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Design and Implementation of FAIR principles in digital health data in Uganda, Africa

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Chapter 2

VODAN Africa and Asia

This chapter is partially based on the following publications:

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Mirjam van Reisen, Mia Stokmans, Munyaradzi Mawere, Mariam Basajja, Antony Otieno Ong'ayo, Primrose Nakazibwe, Christine Kirkpatrick, Kudakwashe Chindoza; FAIR Practices in Africa.Data Intelligence 2020; 2 (1-2): 246–256. doi: https://doi.org/10.1162/dint_a_00047

Abstract

This chapter provides the global perspective on the transformative role of FAIR principles in scientific data management and stewardship with a specific focus on Africa. This highlights the persistent challenges within African healthcare systems, as illustrated in Table 2.2, underscoring the urgent need for inclusive and equitable FAIR practices in diverse scientific domains. A detailed analysis of FAIR Data implementation across continents and scientific fields was presented, revealing significant disparities. The concentration of initiatives in biological and natural sciences, primarily in Europe and America, raises critical concerns about the global inclusivity of FAIR principles in Africa and Asia. Building on this context, the chapter examines how the Virus Oubreak Data Network(VODAN) initiative addresses key challenges, including barriers to collaboration, limitations in data reuse, sustainable development, and the co-creation of knowledge. Kingdon's theory of agenda setting is applied to the African context to explore the adoption of FAIR Data, emphasizing the pivotal role of policy actors in facilitating this transition. Within this framework, the chapter positions VODAN-Africa as a leading advocate for FAIR principles in Africa, highlighting its strategic efforts to address these challenges. Reference is made to the GO BUILD programme, which enhances stakeholder awareness and promotes the development and use of FAIR Data. These efforts underscore VODAN-Africa's unwavering commitment to fostering the adoption of FAIR principles, ultimately contributing to a more inclusive and sustainable data ecosystem in the region.

Keywords: FAIR Data, health, digital health, digital health in Africa, mHealth, data-driven science, FAIR Implementation networks, GO-FAIR

2.1 Introduction

The global landscape of scientific data management and stewardship has been transformed by the implementation of the FAIR principles [30]. Designed to enhance the findability, accessibility, interoperability, and reusability of data, these principles represent a significant milestone in promoting effective data management and collaboration across diverse scientific disciplines [31]. The adoption of FAIR practices is a key factor that has emerged to provide the necessary innovative remedies rooted in digital health frameworks for the issues faced in African healthcare systems [37]. The FAIR principles are vital as they offer a structured framework for managing data, which is essential to address challenges in disease surveillance and healthcare delivery.

While the global impact of FAIR principles has grown considerably [37], Africa's healthcare systems present unique challenges that demand special attention. This is evident in the dominance of FAIR data management within current health systems and the bio-ecology field in Africa, despite limited application of FAIR principles in other scientific disciplines and communities across the continent [38]. To address this, African institutions must increase the implementation of FAIR principles to ensure that best practices outlined in the FAIR guidelines are consistently applied across diverse disciplines.

To resolve the challenges facing existing healthcare systems, FAIR principles must be integrated into digital healthcare. Van Reisen and others highlight a geographical imbalance in the adoption of FAIR initiatives, with widespread implementation in the biosciences of Europe and the United States. In contrast, the systems in Africa remain in the early stages of adopting FAIR principles [39]. This chapter, therefore, focuses on introducing VODAN (Virus Outbreak Data Network), which is a program that is designed to address the challenges that are associated with data on viral outbreaks in Africa and Asia. Furthermore, the chapter highlights the significance of VODAN Africa and Asia in addressing data management challenges across these continents. By presenting this information, the chapter contributes to a broader understanding of the global application of FAIR Data.

2.2 Implementing FAIR Principles in Africa and Asia

The Virus Outbreak Data Network (VODAN) is a pioneering initiative driving transformations in data management, aligned with advancing the adoption of FAIR principles across Africa and Asia. To understand the context of FAIR Data use, it is essential to examine the distribution of efforts across scientific disciplines and continents, as illustrated in Table 2.2. This table[1] provides valuable insight into the current state of FAIR adoption worldwide, emphasizing the importance of broad coverage across scientific disciplines.

