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ICT in Business

FAIR-based digital health in the East African Community:

Designing an Eldoret FAIR Data Point

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MASTER'S THESIS

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Abstract

The cross-border healthcare in the East African Community (EAC) experiences challenges due to the limited real-time accessibility of data to enable informed decision making. Digital health has been proposed as a method to improve the current state of cross-border healthcare so that, even the remote areas can access data. However, due to the various forms of health delivery systems, finding and accessing the data can be challenging. This presents a need for using new methods to improve the way that data is managed. The FAIR principles are guidelines that can facilitate the Findability, Accessibility, Interoperability, and Reusability (FAIR) of data which do not focus on centralizing the data but rather assigning the data metadata and ensuring that it is machine readable. This makes the data not only human but machine actionable. These principles would benefit the EAC due to the fact that they won't require data to be centralized to ensure cross-border healthcare.

In this study, the use of FAIR principles in the digital health systems in the EAC is explored. The Kingdon and the Technology Acceptance Model (TAM) are employed as theoretical frameworks to explore the relationship between public policy and the acceptance of the FAIR principles as well as the newly introduced digital health systems. Literature reviews are included to provide contextual information regarding cross-border healthcare and matters on data governance and data management in the EAC. In addition to literature, expert meetings, and interviews are conducted with the aim of gaining a deeper understanding on the subject area in order to facilitate the design research activities where a FAIR data point model is developed for the EAC.

The findings on the acceptance of digital health concurred with TAM which indicated the perception on usefulness and ease of use of the newly introduced digital health systems affected the outcomes of the digital health interventions in the EAC. Additionally, the need for a change in public policy on data governance and data management in the EAC was highlighted to improve the methods currently in use. The FAIR principles can be incorporated into digital health systems if the users find the FAIR principles useful and practical, and if the public policies are formulated to adopt the FAIR principles.

Key words: The East African Community, Digital health, Digital health governance, FAIR principles

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Table of Contents

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1 Introduction

Technologies such as smartphones, social media, and internet applications have transformed the way that communication happens today (Castells, 1990). In terms of healthcare, they have provided innovative ways in which individuals can monitor their health and lifestyle and have revolutionized the ways in which health professionals and health providers can deliver healthcare (Neubert, 2017). An example of this is patients using sensors and Near Field Communication to monitor glucose levels (Bailey, Bode, Christiansen, Klaff, & Alva, 2015). The use of these technologies alongside genomic revolution is known as digital health (Digital Health & Care Institute, 2018). Digital health has enabled better tracking and management of healthcare, the aim being to improve access, efficiency, and quality as well as provide personalised healthcare (Digital Health & Care Institute, 2018).

The East African Community (EAC) is a region that could benefit from digital health due to its *"double burden"* of both Communicable Diseases (CD) and Non-Communicable Diseases (NCD) (Celi, et al., 2017). The health systems in the EAC are proving to be inadequate to deal with this burden (Celi, et al., 2017). Additionally, the EAC would like to have cross-border health care due to the free movement of diseases that has resulted from the free movement of people in the region (fhi360, 2018; Pindolia et al., 2014). The goal is to have Universal Health Coverage (UHC) to reduce health inequalities and improve patient care through the use of digital health technologies (Garrett, Chowdhury, & Pablos-Méndez, 2009; Kinoti, 2018). According to the broadband commission, digital health could potentially solve the healthcare challenges faced by middle-low income countries (Scott Gegenheimer et al., 2018).

However, digital health functions with data which can be challenging when it comes to processing and analysis (UniProt, 2016). The unstructured nature of data elements can make it hard to find and analyse data and the growing size of data does not make this process any easier (Harvey, 2017). Good data governance and management practices are key to enable data to be fully exploited of its potential (Wilkinson, et al., 2016). FAIR data principles are guidelines that intend to improve the manageability and governance of data (Wilkinson et al., 2016). FAIR is an acronym that stands for Findable, Accessible, Interoperable and Reusable (Wilkinson, et al., 2016). The objectives of these

guidelines are to make data better machine and human-discoverable, easily accessible by authorised people and machines, interoperable, for data to be able to be integrated with other data to provide more insights and lastly re-usable by other parties with permission from the original author or owner (Wilkinson, et al., 2016). These principles can help with data challenges that may arise with digital health systems in the context of cross-border healthcare which involved multiple streams of data.

1.1 Problem statement

The current health systems in the EAC are plagued with various problems such as drug stock-outs, poor communication between health workers and an over-reliance on paper-based data collection methods that digital health shows promise of resolving. For instance, digital health can enable timely access to information by health workers for informed decision making (Asiimwe et al., 2011). To attain cross-border health care using digital health, data will need to be exchanged between the different health systems in the member countries. However, in Africa health systems suffer from data issues such as; availability of data, data duplication, and data analysis that does not arrive on time, (Adedeji et al., 2011; Steele & Orrell, 2017). For the data problems experienced, FAIR principles present an opportunity of guiding the way data is managed and governed. Likewise, for the effectiveness of the digital health systems that involve multiple countries, it is important for the data to be Findable and Accessible when needed, Interoperable and Re-usable (Wilkinson et al., 2016). This formulates the following research question: **How can the FAIR principles be incorporated in digital health systems in the East African Community to improve cross-border access to health?**

Objectives and Research questions

Derived from the main research question are the research sub questions and the research objectives presented in table 1.

Table 1:

Objectives and sub questions

	OBJECTIVES:	SUB QUESTIONS:	METHOD:	FINDINGS:
1.	**To highlight the current situation of cross-border health in the EAC and how digital health systems can improve the current state**	***Sub question 1:*** *What is the current state of cross-border health in the EAC?*	Interviews Expert meetings Literature review	**Chapter 4**
		Sub question 2: *To what extent can digital health improve the current state of cross-border health?*		
2.	**To assess the impact FAIR data principles can have on data-related problems in the East African Community**	***SUB QUESTION 3:*** *Can FAIR data solve data-related problems in the EAC?*	Interviews Expert meetings Literature review	**Chapter 5**
3.	**To develop a FAIR data-based model that illustrates how the cross-border health challenges can be tackled in the EAC**	***SUB QUESTION 4:*** *What would be a suitable FAIR data-based model to address the challenges of cross-border health in the East African Community?*	Interviews Expert meetings Design research	**Chapter 6**

1.2 Research relevance

Academic relevance

This research is the first to investigate the impact FAIR can have on digital health systems in the EAC. The analysis of various scientific articles relating to FAIR have illustrated that there have been various investigations on FAIR based digital healthcare in Europe and America but in comparison, FAIR based digital health in East Africa, and Africa in general has not received much attention. These articles were

grouped according to their topic, their geographical location, and whether they were articles on FAIR or that have cited FAIR. In light of this limitation, the current research provides such an investigation combining it with public policy agenda setting; to discuss how the FAIR principles implementation in the EAC can be influenced by a group policy entrepreneurs and how that process might be.

Societal relevance

The integration of the EAC with the realization of open borders means that people are free to move within the EAC and seek healthcare anywhere. If the health systems incorporate the FAIR principles, healthcare systems can be able to find decentralized data from the various health systems, patients can be able to access their healthcare despite their location, the health systems can be interoperable without the need of centralization of data, the application of provenance metadata will ensure there is evidence, there is proper management, use, and organization of data between the different health systems, government ministries such as the Ministry Of Health (MOH), and data collection organization such as National Statistics Offices (NSO) among others (Bizer, Heath, & Tim Berners-Lee, 2009).

1.3 Outline

The first chapter introduced the topic, defined the problem statement alongside the objectives the main and sub research questions aim to meet and lastly the research significance. Chapter 2 contains the theoretical frameworks of the study. As a preface, the FAIR principles are presented thereafter, the Kingdon agenda setting model and the Technology Acceptance Model (TAM) are discussed. Chapter 3 presents the research methodology used in this research. The research design, the data collection methods, and the design-research process are described. Chapter 4 presents the findings on digital health in the EAC, firstly the state of cross-border health is presented, then the digital health developments and interventions in the EAC are evaluated and lastly the chapter highlights factors to consider in governing digital health in the context of cross-border health . Chapter 5 presents the findings on data management and governance. Firstly, it begins by discussing the data-related problems in the EAC followed by how FAIR data can solve these problems. Chapter 6 describes the process behind designing a FAIR data-based model and demonstrates the proposed solution for cross-border health in the EAC. The last chapter is the conclusion and the discussions.

