusions drawn by researchers who implemented the study on the FAIR Equivalency of the regulatory frameworks in Uganda [15], Kenya [19], Ethiopia [20], Zimbabwe [21] and Indonesia [22] and the comparative analyses presented in [8].

Table 5. FAIR Equivalency in the policy documents analysed.

SN	Policy document	F1	F2	F3	F4	A1	A1.1	A1.2	A2	I1	I2	I3	R1	R1.1	R1.2	R1.3	FE-Score	
1	Constitution of Federal Government of Nigeria	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	1	2
2	Freedom of Information Act	1	0	0	1	1	1	1	0	0	0	0	0	0	0	0	1	6
3	Nigeria Communication Commission Act	0	0	0	0	0	1	0	0	1	0	0	1	0	0	0	0	3
4	Nigeria Identity Management Commission Act	1	1	0	0	1	0	1	0	1	0	0	1	0	0	0	0	6
5	Cyber Crime Act	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
6	HIV and AIDS Act	1	0	0	1	1	1	1	0	1	0	0	1	0	1	0	1	9
7	National Health Act	1	0	0	1	1	1	1	0	1	1	0	1	0	1	0	0	9
8	Consumer Code of Practice Regulation	1	1	0	1	1	0	1	0	1	0	0	1	1	1	1	1	10
9	Registration of Telephone Subscribers	1	1	0	1	1	0	1	0	0	0	0	1	1	1	1	1	9
10	Nigeria Data Protection Regulation	1	1	0	1	1	1	1	0	0	0	1	1	1	1	1	1	11

6. CONCLUSION

The general objective of this study was to assess the extent to which FAIR Guidelines or FAIR Equivalent principles are contained in Nigeria's health and ICT policy documents. The results show that FAIR Guidelines are not mentioned in any of the policy documents analysed in this study. However, 70% of the documents mention FAIR Equivalent principles. The Nigeria Data Protection Regulation has the highest FE-Score of 11 out of 15.

Policies such as the adoption of the NIN as a unique identifier in Nigeria's national identity management system can enable 'Findability', 'Interoperability' and 'Reusability'. The recent policy of linking the NIN number to mobile phones is one notable step in this direction. The core ICT policy documents had the highest FE-Scores, indicating that there is some level of awareness about FAIR in the ICT sector. The FE-Scores for health-related policies also indicates some degree of alignment with the FAIR Guidelines.

In summary, there is a good (70%) reflection of FAIR Equivalent principles in Nigeria's ICT and health policy documents, which have an encouraging overall FE-Score. However, there is a need to ensure that the FAIR Guidelines are reflected more prominently in health policy documents [10, 11]. Given the strategic role of the Nigeria Data Protection Regulation and the NIN regulations in the Nigeria ICT and eHealth ecosystem, it can be said that a policy window is open for the FAIR Guidelines to be adopted and implemented in Nigeria's eHealth sector. Stakeholders can leverage this window to strengthen existing policy for eHealth governance in Nigeria, as the cultural entropy [23, 2] underpinning the values of FAIR and of the regulatory framework for (e)Health in Nigeria appears to be relatively small.

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AUTHORS' CONTRIBUTIONS

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methodology and validation. Francisca Oladipo (francisca.oladipo@kiu.ac.ug, <https://orcid.org/0000-0003-0584-9145>): supervision, and Writing—review and editing. Hauwa Limanko Ibrahim (ibrahimhauwa977@gmail.com), 0000-0002-4056-6442): investigation and data curation.

CONFLICT OF INTEREST

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

ETHICS STATEMENT

Tilburg University, Research Ethics and Data Management Committee of Tilburg School of Humanities and Digital Sciences REDC#2020/013, June 1, 2020-May 31, 2024 on Social Dynamics of Digital Innovation in remote non-western communities

Uganda National Council for Science and Technology, Reference IS18ES, July 23, 2019-July 23, 2023.

Letter of Endorsement by the Government of the National Regional State of Tigray, Bureau of Health. Ethiopia, SAS/277/2020, October 7, 2020

Data Processing Agreement between Kampala International University and Musa Ango Abdullahi, Registrar, IBBUL (Nigeria), November 9, 2020

Data Processing Agreement between Kampala International University and Dr Sakinat Folorunso, OOU (Nigeria), November 8, 2020

Data Processing Agreement between Kampala International University and Prof. Meriem Ghardallou, Université de Sousse (Tunisia), November 9, 2020

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APPENDIX 1. THE FAIR GUIDELINES

The following FAIR facets are excerpts from: Wilkinson, M. D., et al.: Comment: The FAIR Guiding Principles for scientific data management and stewardship. *Scientific Data* 3(1), 1–9 (2016)

To be findable:

- F1. (meta)data are assigned a globally unique and persistent identifier
- F2. data are described with rich metadata (defined by R1 below)
- F3. metadata clearly and explicitly include the identifier of the data it describes
- F4. (meta)data are registered or indexed in a searchable resource

To be accessible:

- A1. (meta)data are retrievable by their identifier using a standardized communications protocol
 - A1.1 the protocol is open, free, and universally implementable
 - A1.2 the protocol allows for an authentication and authorization procedure, where necessary
- A2. metadata are accessible, even when the data are no longer available

To be interoperable:

- I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation
- I2. (meta)data use vocabularies that follow FAIR Guidelines
- I3. (meta)data include qualified references to other (meta)data

To be reusable:

- R1. meta(data) are richly described with a plurality of accurate and relevant attributes
 - R1.1. (meta)data are released with a clear and accessible data usage license
 - R1.2. (meta)data are associated with detailed provenance
 - R1.3. (meta)data meet domain-relevant community standards