[1]**Source:** van Reisen et al. [30]

Table 2.1: Global distribution of FAIR Data implementation efforts across continents and scientific disciplines (n=100)

	Africa	America	Europe	Europe+	Other	Unknown	Total
Bio-science	1	11	53	5	2	12	84
Natural science	0	3	5	1	0	2	11
Social science	0	0	3	0	1	1	5
Total	1	14	61	6	3	15	100

The distribution of FAIR Data implementation efforts reveals significant disparities across continents and scientific disciplines. Notably, most biological science programmes are concentrated in Europe. In contrast, only one programme is situated in Africa, raising critical concerns about the inclusiveness of FAIR principles in the African context. In this context, VODAN is pivotal in advancing FAIR Data processing and management. VODAN primarily targets viral outbreak data in Africa and Asia, addressing critical gaps in data management for infectious diseases. The programme aligns with FAIR principles, contributing significantly to efforts aimed at ensuring data is findable, accessible, interoperable, and reusable. The subsequent sections delve into the challenges VODAN faces in implementing FAIR principles and examine the broader implications of these efforts for digital health solutions in Africa and Asia.

2.2.1 Challenges in Digital Health Implementation

Several inherent challenges shape the effectiveness of digital health initiatives in Africa. This section outlines these challenges and examines their impact on data management and utilisation within the framework of FAIR principles. As shown in table 2.2, these challenges include collaboration challenges, data reuse issues, limited scalability issues, lack of knowledge sharing, and insufficient short-term effort.

Table 2.2: Challenges in Digital Health Implementation in Africa

Challenges	Description
Interoperability challenges [4-8]	Diverse digital health systems face obstacles in achieving seamless data exchange and integration, hindering collaborative efforts.
Data reuse issues [2, 7, 9]	Challenges that are associated with data reuse remain, including disparate systems, inconsistent documentation, and divergent data standards, preventing a unified digital health system.
Limited sustainability [2, 10-13]	Digital healthcare often has difficulty maintaining long-term impact and relevance. Many initiatives focus on short-term goals, preventing the development of robust, scalable solutions.
Lack of co-knowledge building [2, 14, 15]	Collaborative knowledge-building efforts among stakeholders are insufficient, limiting collective impact.

Collaboration challenges present a major obstacle, as digital health systems often fail to achieve seamless data exchange and integration. These challenges hinder collaborative efforts and restrict the ability to achieve comprehensive and integrated healthcare solutions. Data reuse challenges exacerbate the situation, as varying formats, incompatible documentation, and disparate data standards impede the development of a unified digital health ecosystem. Limited sustainability remains a pervasive issue, with digital healthcare initiatives frequently needing support to maintain long-term impact, relevance, and scalability. Such limitations hinder the development of robust and scalable solutions. Additionally, insufficient knowledge sharing among stakeholders constrains collaboration and diminishes the overall impact of digital health interventions.

2.2.2 Understanding the Adoption of FAIR Principles

Kingdon's theory, also known as the multiflow model [48], is a framework that is used to explain the administrative process. It can also be applied to the process of technology adoption in organizations. Technology adoption occurs when all three strands come together at the same time. This requires the presence of a problem to address, a viable technical solution, and the political will to adopt the solution. The theory also recognizes the importance of structure involving professionals who consist of individuals or groups working to focus attention on a problem or a solution and mandates adoption, the planning staff in technology adoption, such as IT professionals, consultants, or other stakeholders who have basic technical skills, and other stakeholders who advocate for the adoption of a particular technology. Overall, Kingdon's theory offers a valuable framework for comprehending the complex process of technology adoption. It also highlights

the need to address problems, devise viable solutions, and navigate the political landscape to successfully implement new technologies within organizations. This discussion examines how VODAN aligns with Kingdon's theory of abundant water, emphasizing its role in lobbying for FAIR principles and highlighting the program's function as a policy agent advocating for their adoption in the region. [2]

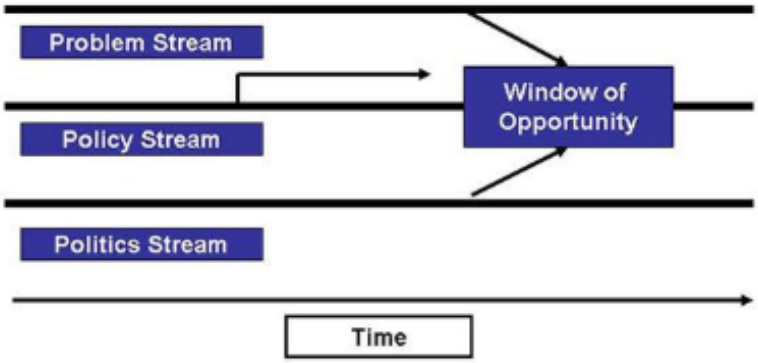

Figure 2.1: Conceptual representation of the Kingdon's multiple streams framework, illustrating the convergence of the problem, policy, and politics streams to create a window of opportunity for policy change