2 Theoretical framework

This chapter contains the theoretical frameworks defining this research. Two models are used, one on public policy agenda setting by Kingdon and the other is the technology acceptance model by Venkatesh and Davis. The two frameworks will provide an understanding on the public policy agenda setting of the FAIR principles and what will affect the acceptance of digital health and the FAIR principles in the EAC. The chapter begins by introducing the FAIR principles, giving the context and the background of FAIR, and how they will be applied in the EAC. Thereafter, the Kingdon and acceptance models will be discussed.

2.1 FAIR principles

This section will give a brief overview of FAIR Principles, the Semantic web and linked data

What are the FAIR principles?

The FAIR principles as a set of community-developed guidelines ensures that data or any digital object are Findable, Accessible, Interoperable and Reusable (Wilkinson et al., 2016). The principles specifically emphasize enhancing the ability of machines to automatically find and use data, and support its reuse by individuals/ machines (Wilkinson et al., 2016). The goal is to better manage data to be machine and human-discoverable and re-usable (Wilkinson et al., 2016). In the context of digital health in the EAC, such principles can provide the guidance on how to govern and manage data to seek the most potential from it and combat the data problems that they may incur.

Context of FAIR

Data has become an integral part of daily life, once processed, it is able to produce useful information and provide more insight. As the methods of data analysis and use of algorithms have adapted to the latest trends such as machine learning and business intelligence, the data management systems have fallen behind whereby, they are not are able to properly maintain data, data that can be used and referred to by future generations (Bauch et al., 2011). An area where data is crucial is in science, i.e. from the perspective of health, scientists rely on data when doing research to discover new characteristics of diseases, find cures, and treatments. However, the system around data does not enable the data to be optimally used especially when it comes to

reproducibility (Wilkinson et al., 2016). When one wants to re-use data, the data is either lacking relevant detailed information about the origin, what the data contains, and the structure of the data it holds, how users can gain access to the data and what they need i.e. licence requirements or to contact a person in charge to assist them with the access (Wilkinson et al., 2016). Additionally, in this era of e-Science (University of California Curation Center (UC3), 2012), data needs to be machine-actionable due to the limitations human beings possess in comparison to the complexities of e-Science (Wilkinson et al., 2016).

In 2014, stakeholders from various fields gathered in the Netherlands to discuss on how improve the ecosystem around data. From this discussion, the FAIR principles were formed to make it easier to find, access, interoperate and re-use data (Force 11, n.d.). They were formulated to create a cultivating data environment for researchers, data practitioners and data users that drives innovation and knowledge development, and that is a data-driven evidence backed environment (Wilkinson et al., 2016). In a digital world where data is growing exponentially, it has become difficult to manage and govern the data to achieve this kind of environment and the FAIR principles provide guidelines on how this can be improved (Mons, 2018). The next section presents the FAIR data principles.

FAIR data principles

Findability principle

The Findability principle assists humans as well as computer agents to firstly discover data from wherever it is stored. Especially with decentralized data, the principle encourages data to be accompanied by metadata which defines the data adequately (Wilkinson et al., 2016). In the discovery process, the metadata will be used to locate the data from the decentralized locations, instead of trying to store the data in a central location (Wilkinson et al., 2016). The findability principle also urges (meta)data to be registered and through its assigned registered ID that will distinguish the data from other data, the (meta)data can be searched (Wilkinson et al., 2016).

Accessibility principle

Second, is the Accessibility principle whereby, the registered ID is used to retrieve the (meta)data. This is to be done via a *"standardised communication protocol"* that can be adapted anywhere in the world (Wilkinson et al., 2016). The protocol needs to have provision for *"authorization"* and verification, if the necessary permissions are met i.e. license requirements, the data can be accessed (Wilkinson et al., 2016). The principle also notes that a data user should be able to access the metadata despite the data no longer existing (Wilkinson et al., 2016).

Interoperability principle

The Interoperability principle facilitates interoperability as its name suggests whereby, data can be accessed and used in combination with other data, this can be newly generated data or old data formats to provide more insight into a subject area (Wilkinson et al., 2016). However, for that to be achieved, the Interoperability principle encourages (meta)data to use shared vocabularies, vocabularies that can be commonly used for a wide range of subjects, and vocabularies that adhere to the FAIR principles (Wilkinson et al., 2016). The (meta)data should also use proper citation (Wilkinson et al., 2016).

Reusability principle

The Reusability principle specifies that meta(data) should be represented with appropriate lavish details, that contain clear usage requirements for the (meta)data (Wilkinson et al., 2016). The (meta)data should be accompanied by comprehensive provenance details and that meet *"domain-relevant community standards"* (Wilkinson et al., 2016).

Machine-actionability

A distinguishing factor of the FAIR principles is machine-actionability (Wilkinson, et al., 2016). This is when a digital object contains detailed information that it can provide to an *"autonomously-acting computational data explorer"* (Wilkinson et al., 2016). The information provided can enable the agent to:

- Recognise the type of data item (Wilkinson et al., 2016).
- Determine if the data is useful to them by examining the (meta)data (Wilkinson et al., 2016).
- Determine if they can use the data in terms of licenses, consent, or any other restrictions placed on them (Wilkinson et al., 2016).
- Act in the same manner a human being would behave in such a situation (Wilkinson, et al., 2016).

In the case of computer agents autonomously acting on the behalf of humans, when they need to access different types and formats of data, the records will be kept for proper citation of the source of the data (Wilkinson, et al., 2016).

Example of FAIR-ness

The individual elements in the FAIR principles are related but can be used independently (Wilkinson, et al., 2016). Each principle having the fundamental elements described, makes the barriers to entry for data producers, publishers and stewards who would like to make their data FAIR low (Wilkinson et al., 2016). The principles may be combined freely as the degree of 'FAIR-ness' grows in the environment of publishing data (Wilkinson, et al., 2016). An example of FAIRDOM is provided below:

> "**FAIRDOM**: integrates the SEEK (Wolstencroft et al., 2015) and openBIS (Bauch et al., 2011) platforms to produce a FAIR data and model management facility for Systems Biology. Individual research assets (or aggregates of data and models) are identified with unique and persistent HTTP URLs, which can be registered with Digital Object Identifiers (DOI) for publication ('**F**'). Assets can be accessed over the web in a variety of formats appropriate for individuals and/or their computers (RDF, XML) ('**I**'). Research assets are annotated with rich metadata, using community standards, formats and ontologies ('**I**'). The metadata is stored as RDF to enable interoperability and assets can be downloaded for reuse ('**R**')"(Wilkinson, et al., 2016).

Example of FAIR data-based healthcare

Personal Health Train (PHT) is an initiative that is embracing the move into personalised healthcare and medicine by using biomedical data that are FAIR (DTL, 2017). 'Trains' which are workflows, collect health data of individuals from distributed environments the data is contained in, and places them in FAIR stations where they are made Findable (DTL, 2017). These workflows also follow the rules enforced on pieces of data stored in the various environments (DTL, 2017). Each data element contains a licence detailed as metadata with information on what can/cannot be done to that data by a 'visiting train' (DTL, et al., n.d.). The patient provides these permissions as the owner of the data from a secure 'station' (DTL, et al., n.d.). A 'visiting train' also needs to authenticate itself before it is allowed entry into a station making it accessible and re-usable by anyone with the necessary license (DTL, et al., n.d.). In regards to interoperability, patients can give permission to researchers to use their data for example, HIV/AIDS patients can give their viral loads (DTL, 2017). Researchers can test the effects of a drug on their viral load and make quality references and assessments (DTL, 2017). Researchers can also work together in hubs to study different data samples for shared problem solving or idea generation (DTL, et al., n.d.).

The advantage PHT has is the empowerment of the patients, they are essentially in control of their data (DTL, et al., n.d.). For instance, whether they want to share their data with researchers or not is up to them to give consent to the data being used (DTL, et al., n.d.). This form of FAIR-based healthcare can also enable different health facilities that have patient data to communicate, avoiding duplicates by containing one integrated record. The patient can also freely access this data (DTL, 2017). For privacy purposes and avoiding misuse of patient data, anonymization of data can be achieved improving the security of the data (Saliba et al., 2012).

Where do the FAIR principles stem from?

This section will give a brief overview of the Semantic web and linked data where the FAIR principles stemmed from.

