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

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Chapter 9

Discussion, Outlook and Conclusion

9.1 Observations Answering the Research Questions

The study sought to address the core question that revolved around whether FAIR data principles can overcome the issues of data non-interoperability and limited reuse within Africa. This question is vital to determine the viability of FAIR data to solve fundamental problems in digital health environments.

To answer this, the following specific research questions were defined:

> To what extent is the lack of policy on data management, data sharing, and data analysis a contributing factor to the lack of use of clinical and health data in Uganda, Africa?
>
> Can the introduction of systematic use of the FAIR principles help overcome the challenges of interoperability and reusability to the development and maintenance of digital health data in Uganda?
>
> How can data analytics of health data be propagated, integrated, and maintained through FAIR data?
>
> Can FAIR Data support and strengthen the accessibility of different types of health data, as well as aggregated health data analytics and machine learning models?

The unique contribution of this research lies in its demonstration of how the principles of FAIR data can be successfully implemented in resource-limited healthcare settings, such as Uganda. Specifically, this study shows that applying FAIR principles not only addresses data interoperability and reusability challenges but also facilitates privacy-preserving accessibility, hence opportunities like machine learning and federated learning improvements, which are crucial for advancing collaborative research among different institutions. By proving the feasibility of FAIR data in these settings, this research fills a critical gap in the existing literature.

The findings of this research affirm the enormous possibilities of implementing FAIR data principles in transforming digital health systems in Uganda. One of the findings is that the absence of well-coordinated policies on handling, sharing, and utilising big data makes their use nearly impossible. This gap poses difficulties in interoperability and data reuse, which are key factors in developing a sustainable framework of effective and efficient digital health systems. These are the problems that systematic deployment of FAIR principles can help solve, as shown by the experience of creating the VODAN (Virus Outbreak Data Network) in Africa and Asia. This endeavor embodies the virtues of the FAIR principles when it comes to handling and merging health data, especially after viral epidemics [30, 230].

The focus of this research is not on improving individual patient care but rather on using aggregated health data to identify population-level patterns. By analyzing large datasets, the research highlights key trends in disease outbreaks, health behaviors, and treatment outcomes, which can inform public health policy and resource allocation at the national level. This approach has the potential to improve healthcare systems by providing insights that go beyond individual treatment and contribute to the systemic management of health challenges.

Despite the promising outcomes of applying FAIR principles, several bottlenecks were encountered during the implementation phase, especially when transitioning from paper-based records to digital systems. Resistance from healthcare staff accustomed to paper-based processes was a significant hurdle. Furthermore, challenges related to data standardization and

ensuring interoperability among diverse health institutions were prevalent. However, by training personnel and emphasizing the benefits of FAIR data, these challenges were mitigated, and health facilities gradually embraced the digital shift. Moreover, some issues related to data security and privacy concerns arose, but the careful implementation of FAIR's access control mechanisms helped alleviate these concerns.

One of the main observations in this research is that the adoption of the FAIR principles has the potential to contribute significantly to the interoperability and reusability of data. It is easy to understand why the principles are advantageous after synthesizing the ideas from this thesis and especially the case studies where the FAIR principles were applied to existing data management architecture in Uganda. Generally, FAIR data have contributed to improving data access and reusability by researchers among multiple organisations and improving disease management [231].

In addition, the application of FAIR principles has shown promising outcomes regarding data analytics, as applying these principles ensures that data are easily accessible for analysis. Consequently, the analyzes gain an enhanced potential to provide the means for developing knowledge that is useful in informing the policies that are required and the practices in data management employed. This is especially the case in Uganda, where the proper use of data could significantly improve healthcare systems in the country. In addressing the research questions, the study found that the lack of a data management policy was a significant barrier to effective use of health data in Uganda. The introduction of FAIR principles helped overcome these barriers by establishing a framework for data interoperability, secure sharing, and reusability. As a result, machine learning models have been more effective in predicting disease outbreaks and assessing health risks. Furthermore, systematic use of FAIR data has improved the accessibility of various types of health data, improving the ability to track health trends and guide policy decisions.