The theoretical framework underpinning this thesis is partially derived from Kingdon's three-stream model. Kingdon posited that the process of policy agenda-setting comprises the problem stream, the policy stream, and the political stream. Kingdon identified that new ideas could enter the policy agenda when the problem, potential policy solutions, and political relevance of the problem are aligned. At such a point of alignment, a policy window opens, which is a specific moment in time, when a new idea can enter the policy agenda [49]. The dynamic process that Kingdon describes allows for the investigation of how policy changes and the role of policymakers and other policy entrepreneurs, who are 'members' of policy networks in a certain domain [39, 49].

Van Reisen and others explain that the discrepancy between the FAIR Principles and the opinions and beliefs of researchers and practitioners who are expected to use these Guidelines can be considered cultural entropy [42]. The authors go on to argue that if cultural entropy is large, it will hinder the acceptance of the FAIR Principles, as it is likely to result in a discrepancy in terms of what is perceived as the problem and what the solution could be. Kingdon's theory has been used to analyze the FAIR Principles [30]. It has also been applied to the implementation of the FAIR Principles when managing scientific data [48, 50]. The framework that is presented in Kingdon's theory has been used widely since the publication of Kingdon's "Agendas, Alternatives and Public Policies" in 1984. This theory has also been used to examine the cause of the gaps that are in modern

[2]Source: `https://www.policynl.ca/`

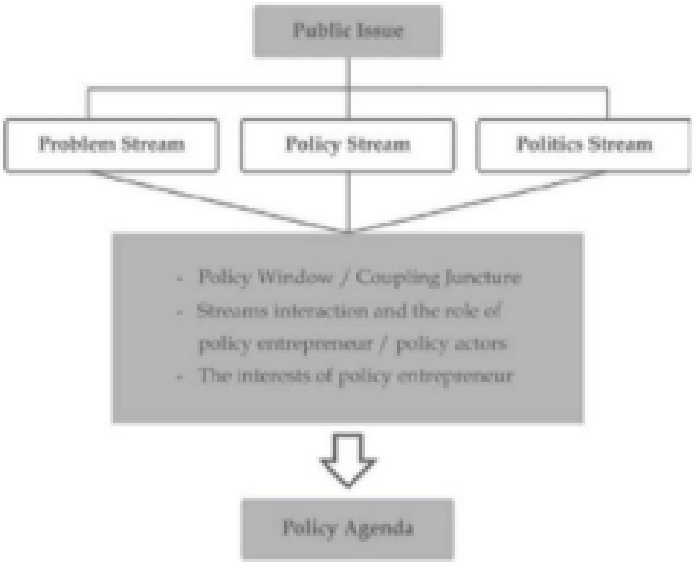

Figure 2.2: Kingdon's multiple streams theory of agenda setting.

slavery policies [49]. It is often used to understand the reasons for policy changes and the processes that are followed in making those adjustments. Kingdon's theory starts by acknowledging that the process of change is not linear or logical and that actors causing this change are limited by bounded rationality. Kingdon's framework is relevant to a wide range of governance systems and policy applications, including implementation in both national and sub-national layers of governance.

Initiatives like VODAN are pivotal in advancing FAIR principles through actively advocating for the adoption of these principles and facilitating the implementation of FAIR-compliant data management practices. Lastly, the "political" stream encompasses the broader socio-political landscape that influences policy decisions. Political support and commitment from key stakeholders are important to driving the systemic adoption of FAIR principles.

2.2.3 Conceptual Framework

This study uses Kingdon's multi-stream theory of agenda setting as a conceptual framework. Kingdon's model, which is illustrated in 2.2, provides a comprehensive understanding of policy and policy establishment. These three elements are interrelated in the theory: problem streams, policy process, and politics.