Semantic web

Berners-Lee et al (2001) describes the Semantic web as the extended world wide web (www) whereby, *"information is given well-defined meaning"* so that both people and machines can understand the information better and they can work together efficiently (Berners-lee, Hendler, & Lassila, 2001). Unlike the traditional methods of knowledge representation which have been centralized, where the increase of data has made them unmanageable, the Semantic web is decentralized in nature (Berners-lee et al., 2001). The technologies of the Semantic web, facilitates building of repositories on the web, building of vocabularies and formation of rules on the operations of data from any system of knowledge-representation (W3C, 2019)(Berners-lee et al., 2001). The end goal is to have a web of linked data defined as: "*data published on the Web in such a way that it is machine-readable, its meaning is explicitly defined, it is linked to other external data sets, and can in turn be linked to from external data sets*" (Bizer et al., 2009).

Linked data

An important aspect of the FAIR principles is reusability of data. For people and machines to understand data, it needs to have a well-defined structure (Bizer et al., 2009). The web uses an Application Programming Interface (API) to provide data that is structured, through standardized formats used in the www such as XML and JSON. Linked data is concerned with the relationships between these structured data, how diverse data from various sources such as books, people, and scientific publications, can be published and be linked to each other in a consistent way, and be machine-readable with its meaning *"explicitly defined"* (Bizer et al., 2009). Berners-Lee (2006) created a set of rules to achieve linked data (Tim Berners-Lee, 2006):

1. **Use URIs as names for things-** URIs are as unique identifiers assigned to data resources on the web. The most common is the URL which identifies websites.

2. **Use HTTP URIs so that people can look up those names-** HTTP is what the www uses to enable communication between a web browser and a web server, one can be able to find more information about URIs.

3. **When someone looks up a URI, provide useful information, using the standards (RDF, SPARQL)-** RDF is a graph-based data model used to structure and link data. It encodes the data into subject, predicate and object triples. The subject and object of a triple are URIs and the predicate states the relationship between the subject and the object. SPARQL is used to query heterogenous data sources and it is an RDF query service language (Eric Prud'hommeaux & Andy Seaborne, 2013).

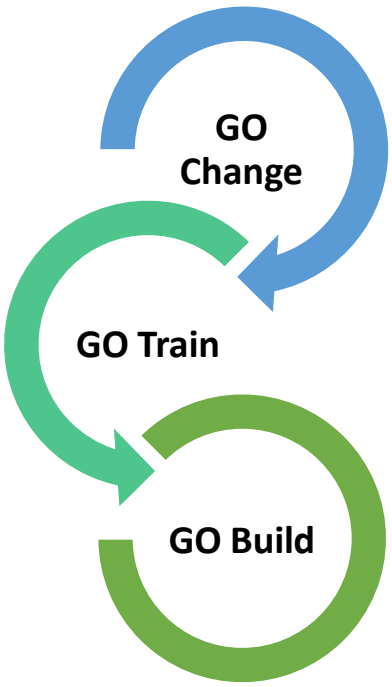
4. **Include links to other URIs, so that they can discover more things-** this is in line with having data linked to/ from external datasets as per the definition.

Linked data aims at improving reuse, external linkages to/ from data, and consumption of data. However, the FAIR principles address limitations of linked data identified by Bechhofer et al (2013) which are on lifecycle, ownership, versioning, and attribution (Bechhofer et al., 2013). Linked data is not specific on how data should be organized, managed, or consumed which is important for reusability (Bechhofer et al., 2013). In the case of linked data, data that is associated with other data should be accompanied by metadata containing the creator and creation date but does not include how the data should be used, managed, and organized (Bizer et al., 2009). The Reusable principle addresses these concerns through the need for (meta)data to have *"detailed provenance and clear and accessible data usage license"* (Wilkinson et al., 2016).

Application of FAIR in the case of the EAC

In the EAC, there is a need for cross-border Findability, Accessibility, Interoperability and Reusability of data to support the various healthcare systems. The digital REACH has endorsed the use of FAIR principles for the exchange of data within the EAOSHC. The principles will help link information from

different medical fields across the EAC and make access to information on different usage scenarios across the EAC possible. As a result, a conducive working environment for researchers, data practitioners, and medical practitioners is created. Following the endorsement of the digital REACH, there has been further development of FAIR setup in the EAC that involves GO FAIR. The GO FAIR is an initiative driven to actualise the use of FAIR in management and governance of data and services (GO FAIR, n.d.-a). They are behind FAIR Implementation Networks (a group of organizations focussed on making specific materials and instruments to use to achieve an Internet of FAIR Data and Services (IFDS) and they provide support to the INs (GO FAIR, n.d.-a) . Through the Implementation Networks (INs), they would like to push three agendas: GO Change, GO Train, and GO Build (GO FAIR, n.d.-a).



1. GO Change: Changing the culture around data to be guided by FAIR principles (GO FAIR, n.d.-a).

2. GO Train: Train data agents to be FAIR-compliant and ensure data is managed and governed properly (GO FAIR, n.d.-a).

3. GO Build: Build and ensure technology abides with the FAIR principles. i.e. implementing standards that adhere to FAIR principles (GO FAIR, n.d.-a).

Figure 1: The Implementation Network responsibilities(GO FAIR, n.d.-a).

Africa formed an IN following an expert meeting held at the GO FAIR offices and it is to focus on the three agendas of GO Build, GO Change and GO Train in the context of Africa. The needs addressed will include the building of data discovery tools that are interoperable, adoption of common and suitable standards, data stewardship training, enhancing metadata to deal with the multilingualism among others (IN Africa, 2019a). But how did the FAIR principles in the EAC get here and what role

will the Africa IN play? what will impact its adoption in terms of acceptance and public policy? The next section will discuss the public policy agenda setting process that will be involved in the EAC according to the Kingdon model, alongside the technology acceptance model by Venkatesh and Davis to provide a theoretical lens to analyse what can influence the uptake of both digital health and the FAIR principles in the EAC.

2.2 Kingdon agenda setting model for the FAIR principles in the EAC

Kingdon, (1995), defines agenda as the *"the list of subjects or problems to which governmental officials, and people outside of government closely associated with those officials, are paying some serious attention at any given time"*(John Kingdon, 1995). Agenda setting on the other hand, is the procedure in which particular public issues are recognized, and solutions or alternatives are created and considered then linked to these issues (Liu, Lindquist, Vedlitz, & Vincent, 2010). The Kingdon model of agenda-setting further describes how, why, and by whom some ideas are chosen over others to form public policies (JW Kingdon & Thurber, 1984). To address this concern, Kingdon defined three streams that are involved in the decision-making process of setting public policies: problems, policy, and politics (Wilson, 1993). According to Kingdon, public policies are developed if a window of opportunity is taken and the three streams are coupled otherwise, policies won't change (Ridde, 2009). A group of policy entrepreneurs interested in policy change will couple these three streams and take the window of opportunity whenever it arises (Ridde, 2009). The entrepreneurs may not necessarily come from the policy stream, the situation at hand and the dominant stream determines which stream they come from (Ridde, 2009). These three streams are discussed below and will be used to outline the agenda setting behind the FAIR principles in the EAC.

Problem stream

The first stream is the problems stream where issue(s) are recognized by catching the attention of decision makers. One way to catch the attention of the decision makers is to include budgetary implications of an issue in the agenda (John Kingdon, 1995). In the case of this research, it is the issue of data not being easy to find, access, integrate data with other data, reuse it by both humans and machine which caught the attention of the European Union (EU). A report published by the EU

concluded that resolving the issue would result in billions of euros being saved (PwC EU Services, 2018). This is represented by the problem stream arrow in Figure 2.

Policy stream

People in the government generally have legal powers that influence policy agendas (John Kingdon, 1995). However, people outside the government can affect the agenda setting process (Liu et al., 2010). In the policy stream, various ideas are generated from expert groups i.e. researchers, academics and data analysts which relate to the problems defined in the problem stream. These ideas are gathered, refined and proposals are created. Ideas may be selected if it's technical feasible, its value is accepted, and if it anticipates future constraints (John Kingdon, 1995). The ideas may be newly formed ideas, or they may stem from existing bodies of knowledge, in a process of recombination, they form other concepts which are the FAIR principles in this case. The FAIR principles were generated by expert groups and they stemmed from the Semantic web and Linked data as illustrated in Figure 2 (Bizer et al., 2009).