The principles of FAIR have helped to maintain privacy-preserving accessibility in the management of health data. This has the potential to foster trust and increase data access and re-usability among different countries. The study identified several cases where FAIR data principles were applied to health data analysis to ensure access and reusability under well-defined terms. This is relevant as data privacy are increasingly becoming core issues in data handling [232]. The main contribution of this research lies in its demonstration that the application of FAIR data principles can significantly improve the accessibility of health data, the collaboration between institutions, and the reuse of health data for machine learning in a resource-limited setting. This work provides a conceptual framework and a practical example of integrating FAIR principles in digital health systems, paving the way for more effective disease management, health policy decisions, and predictive modeling in Uganda and similar settings across Africa.

9.2 Implications for Practice

The application of the FAIR principles provides a variety of solutions to the problems associated with the sharing and reuse of data in the Ugandan digital health system. Therefore, the application of the FAIR principles supports research efforts and data protection. The principles of FAIR raise the possibility that health professionals, policy makers, and data managers in Uganda should embrace the management of health data in a manner that would allow them to provide efficient public health services and promote health outcomes in Uganda.

This thesis illustrates the practical implications of advancing patient care through the efficient handling of health information. When the FAIR principles are applied to healthcare practices, patient data can be accessed to perform data analytics whenever needed. The findings of this can be used to provide patients with better care promptly [233]. Moreover, applying FAIR data principles to the monitoring of public health challenges supports the management of such public health phenomena through improved data collection and analysis [234].

Long-term partnerships are advantageous because overall cost benefits will be realized through improved data management, as redundancy of original data structures will not be as much of an issue. Consequently, healthcare facilities can improve operational efficiency and reduce data storage and management costs [235]. In addition, the application of FAIR data principles can help develop innovative solutions for healthcare systems. For example, using high-quality, interoperable data can make machine learning and other advanced analytical techniques more productive. Contributes to the development of predictive machine learning models and other tools that can be used to improve health care services and outcomes [29].

One of the most significant benefits realized after FAIRifying health data in Uganda was the improved access of data between institutions, enabling better collaboration among healthcare providers. With improved interoperability and data sharing, healthcare professionals were able to access real-time analytics, leading to better-informed decision-making in disease management and resource allocation. Furthermore, the increased data reusability fostered innovation in predictive modeling for disease outbreaks, improving public health responses. [29]

9.3 Limitations of the Study

While this research provides various valuable insights into the adoption of FAIR principles, several limitations need to be acknowledged. This study was primarily focused on some of the health facilities in Uganda and, therefore has not been adopted throughout Uganda; therefore, there are limitations in the generalizability of this study in other related settings without further validation. Furthermore, the implementation of FAIR principles has been successfully implemented within the VODAN-Africa project, which comprises a variety of countries, thereby indicating a level of technological readiness within these countries. Although insights from the VODAN initiative form a rich case study, more data from different health facilities could strengthen the conclusions made. Moreover, the research did not dive fully into the economic effects of FAIR. The principles of FAIR have helped to maintain privacy-preserving accessibility in the management of health data. This has the potential to foster trust and increase data access and re-usability among different countries. The study identified several cases where FAIR data principles were applied to health data analysis to ensure access and re-usability under well-defined terms. This is relevant as the FAIR principles can potentially serve as a strength for decision-makers [236]. Adopting FAIR data principles involves changing the practices employed in managing, reproducing, and sharing data, which is difficult in environments where conventional practices have been established, for example, the use of paper registers. Mitigating this resistance will be a challenge that will require specific initiatives to sensitize and involve the various stakeholders at different levels [237].