Source: [271]

In the problem stream, issues are identified and recognized as problems that require solutions. For example, this study recognizes the inefficient use of data and the need to effectively manage data in emergencies. Planning strategies are then developed to

address the problems that were identified. The policy stream involves developing policy alternatives to address the identified problems. Here, the FAIR Principles are a solution to the under-utilization of data. The political stream also identifies the political will to shape how a specific issue is addressed. In the context of this research, political support from entities like the European Commission and African governments helps to support FAIR Principles.

The intersection of these three streams creates a "policy window," which is a critical moment where new ideas, such as the global adoption of FAIR principles, can enter the policy agenda. This framework provides guidelines for analyzing the global adoption and implementation of FAIR principles. It considers the interplay between identified problems, proposed solutions, and the political will to adopt these solutions on a global scale. This conceptual framework provides a lens through which the dynamics that influence the adoption of FAIR Principles can be examined. In turn, this emphasizes the role of policy actors, the urgency of the problems that have been identified, and the alignment of political will for the FAIR principles to be implemented worldwide in the Internet-based FAIR Data and Services (IFDS) [53].

2.2.4 The Acceptance of FAIR Data principles and their Implementation

The factors that influence the acceptance and successful implementation of FAIR principles include perceived usefulness, ease of use, and the alignment of FAIR design and implementation with the changes that are constantly occurring within the Information and Communication Technology (ICT) sector.

The GO FAIR initiative [117], originally launched on their official website during its actively funded phase (2017-2020), emerged as a global network of offices and implementation networks aimed at kick-starting FAIR-aligned data infrastructures, initially within the context of the European Open Science Cloud (EOSC). Over time, GO FAIR evolved beyond its original European mandate, with offices and implementation activities spreading globally, reflecting the broader and continuing need for FAIR guidance across domains and regions.

In its current phase, often referred to as GO FAIR, GO FAIR functions as a loosely federated international network of offices, supported and coordinated through the Dutch GO FAIR Foundation (GFF), which now acts as the primary legal entity sustaining the initiative. The GFF founded the GO FAIR brand and logo and plays a central role in maintaining continuity, coordination, and strategic direction in the absence of large-scale central funding. Rather than evolving into a bureaucratic organization, GO FAIR has intentionally remained lightweight, emphasizing facilitation, interpretation, and practical implementation of FAIR principles, particularly with a strong focus on machine-actionable aspect of FAIR.

Strategically, GO FAIR continues to operate through three interrelated pillars: GO CHANGE, GO TRAIN, and GO BUILD. GO CHANGE focuses on socio-cultural transformation by promoting policies, incentives, and stakeholder engagement that support

the adoption of FAIR principles. This pillar addresses the diverse beliefs, motivations, and concerns of stakeholders involved in data collection, sharing, and reuse. GO TRAIN coordinates awareness-building and skills development, with an emphasis on cultivating competent data stewards capable of designing and implementing FAIR-compliant data management plans. GO BUILD concentrates on aiding to choose, align and coordinate FAIR-aligned technical standards, best practices, and interoperable infrastructure components required for effective FAIR data implementation. Together, these three pillars form a coherent strategy that positions GO FAIR as a facilitative framework guiding communities toward robust FAIR adoption.

The ICT architecture exemplified by GO BUILD helps shape perceived usefulness and ease of use, which influences the implementation of the FAIR principles for digital health data in Africa [30, 31, 117]. In the process of building applications, decisions are made about including specific research characteristics and how they should be implemented within a framework that is aligned with the FAIR principles. These decisions, driven by human choices, contribute to the utility of FAIR for specific research purposes within defined frameworks. However, it is important to acknowledge that the current design of the FAIR principles may not fully account for the diversity of research practices and contexts in the real-world. This implies that it is necessary for FAIR Data implementation to be adaptable and applicable to a broader range of research settings beyond the controlled environments in which it may have been initially conceptualized or tested, that is, bio-science, natural science, and social science. These oversights pose challenges to the broader acceptance of FAIR in diverse research practices, especially within FAIR Data Implementation [30, 31].