Political stream

Lastly, is the political stream which is concerned with policy making. Proposals can be considered if the political climate is good (Wilson,1993). For this research, the political stream is the digital REACH endorsing the FAIR principles to be used for the EAC region on matters regarding data sharing for the EAOSCH (EARHC, 2017). For the realization of the EAOSCH, the problem of finding, accessing, integrating and reusing data was recognized and a solution was proposed which were the FAIR principles (Ridde, 2009). The politics stream is represented by the proposals stream arrow in Figure 2.

Policy entrepreneurs

The three streams work independent of each other having their own rules however, a group of people who are determined to push their own proposals or who have set the attention to certain problems play a big role in the coupling of the three streams, since the policy and the political will is key to solving an issue, and how the problems is portrayed will determine if it will grab the attention of decision makers (Wilson, 1993). This group may provide their proposals to problems they can solve or they can advocate for the proposals from the proposals stream when the political climate is good

(Wilson, 1993). They may push an agenda when a window of opportunity arises, this is known as the policy window (Wilson, 1993). The group of people in the case of this thesis is the Africa IN represented by the red dotted rectangle in Figure 2 (IN Africa, 2019b). They have their proposals together, with an activity plan ready for a policy window to introduce the FAIR principles in Africa, to build on the semantic web as well as provide a possible solution that will address the unique data challenges faced in Africa (IN Africa, 2019a). Figure 2 outlines the agenda setting for the uptake of FAIR in the EAC. An example of a possible solution to the problem at hand is the FAIR Data Point model being developed in this research.

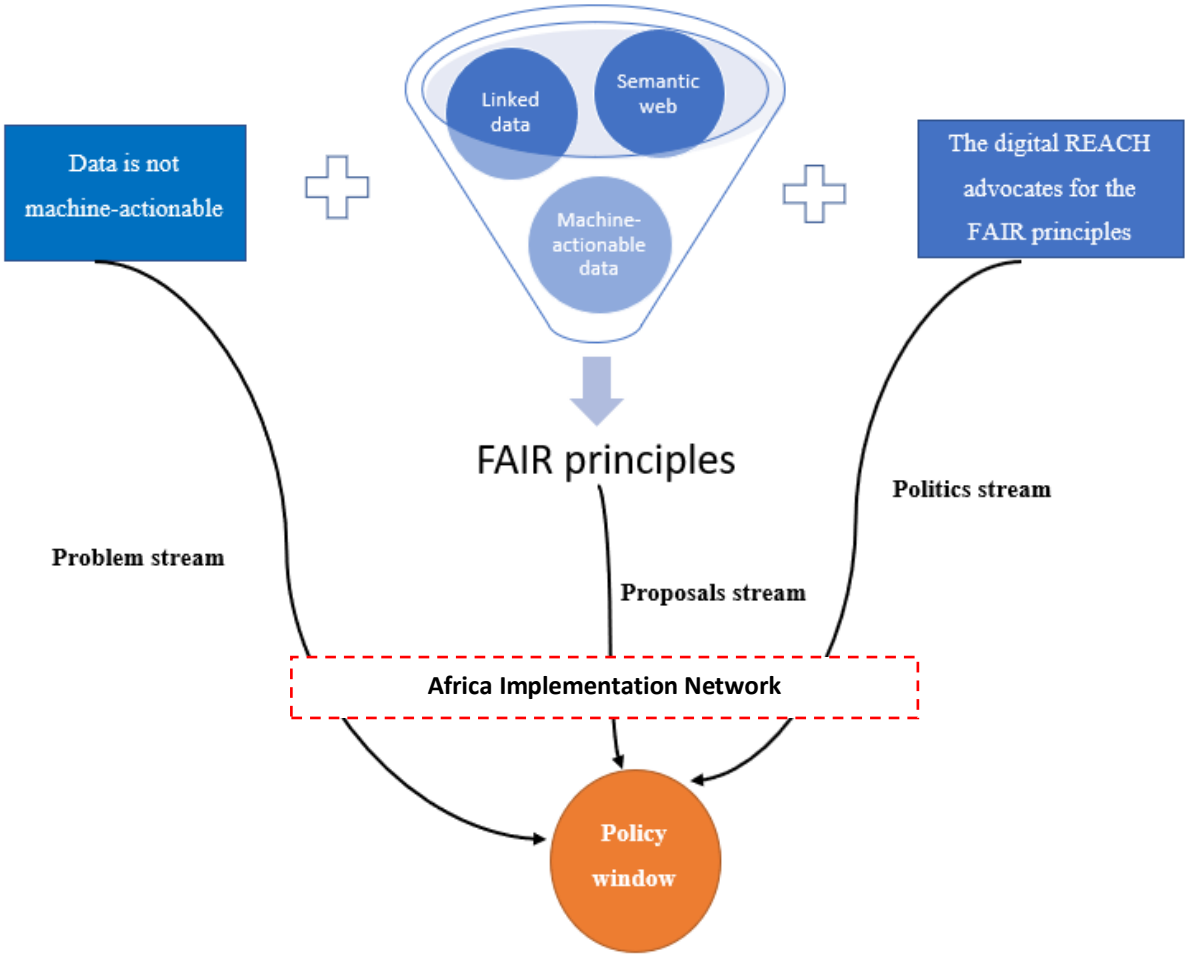


Figure 2: Agenda setting of FAIR principles in the EAC (Bechhofer et al., 2013; Berners-lee et al., 2001; Bizer et al., 2009; IN Africa, 2019b; Tim Berners-Lee, 2006; Wilkinson et al., 2016).

2.3 Technology acceptance model

The Technology Acceptance Models (TAM) by Venkatesh and Davis aims to understand what influences people to accept and use new Information Technologies (IT) (Venkatesh & Bala, 2008). It is influenced by the work of Ajzen (1975) who developed the Theory of Planned Behaviour (Fishbein & Ajzen, 1975). Venkatesh and Davis discovered two determinants that make people use new IT: perceived usefulness (if a person believes that the IT will make them perform better) and secondly

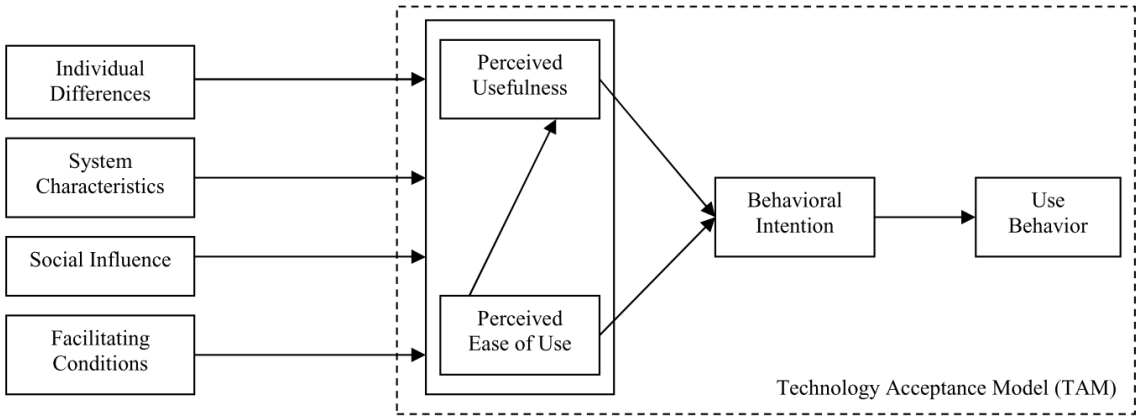


Figure 3: Technology Acceptance Model (Venkatesh & Bala, 2008).

perceived ease of use (if the technology will be easy to use) (Venkatesh & Bala, 2008).

As illustrated in Figure 3, there are four things that determine the perceived usefulness and perceived ease of use: individual differences i.e. personality, important system characteristics that make people perceive it as useful or easy to use, social influence and facilitating conditions which is the support people get when using IT (Venkatesh & Bala, 2008). Venkatesh and Davis (2008), extend the model above into TAM2 by adding individual determinants to perceived usefulness which are: image, job relevance, output quality, result demonstrability categorized under system characteristics and subjective norm and perceived ease of use which is under social influence according to Figure 3 (Venkatesh & Bala, 2008). Further defining this, are two *"theoretical processes"* that expound on perceived usefulness and behavioural intention presented below (Venkatesh & Bala, 2008).