9.4 Call to Action

To reach the tipping point of the application of the FAIR data principles, the combined efforts of stakeholders and policymakers to prioritize the development and implementation of supportive policies and frameworks are required. Health professionals and data managers must be trained on the relevance of FAIR principles to embrace them FAIR principles, and as a result, they would embrace these and build their capacity on the principles for better application. More research is needed to create and share appropriate guidelines and innovative methodological approaches for the process followed in implementing the FAIR data principles [238]. Moreover, it is now important for international organizations and donors to support the initiatives that promote the adoption of the FAIR principles in developing countries. Such organizations can contribute funding and technical assistance to establish the framework and expertise necessary for the implementation of FAIR data [239]. Stakeholders are encouraged to embrace FAIRification and data collaboration, as this will help improve the health of the population [240]. The sustainability of FAIR data practices must be checked regularly. This will help identify the areas that require more growth to improve the effective use of these principles. Therefore, the recommendations of stakeholders should be taken into account while the process of enhancing data management practices is ongoing [241].

The adoption of FAIR data principles offers substantial benefits, including streamlined data access, reduced duplication in data management, and enhanced data security. To realize these benefits on a larger scale, healthcare professionals and policymakers must prioritize the integration of the principles of FAIR into healthcare practices, ensuring that health data are not only secure but also useful for improving patient outcomes and public health management.

To fully realize the potential of FAIR data, health professionals, policy makers, and international organizations need to collaborate on the implementation of supportive policies and frameworks. Capacity building and training programs for healthcare professionals will be key to ensuring that FAIR data principles are adopted and integrated into routine healthcare practices, ultimately improving the quality of health systems.

9.5 Future Research Directions

Future studies should promote the development and enactment of political strategies that facilitate the use of FAIR data in Uganda. This encompasses policies and practices that meet the international standards of data collection, storage, utilization, and analysis thus encouraging policy development and implementation. Such guidelines should also incorporate the unique circumstances that may surround the handling of data [242]. Stakeholders should also be educated about the impacts that policy interventions have on information processing and the resulting health consequences of implementing them.

To support the principles of FAIR, educational courses for capacity building and training must be developed and launched to enhance the capacity of healthcare professionals and data managers to implement these principles. These courses should be able to provide information presentations that are aimed at ensuring the maximum level of awareness is achieved with the key competencies required to implement the FAIR data principles [243]. The interventions provided by these training programs should be assessed to understand the effectiveness of the implementation.

Further studies should focus on the development of the technical infrastructure and tools

that support FAIR principles. In this sense, such solutions and initiatives include the financial investment in digital solutions and platforms that aim to communicate and implement the principles of FAIR in data interoperability, access, and reuse [244]. Investigations should also factor in the costs and efficiencies of the options available in different industries and identify how different management strategies could be applied to those options. There is a need for advanced directions in applying the FAIR data principles to other progressive solutions, including artificial intelligence and blockchain. Studies in this field can find best practices that use these technologies for the FAIR data framework [248]. Researchers should also assess the preparedness of various health systems for these technologies and identify various hurdles to implementation.

Case studies should be conducted in areas or institutions that have successfully used the FAIR data principles, as this could reveal recommendations that can be used in different contexts. Relative research can be useful in defining the factors that can be influential in the effective implementation of the FAIR approach [245]. Recording and sharing such practices can help other countries and organizations to apply FAIR principles more effectively since they are based on the experience of other nations.

For future research, it is relevant to investigate the changes in health outcomes and efficiency of healthcare systems due to the implementation of the principles of FAIR data for impact assessment and evaluation. This involves evaluating how well FAIR data have improved data quality and decision-making while being of value to public health initiatives [246]. Actual patient health studies that monitor outcome indicators will be more informative about the practical effects of implementing FAIR data principles over time.

Future work should also analyze how to encourage stakeholder participation and collaboration, such as government bodies, healthcare organizations, and societies, to embrace the principles of FAIR data. It is crucial to have multi-stakeholder engagement approaches that can increase the sustainability and FAIRness of data [247]. Studies should be carried out on the patterns of interconnection between participants and knowledge of the approaches to cooperation.