In the context of African healthcare care, the acceptance of FAIR faces obstacles related to contextual understanding, limitations in digital connectivity, and skepticism about the intentions of this European idea. Historical interactions with European initiatives, marked by extraction and exploitation, have created a perception that Europeans, in this case, are extracting and storing data out of reach of African communities. Moreover, existing data gathering practices are often Eurocentric as they fail to consider African perspectives, objectives, and epistemology. To counteract these challenges, the African scientific community must become a major player in co-designing, co-implementing, and co-monitoring the FAIR architecture for Africa. This has been done by VODAN Africa in collaboration with Universities, Hospitals, and Ministries in policy formulation [56].

To advance FAIR globally, it is crucial to explore the barriers and opportunities associated with its implementation. Two key perspectives for analysis are the public policy agenda-setting that shaped the FAIR Data architecture and the acceptance of FAIR Principles by researchers and practitioners in their daily practices.

From a public policy perspective, the acceptance of FAIR Data depends on opening a policy window that aligns with societal needs. This also requires a synergy between the problem stream, policy stream, and political stream, as described by Kingdon [30, 31, 49]. Social entrepreneurs play a vital role in identifying challenges, promoting ideas, and activating political will to embrace FAIR. Events that change the dominant issues on the

agenda can trigger synergy among the streams, emphasizing the importance of focusing on such events for the worldwide implementation of FAIR. Motivations, beliefs, and opinions of different stakeholders influence the acceptance of FAIR Principles. Social entrepreneurs must be aware of these varying motivations and objectives among policymakers, data managers, researchers, and practitioners. The GO CHANGE initiative is critical in motivating potential users and fostering acceptance. It does this by addressing diverse beliefs and opinions about data collection, use, and reuse. In order for FAIR to gain broad global acceptance, it is essential that cultural entropy is addressed, diverse research domains are considered, and alignment with the beliefs and practices of the research community is ensured. When initiatives like GO CHANGE and GO BUILD are implemented together, they can significantly contribute to overcoming barriers and facilitate the global adoption of FAIR Principles.

2.2.5 Conclusion

The FAIR principles have achieved significant acceptance and implementation, representing a major milestone in the advancement of data management and stewardship. Nevertheless, the current implementation landscape demonstrates that FAIR adoption remains disproportionately concentrated in the Western hemisphere, particularly within the bio- and natural sciences. Expanding FAIR adoption globally, therefore, requires broader disciplinary coverage and contextual adaptation, ensuring that FAIR applications are relevant across diverse research domains and epistemologies. Such inclusivity is essential not only for improving the generalizability of research outcomes but also for enabling the development of robust, context-sensitive research and implementation models. For FAIR to achieve sustained global uptake, it is imperative that researchers, practitioners, and policymakers collectively recognize its value while acknowledging variations in digital infrastructure, research cultures, and data governance norms.

Within this evolving landscape, the GO FAIR movement continues to play a pivotal facilitative role. Following its initial centrally funded phase, GO FAIR has transitioned into a lightweight, internationally federated network of offices, coordinated and sustained through the GO FAIR Foundation. Rather than operating as a prescriptive or bureaucratic authority, GO FAIR increasingly functions as a FAIR co-pilot, supporting communities in interpreting, implementing, and aligning FAIR principles with local needs and capacities. The GO CHANGE initiative remains particularly significant in this regard, as it addresses socio-cultural diversity, stakeholder motivations, and resistance to change through awareness-building and engagement. The training and coordination of Implementation Networks (INs) under this pillar continue to be central to fostering acceptance and enabling FAIR-aligned practices across domains. As architects of interoperable FAIR data spaces, INs contribute to the development of foundational frameworks that support FAIR integration across heterogeneous academic and applied research environments.

VODAN-Africa and Asia represent critical regional contributions to the global FAIR implementation journey. Established in 2019 as African-led initiatives, these networks bring together partners across multiple countries to address region-specific challenges

such as contextual misalignment, infrastructural constraints, and concerns regarding data ownership and sovereignty. Their work demonstrates how FAIR principles can be operationalised in ways that respect local priorities through approaches certified as Findable, Accessible, Interoperable, and Reusable with Ownership, Localization, and Regulatory Compliance (OLR). By engaging in initiatives aligned with GO BUILD and participating actively in policy formulation alongside universities, hospitals, and ministries, VODAN-Africa and Asia exemplify how FAIR can be co-designed, co-implemented, and co-governed. Such regionally grounded engagement underscores the importance of combining technical guidance with socio-political sensitivity, reinforcing the role of GO FAIR and its partners in enabling equitable, sustainable, and globally relevant FAIR data ecosystems.