Perceived Usefulness

According to TAM2, there are two factors that influence the perceived usefulness and the behavioural intention of a person: social influence and cognitive instruments (Venkatesh & Bala, 2008). Social influence includes compliance (a person's behaviour is affected by whether or not they will be rewarded or punished) (Miniard & Cohen, 1979), identification (a person behaviour is affected by the belief that they will raise their social status within a referent group) (Venkatesh & Davis, 2000) and lastly internalization *("the incorporation of a referent's belief into one's own belief structure"* (Warshaw, 1980). And as for the cognitive instruments, there are factors that influence perceived usefulness which include job relevance, output quality, result demonstrability, and perceived ease of use (Venkatesh & Bala, 2008). Perceived ease of use is covered next.

Perceived Ease of Use

TAM2 states that the person's perceived ease of use is affected by the way they view computers. These include their abilities on using computers, if they are apprehensive about using computers and *"computer play-fullness",* and perceptions of whether or not they are supported and they have adequate resources to use the new IT (Venkatesh & Davis, 2000).

These two theoretical models are used as an analytical lens to describe how users of digital health interventions in the EAC perceived the newly introduced systems and the outcomes which is presented in Section 4.3.1. Elements such as output quality, compliance, ease of use and support will be used to judge their reception of the new systems which will give an indication on what will affect the uptake of digital health in the EAC to improve the current state of healthcare.

Perceived usefulness and Perceived ease of use for the FAIR principles in the EAC

The FAIR principles adoption in the EAC will be affected by the GO change and GO build agendas mentioned in Section 2.1. Both the perceived usefulness and perceived ease of use of FAIR will depend on the reception of the people the FAIR principles will be introduced to. For data management and governance in the EAC, those dealing with such matters will decide on the usefulness FAIR before they can accept them (Reisen & Stokmans, 2019). The entrepreneurs with the interest of changing the policies around data to adopt a FAIR way and taking the window of

opportunity when it arises, they should be conscious of the different needs of the data users (Reisen & Stokmans, 2019). If there is any apprehension on using the FAIR principles, it will affect the acceptance. Furthermore, the GO change activities can impact the perceived usefulness and according to the support the people will have access to i.e. support from the GO FAIR offices in the Netherlands and other countries, and the resources availed to them by the GO build and GO train agenda. This which will have an effect on their perceived ease of use. These three will be critical to the acceptance of the FAIR principles use in digital health systems in the EAC for cross-border health which is what this research is investigating.

3 Research methodology

Research methodology is a systematic way to solve a problem (Ram, 2010). It is a science of studying how research is to be carried out (Ram, 2010). Essentially, the procedures by which researchers go about their work of describing, explaining and predicting phenomena aiming to give the work plan the research takes (Ram, 2010). This research methodology chapter contains the research design which gives the overall work plan, the data collection methods used to describe and explain the phenomena, the literature review techniques, and how the FAIR data-based model was developed.

3.1 Research design

The research design of this study is qualitative and applies the exploratory case study research strategy. The aim of executing this strategy was to obtain a deeper understanding on a specific phenomenon (Yin, 2009) which is the FAIR principles implementation in cross-border digital health in the EAC which has not yet been studied (Shields, 2013). The methods used to collect the qualitative data were literature review, expert meetings and interviews. The exploration of the phenomena gave insight behind the creation of the model. The FAIR data-based model used Generative design research. Figure 4 illustrates the steps taken to conduct the research.

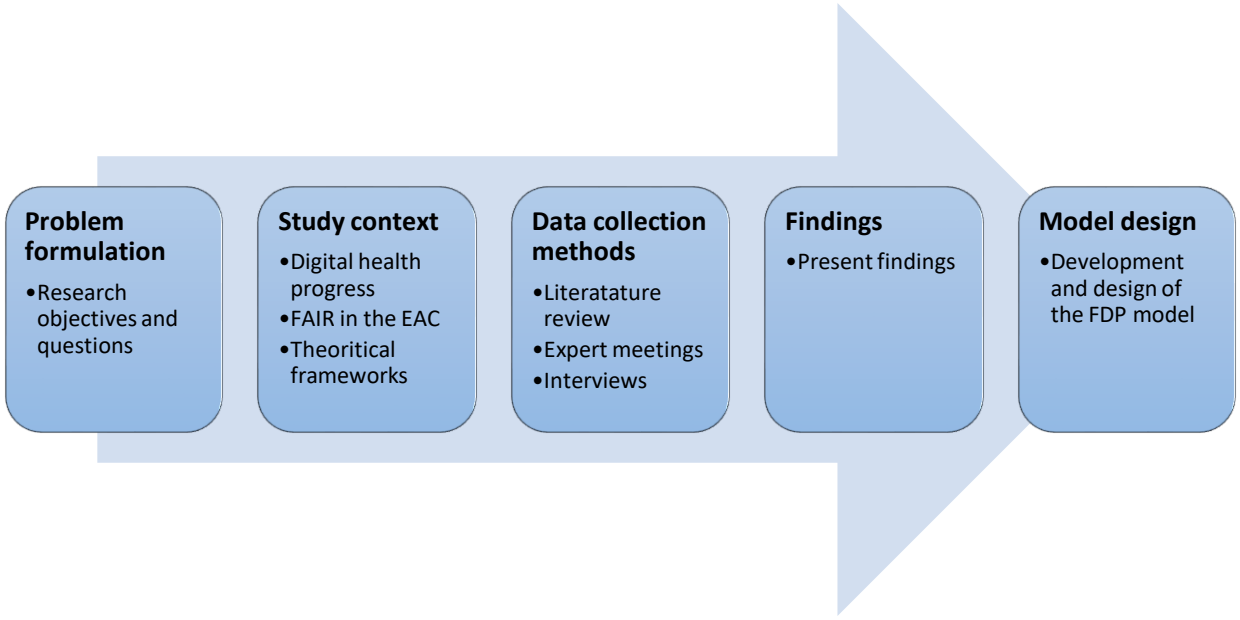


Figure 4: Research process

3.2 Literature Review

To break down the phenomenon, a literature review was performed to understand the current state of cross-border health in the EAC and gauge potential digital health can improve the current state, and to identify the data-related problems experienced in the EAC to discuss the possibilities the FAIR principles present to tackle them. This was used to gather findings for the research questions formulated. The literature search was conducted on Google to find related newspaper articles and publications on the web, Google scholar to obtain scientific articles, African Journals Online (AJOL) to gather more specific information on Africa, government sources such as the East African Community website (https://www.eac.int/), international organizations websites such as the World Bank (https://www.worldbank.org/) and World Health Organization (https://www.who.int/) and the EAC member countries' MOH websites also provided literature on health policies and health systems. Both systematic and snowballing techniques played a key role in identifying articles on the relevant topics. The snowballing search strategy was more effective in producing relevant sources especially those linked to FAIR compared to searching about FAIR on Google or Google scholar which produced limited information. The limitation faced were data from some of the East African countries; South Sudan and Burundi being difficult to find, and not finding enough scientific articles on data-related problems in the EAC. This resulted in the use of non-scientific articles found from Google. Additionally, there was a lack of articles on FAIR in the EAC. In an article by Reisen et al (2019), the findings indicate that the implementation of FAIR is mainly concentrated in European countries and Africa is barely represented which is also a reason why this research is important (Reisen & Stokmans, 2019). It adds to the pool of resources of FAIR implementation in Africa.

3.3 Expert meetings

A total of three expert meetings were attended to gather as much knowledge on digital health and FAIR principles. The expert meetings were important since the FAIR principles were in full development yet not everyone especially Africans were aware of the initiative. The groups present in the second expert meeting which was to discuss about implementation networks of FAIR was highly represented by European organizations and less by other countries. The first expert meeting was to discuss digital health, introduce the FAIR principles, and discuss on how they can be implemented in Africa. The second meeting was to learn about the progress of FAIR, who was involved in the

implementation of FAIR, how are they implementing them, and in which areas. The last expert meeting was as a result of the second where there was a need to discuss on an Africa Implementation Network due to the lack of representation from Africa. They are discussed individually below.