Future research should investigate the evolving role of the GO FAIR initiative as a lightweight long-term coordination mechanism for the implementation of FAIR. As GO FAIR has transitioned from a centrally funded project into a loosely federated international network of offices, coordinated through the GO FAIR Foundation, further studies are needed to assess how such non-bureaucratic governance models can sustainably support FAIR adoption across diverse regions and disciplines. In particular, research should explore the effectiveness of GO FAIR's emerging *FAIR co-pilot* role, which focuses on guiding communities to implement FAIR principles properly rather than prescribing uniform solutions.

Additionally, future studies should examine how national and regional GO FAIR offices, operating with minimal resources, can maintain networking value, knowledge exchange, and interpretative guidance in the absence of central funding. Comparative analyzes between regions could provide insight into how GO FAIR coordination interacts with local policy environments, capacity-building initiatives, and technical infrastructures. Such research would contribute to understanding whether federated coordination models, supported through modest pooled resources and collaborative governance, can offer a scalable and resilient pathway for sustaining FAIR principles globally [117]. When it comes to health data, it is pertinent to highlight ethical and privacy considerations that are relevant to the discussion of the principles of FAIR data. It is also important that future studies emphasize best practices in data privacy and security

while at the same time encouraging data reuse [248]. This covers the issues of data accessibility, privacy protection, and the possibilities of finding a workable formula on how to best address these objectives.

Future work should also include highly specific, versioned analyzes of economic aspects of the adoption of the FAIR data principles. This would include a cost-benefit analysis, identifying the main financial implications and proposing financing models geared toward long-term implementation [249]. An accurate perception of the economic impact of FAIR data is another beneficial factor, as it would formulate a base to decide on how funds are to be spent.

Longitudinal patient health studies that include monitoring outcome indicators will be more informative on the practical effects of implementing the FAIR data principles over time. Such studies can help reveal trends, determine the long-term impact of data interoperability, and establish the new policies required [250]. Investigations should also be conducted to discover the determinant constructs that make up sustainable FAIR data.

With the ongoing development of digital health and biomedical research, the ability to access distributed data will become one of the major areas that will promote innovation. The emphasis should no longer be on having the data centralized at a single point but accessible in a distributed architecture. This distributed access is also key to facilitate collaboration and improve efficiency in health research. The fact that data need to be not only available but also findable and usable across geographies cannot be overstated, and this is particularly the case as the amount of health data continues to increase exponentially.
Researchers should be able to access various datasets distributed in various hospitals, health organizations, and even countries. It is imperative to ensure that even when data are made accessible, no security or privacy being jeopardized, and the new developments in technologies such as federated learning and data encryption may allow such data accessibility without privacy concern. Effective data sharing and access have been a major determinant of the future of digital health, and it will be critical to establish systems that enable researchers to access data stored in distributed sources to address health issues in the population and develop new scientific knowledge.

9.6 Conclusion

The use of FAIR data principles is a good solution to address the issues of data interoperability and reuse within the Ugandan context of digital health. These FAIR principles can improve the use of health data both in terms of efficiency and effectiveness by closing the gaps in the policy landscape, data integration, analysis, and hence data reuseability through privacy-preserving access. Therefore, the conclusions of this study serve as a basis for future projects that aim to improve data management approaches in Uganda and other countries. The directions for future research presented in this chapter could potentially enable new contributions to this body of knowledge and expand the knowledge and application of FAIR data principles in Uganda and the rest of Africa's health sector. These initiatives will also help promote better health and advance the availability of information to inform decision-making, as well as strengthen the development of the health system in the region. By embracing FAIR data principles, Uganda and other African nations can unlock the full potential of their health data, drive evidence-based policy, and decisively transform the future of healthcare delivery across the continent.