Expert meeting 1: digital Health in Africa

The meeting was held on the 12th September 2018 in the Leiden Institute of Advanced Computer Science (LIACS), regarding digital health in Africa touching on the FAIR principles. The meeting was between researchers, professors, doctors, a computer scientist and students from Netherlands, Zimbabwe and Belgium who were nine in total. The discussion surrounded issues on digital health, data governance, digital health growth in Africa and the privacy of health data, how tailor-made solutions of healthcare can come from the society, how to ensure digital health respects relationship dynamics that occur in natural settings, how data from African countries are exploited by parties in the Western world, and how this should change by advocating for countries to host their own data. Additionally, the impact of devolution on healthcare systems if digital health is introduced was discussed, and how when solutions are created, they should be properly done to avoid doubt and accept change. Due to the explorative nature of this research, an interview was conducted thereafter between the doctor and computer scientist from Zimbabwe which will be discussed in section 3.4 below.

Expert meeting 2: driving towards convergence of an Internet of FAIR and Data Services (IFDS) efforts by Implementation Networks

This meeting was on the 15th and 16th of January 2019 (GO FAIR, 2019). It was organized by and held at the GOFAIR offices to bring together various organizations located in different parts of the world i.e. Germany, Australia, and Brazil , individuals and communities known as implementation Networks (INs), to discuss how their efforts to achieving an Internet of FAIR and Data Services (IFDS) can be merged to catalyse the process and the support that the GO FAIR offices will provide to the INs. A total of 90 INs were present from various backgrounds such as Chemistry, Earth and space sciences, and Agriculture. From this, a lot of internet resources were provided to all that attended the meeting which gave the researcher more insight into the FAIR principles and helped with the design of the FAIR data-based model as well as examples of other forms of applications created to achieve the FAIR principles.

Expert meeting 3: Formation of an Implementation Network for Africa.

The lack of an African representation in the meeting led to the last expert meeting being set up on the 7th of February 2019 to discuss what the FAIR principles mean in the context of Africa. There was a lot of discussion on natural occurrences of research being left out on FAIR, concerns on the acceptance of the principles, it being European led initiative and how some people will be left out especially in the context of natural occurring science. The countries represented were Zimbabwe, Kenya, Uganda, Nigeria, South Africa, Netherlands, and Belgium. Following these discussions, an Africa IN was established to explore on the possibilities FAIR offers Africa, and what it means in the context of Africa. A manifesto was created stating the objectives of the Africa IN (IN Africa, 2019b) and followed by an activity plan (IN Africa, 2019a) of how and which areas to implement the FAIR principles.

3.4 Interviews

An unstructured face-to-face interview between a doctor and computer scientist from the first expert meeting mentioned above was conducted. The aim was to capture the experience from a health doctor working with computer scientists to create solutions for their society, to get a deeper understanding on the issues faced in implementing digital health, and getting their perspective on the FAIR principles, if the principles can be useful to them and what factors will influence the uptake of the principles. Due to limited information gathered from interviews, a different approach of design research was taken. A FAIR data model was designed as a proof of concept of the FAIR principles. The methodology behind the model's development is contained in the next section.

3.5 Design research methodology

The methodology applied will be explained using the general methodology of design research model by Vaishnavi, (2007) which is portrayed in Figure 5 (Vaishnavi & Kuechler, 2007). There are four steps in this model: awareness of problem, suggestion, development, evaluation (which all happen iteratively) and lastly conclusion.

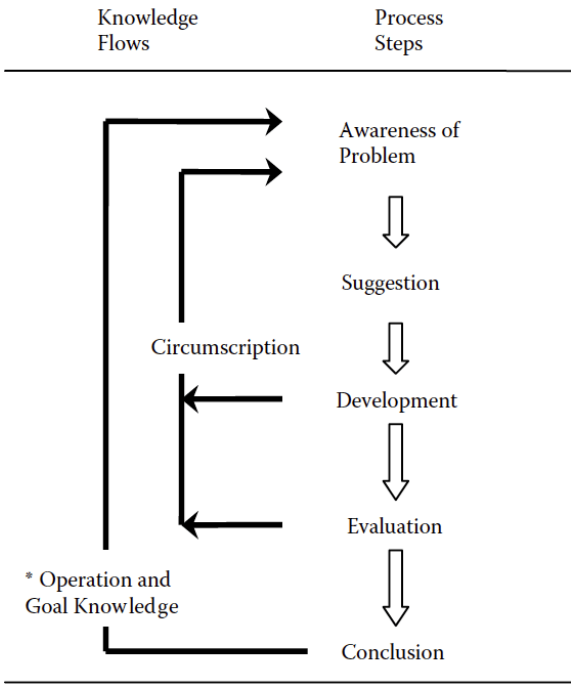


Figure 5: General methodology of design research adapted from (Vaishnavi & Kuechler, 2007).

The first step is the **problem awareness** whereby, a problem may be identified from literature or experience (Vaishnavi & Kuechler, 2007). The problem formulated in this case was from a literature review on the state of cross-border health in the EAC. From that, two challenges of drug stock-outs and real time availability of data were identified (Vaishnavi & Kuechler, 2007).

Once the problems are identified. The next step is **suggestions** as illustrated in Figure 5 which is where a solution is proposed (Vaishnavi & Kuechler, 2007). The solution may come from literature which is where the solution of this research came from (Vaishnavi & Kuechler, 2007). The FDP model was guided by a document provided in the second expert meeting known as the FAIR data point specification document written by the DTL who are designing FAIR tools (Luiz Olavo Bonino(Document Owner), 2016). The document contains the process behind developing the first

version of a FDP software by the DTL FAIR team. This document helped guide the design and set the layout of the FDP. It comprises of various usage scenarios of a FDP, FDP goals, architecture and tables on metadata, and the Graphical User Interface (GUI) of an example of a FDP is also included. The GUI enables the user to explore data through the metadata that is provided in the form of hyperlinks on each page (Luiz Olavo Bonino (Document Owner), 2016). The FDP model of this research adopts the first two goals and the GUI setup.

The third step is **development**. This is where the design according to the suggestions step is done (Vaishnavi & Kuechler, 2007). This is where the knowledge gathered from the previous step is used to design a solution (Vaishnavi & Kuechler, 2007). The solutions may be in form of models, constructs, or computer software (Vaishnavi & Kuechler, 2007). For this research, the solution is in form of a model. The model developed explores discoverability of data, how a FAIR data point (FDP) can discover other FDPs through machine-readable metadata. The model based in a location in Kenya attempts to simulates how a FDP can make datasets discoverable by assigning machine readable metadata to datasets. Through the FDP in Kenya, a FDP in Tanzania can be able to discover the data the FDP holds.

The design from the development step is then **evaluated** whether the goals specified were partly or fully accomplished (Vaishnavi & Kuechler, 2007). Through evaluation, an opportunity to make changes to the design arise (Vaishnavi & Kuechler, 2007). This process is represented by the two arrows in Figure 5. The changes made in the model was to ensure data was available in real time which was a problem with the old model which used Microsoft Access as a database. The Onadata API was used to host the data used in the model in the end. The next change was to move from modelling highly sensitive data such a patient details to data such as drug stocks and reports. One limitation faced in the evaluation step was that the FDP discoverability could not be tested due to the other co-designers not being ready for the testing phase.

Once the evaluation is completed, the **conclusions** from the process are reported (Vaishnavi & Kuechler, 2007). The results and limitations of the FDP model are discussed in this section.

4 Findings on digital health in the East African Community

This chapter contains the findings concerning digital health in the EAC. Firstly, a brief background of the EAC is provided. This is followed by an overview of the healthcare systems in the EAC, particularly matters regarding health delivery, the challenges faced, the health policies, and special health units. Thereafter, the developments of digital health in the EAC, and the outcomes of the various digital health interventions the EAC has previously implemented will be discussed, followed by the factors that should be considered when governing digital health systems for cross-border health.

4.1 The East African Community

The EAC is an *"intergovernmental organisation"* situated in the East of Africa (Ugirashebuja, Ruhangisa, Ottervanger, & Cuyvers, 2017). The founding members were Kenya, Tanzania, and Uganda and had already begun co-operating back in 1917 (GIZ-Team, n.d.). The three countries had a customs union for the trade of goods that would allow the collection of goods at each other's ports. In 1967, the EAC was officially established whereby, the three countries signed the 'Treaty for East African Cooperation'(GIZ-Team, n.d.). The EAC has grown since then. It currently consists of six countries which are; Tanzania, Uganda, Kenya, Burundi, and Rwanda joining in 2007 and the latest member South Sudan which joined in 2016 (Ugirashebuja et al., 2017; UnitedNations(UN), n.d.). Two other countries; the Democratic Republic of Congo (DRC) and Somalia each applied to join the EAC but Somalia was denied due to the political instability and the DRC is still undergoing the vetting process (Aggrey Mutambo, 2019; Godfrey Olukya, 2012). Figure 6 contains the current members(green) and interested members (yellow). It has a population of 150 million of which 22% is considered urban (GIZ-Team, n.d.). The region's economy is growing and the cooperation between them is deepening. This is to mutually benefit politically, economically, and socially (East African Community, 2016). The study focuses on the countries in green, to assess how digital health can be of an impact to their healthcare needs, what needs to be in place for this to happen, the data needs of the EAC, and what can be used to address these data needs especially in the case of improving cross-border health. The next section begins by addressing the first research question on the current state of cross-border health in the EAC. An overview of the various health delivery systems will be described, what obstacles these health systems face, the challenges faced in providing cross-border health care will

be discussed, and what the EAC has planned to do about these issues in terms of policy and setting up coordinated special health units between the six countries.

Figure 6: Map of the countries in the East African Community (https://mapchart.net).

4.2 State of cross-border healthcare

Overview of healthcare delivery systems in the EAC

Patients in the EAC receive healthcare from heterogeneous systems that are comprised of national and regional referral hospitals, provincial, district, county, and state hospitals for South Sudan, health centres, dispensaries, health posts also known as community health services, private clinics, and VCT centres (Besigye & Namatovu, 2014; Leuchowius, 2014; MOH (Rwanda), 2016; MOH (SouthSudan), 2011; Muga, Kizito, Mbayah, & Gakuruh, 2005; Ramana, Chepkoech, & Workie, 2013; Sibomana & Reveillon, 2015; WHO, 2017b; World Bank, 2017). Service delivery in the referral hospitals is the most progressive whereby patients can access a wide range of services and also get treatment from specialised doctors, nurses, and general practitioners(Besigye & Namatovu, 2014; Leuchowius, 2014; MOH (Rwanda), 2015; Ramana et al., 2013). For Burundi, the such services are offered in the national hospitals and for South Sudan in the state hospitals (MOH (SouthSudan), 2012; World Bank, 2017). District/county hospitals offer curative and minor surgical services (Leuchowius, 2014; MOH (SouthSudan), 2016). Health centres mostly give ambulatory care and the services provided are modified to fit the local community (Muga et al., 2005). The health centres can run simple tests and treat minor ailments (Muga et al., 2005, Leuchowius, 2014). The most basic care a patient can receive

is in dispensaries, they offer methods of preventing illnesses and deal with simple illnesses i.e. flu and common colds (Muga et al., 2005, Ramana et al., 2013. Lastly, there are private hospitals and clinics, VCTs in charge of HIV/AIDS testing and counselling (Commonwealth Regional Health Community Secretariat, 2002) and health posts that are run by Community Health Workers (CHW). The services of health posts range from counselling and teaching the community members about good health habits i.e. family planning and importance of vaccinations (Leuchowius, 2014). They are also in charge of reporting cases of suspected disease outbreaks in their area (Leuchowius, 2014). Presented below are several challenges that affect the healthcare delivery systems.

Healthcare system challenges in the EAC

Health systems in the EAC face several challenges that hinder them from providing the best service to patients. It doesn't help that there is a rise of NCD i.e. diabetes, due to the changing lifestyle that results in a *"double burden of diseases"* as they are already coupled with CD. This causes a strain on the already strained health systems in place (Celi et al., 2017). The various challenges the EAC experiences are:

1. Limited health access for remote areas due to the geographical locations and social-cultural factors (Chib, Van Velthoven, & Car, 2014; MOH(SouthSudan), 2012).

2. Inadequate skilled workforce and shortages of qualified staff especially in remote areas (Leuchowius, 2014; MOH (SouthSudan), 2012; Siddharthan et al., 2015). In Tanzania for example, health facilities located in remote areas have problems retaining staff that are skilled, which reduces the quality of care (Kayange & Massawe, 2013). Patients needing specialised care and patients with simple illnesses may end up in referral hospitals that are already burdened with patients (Kayange & Massawe, 2013).

3. Lack of quality (counterfeit), affordable, and available medicine (Siddharthan et al., 2015).

4. Drug stock-outs- health facilities especially in rural areas struggle to keep adequate supplies of essential medicine to diseases such as Malaria due to uncoordinated systems (Asiimwe et al., 2011; Bamenyekanye & Bigirimana, 2015; Barrington, Wereko-Brobby, Ward, Mwafongo, &

Kungulwe, 2010; Githinji et al., 2013; MOH (SouthSudan), 2012; Nditunze et al., 2015; WHO, 2016).

5. Poor communication- for example, between CHW and higher-level healthcare which enables better information flow and counselling to CHW (Perry et al., 2017; Tumusiime et al., 2014).

6. Reliance on paper-based data collection methods- paper-based data collection methods require a lot of manual labour in terms of storage and management and they necessitate high transportation costs which can be time-consuming (Asiimwe et al., 2011). Also, translating these paper-based data into electronic data can be a laborious and a time-consuming process (Asiimwe et al., 2011). Next will be the challenges on cross-border healthcare delivery.

Cross-border health challenges

The EAC aims to improve access to cross-border health services to deal with health threats they are facing (Ssali, 2018).The growth of the EAC's economy has been accompanied by the movement of people throughout the region daily (EAC, n.d.-b). The EAC located in a continent that has high rates of CD, the risk of spreading diseases from one country to another grows (EAC, n.d.-b). This increases the chances of disease epidemics affecting the various countries (EAC, n.d.-b). The common scene in the EAC is people working in one country and residing in another as a result of intergovernmental collaborations in businesses and in industries (fhi360, 2018). Therefore, it is usual for people to seek health services across borders (fhi360, 2018). However, the health services provided are insufficient and they are not supported by the health systems in place making them incapable of catering to the number of patients especially for mobile populations (fhi360, 2018). This is due to not having enough human resources, inadequate patient monitoring systems that lack interoperability between the cross-border health facilities, poor flow of information, and regular experiences with health supply shortages i.e. medication (EAC Secretariat, 2018; fhi360, 2018; MEASURE Evaluation, 2017). In an area that has high rates of CD, surveillance and outbreak preparedness are also important (Irene Lukassowitz, 2018; Kariuki et al., 2013). However, the regional surveillance of diseases is inadequate and suffers from *"fragmented interventions"* (Kariuki et al., 2013). This results in ineffective methods to the prevention of Communicable Diseases (CD) and lack of preparation in case of emergencies

(Kariuki et al., 2013). Section 4.3.1 discusses the potential digital health has in providing solutions to such problems but first the health policies will be discussed to see what the EAC would like to do to tackle the challenges they face.

The EAC health policies

The health policies of the EAC member countries portray an alignment of goals that can be credited to the fact that they experience similar challenges with their health systems. The EAC member countries would like to achieve Universal Health Care (UHC) that is affordable, accessible, and equitable with the hope of reducing the health disparities, according patients with quality healthcare and ensure well-organised health delivery mechanisms. Several of their objectives consist of:

1. Developing key health programs to reduce the burden of diseases and ensure they are managed properly (MOH (Kenya), 2013; MOH (Rwanda), 2015; MOH (SouthSudan), 2016; MOH (Uganda), 2010; MOHCDGEC (Tanzania), 2017; Republique du Burundi, 2016).

2. Strengthening the health support systems for the best performance of health programs. This includes having adequate skilled workforce, accessible health supplies, and information systems that will provide real time information enabling timely decision making (MOH (Kenya), 2013; MOH (Rwanda), 2015; MOH (SouthSudan), 2016; MOH (Uganda), 2010; MOHCDGEC (Tanzania), 2017).

3. To make evidence-based decisions in the case of health interventions and health finance (MOH (Uganda), 2010; MOHCDGEC (Tanzania), 2017).

4. Improving inter-sectoral collaboration for better sustainable healthcare delivery (MOH (Kenya), 2013; MOH (Rwanda), 2015; MOH (SouthSudan), 2016; MOH (Uganda), 2010; MOHCDGEC (Tanzania), 2017; Republique du Burundi, 2016).

5. To improve the response and preparedness to emergencies (MOH (Kenya), 2013; MOH (Rwanda), 2015; MOH (SouthSudan), 2016; MOH (Uganda), 2010; MOHCDGEC (Tanzania), 2017).

6. To guarantee the accessibility and availability of quality and affordable medicine (MOH (Uganda), 2010, 2015; MOHCDGEC (Tanzania), 2017).

The opportunities for cooperation at a regional level are abundant (EARHC, 2017). Despite the varying levels of development in the EAC countries i.e. some member countries not having their national Health Information System (HIS) fully implemented, the national plans for digital health of all the countries apart from South Sudan have been formulated (EARHC, 2017). They are also using *"common technologies"* such as District Health Information Software 2 (DHIS2) and open Health Information Exchange (HIE) (EARHC, 2017). Similarly, they have comparable challenges i.e. inadequate infrastructure and the many fragmented digital health initiatives which can be leveraged in terms of creating a common solution (EARHC, 2017). Presented below are the special units that the EAC has formed to coordinate in the different areas of need that relate to healthcare.

The EAC special health units

The EAC would like to co-operate on improving the health of their residents, to prevent as well as control CD and NCD to avoid epidemics that can be caused by cross-border movements (EAC, n.d.-b). This would involve regional, national, and international parties and would require real time flow of accurate information across the borders (EAC, n.d.-b). Special units have been formed to tackle the health issues and improve access to information which are:

1. Disease Prevention and Control Unit

The strategies of this unit are:

- Creating a system for exchanging information regionally concerning CD and NCD (EAC, n.d.-a).
- Establishing a public health laboratory that can be referenced both regionally and internationally while improving national public health laboratories (EAC, n.d.-a).
- Enhancing health services for preventive, curative, and promotive care of NCD (EAC, n.d.-a).
- Improving the EAC Partner States' methods of detecting and offering of remedies for CD and NCD (EAC, n.d.-a).

2. **Medicines and Food Safety Unit:** this unit aims to guarantee the best medicine, food, and health products are availed to the citizens of the EAC (EAC, n.d.-e). Through regulations, policies, and standards put in in place, the goal is that medicine should be affordable, good quality, and safe (EAC, n.d.-e).

3. **HIV & AIDS Unit:** the HIV & AIDS unit serves for all matters related to HIV & AIDS, to lessen the cases of HIV infections in the region through coordination and harmonisation amongst the member states (EAC, n.d.-d). The main goals are to synchronize the rules, regulations and strategies, have fast responses to reduce the spread of HIV infections in cross-border areas and to access real-time information that can be shared among the members for decision making (EAC, n.d.-d).

4. **Health Systems, Research and Policy Unit:** the health unit is in charge of human resource management, to ensure enough is invested in Health Care Workers (HCW) so as to get quality and inexpensive healthcare provided (EAC, n.d.-c). The research and policy seeks to develop health systems, facilitate health research, and policy making in an integrated effort (EAC, n.d.-c).

5. **Reproductive, Child, Adolescents Health and Nutrition Unit:** this unit supports the *"development, adoption, harmonisation and dissemination of policies, quality standards and guidelines for Sexual Reproductive Health and Rights (SRHR) priority issues, including gender health issues in the region"* in order to achieve the Millennium Development Goals (MDGs)(EAC, n.d.-f).

The current state of cross-border health experiences various challenges mainly to do with lack of real time accessibility to information to inform decisions on the management of patients, drug stock administration, and disease control and management. Additional problems include insufficient workforce, ensuring remote/ rural areas access health services, and lack of interoperable health delivery systems. The objectives of the EAC member countries address these issues and have strategized on how digital health can help them tackle the issues. Digital health will also be supportive to the special health units that have been formed to coordinate the various efforts between the EAC.

In the next section, the capabilities digital health present to improve the current state of cross-border health.

4.3 Digital health development in the EAC

This section will address the second research question which investigates the extent to which digital health can improve the current state of cross border health. Digital health has great potential in the EAC and can be supportive to the health delivery systems in the EAC. In 2014, the EAC contributed to *"over 30% of the global innovative healthcare delivery programs"*, Kenya following India at second place for its *"innovative eHealth programs"* (Excelsior Group, 2014). An advantage that the EAC has is that it does not have legacy systems (outdated systems) to hinder it from development (Reisen, 2017). And due to the growing number of mobile phone subscribers and the success of mobile applications like Mpesa; a mobile money service, there have been endless possibilities thought out for digital healthcare, and how it can be used to achieve Universal Health Coverage (UHC) and Sustainable Development Goals (SDG) (WHO, 2017c). From educating health professionals, to remote data collection, to remote consultations (Kibiki, 2018; Tran Ngoc et al., 2018; Vodafone Group, 2019; WHO, 2017c). The EAHRC (East African Health Research Commission) have envisioned these possibilities and set up an initiative known as the digital Regional East African Community Health (REACH) (EARHC, 2017). The digital REACH are a *"group of policy makers, researchers from universities and civil society with the aim of bridging the gap between health research, policy, and decision making*"(Alliance, 2017). The digital REACH have strategized, through a roadmap, on how they can improve health outcomes in the EAC using digital health solutions (EARHC, 2017). The digital REACH will work with the governments of the EAC member countries, development partners, and the private sector (EARHC, 2017). The collaboration and coordination between these different parties are important to improve the EAC healthcare and actualize digital health in the region (EARHC, 2017). The vision of the digital REACH is to have: *"Interconnected health systems for a healthy and prosperous East Africa*"(EARHC, 2017).

Digital health application areas for the EAC

The digital REACH initiative has identified seven main target areas digital health to be applied in (EARHC, 2017, Kibiki, 2018).

1. Public Health Education and Awareness.
2. Diagnostic and Treatment Support.
3. Health Worker Education and Training.
4. Data Collection, Surveillance and Response.
5. Supply Chain Management.
6. Resource Allocation and Management.
7. Population Health Status.

There are four health programs that have been identified that consist of digital health solutions to support the application areas mentioned above which are listed below (EARHC, 2017)

1. An **East African Open Science Cloud for Health (EAOSCH)** to manage real-time data, for the purpose of storing, retrieving, and analysing regional data.

2. **Cross-border applications** to enable health delivery in remote, mobile, and border communities.

3. Ways of "***supporting country-specific"*** **applications** to facilitate integration with the digital health systems in the region (EARHC, 2017). i.e. an ID that can allow entry to the regional health systems.

4. Use of ***"transformational technologies".*** i.e. Geographic information systems for disease surveillance.

The value of digital health in the EAC will be cost saving, sharing of key resources across the region, improvement of health systems, and health access that are evidence-based, lastly faster and better implementation due to support for health research and sharing of local experts regionally (EARHC, 2017). However, for these four health programs to be realized, there have been seven ecosystem enablers identified for a healthy digital environment as illustrated in Figure 7 (EARHC, 2017). The most important is effective leadership and good governance. This oversees the rest of the enablers. The leadership and governance should ensure that there are enough resources i.e. sufficient health workforce, cost-effectiveness is maintained, the right policies are adopted, effective regulations are enforced, and that strategies concerning each enabler are executed (EARHC, 2017).

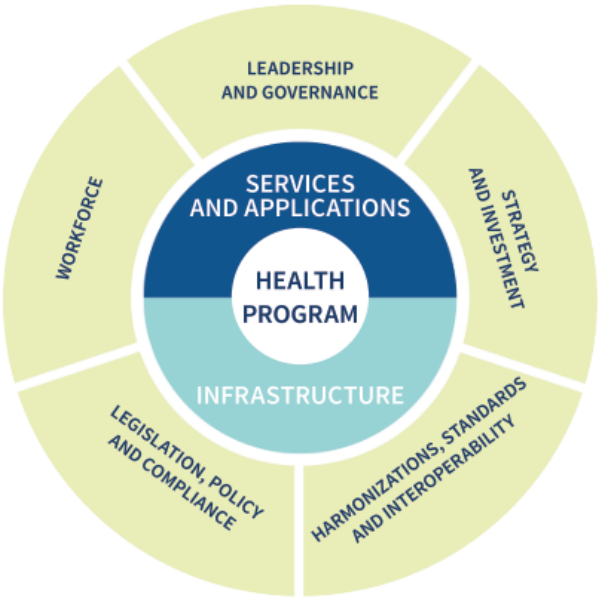


Figure 7: Ecosystem enablers (EARHC, 2017).

The four health programs of the EAC will also require good data management for optimum performance. With digital health, data complexities arise where proper governance and management of data is needed. Data needs to be available in real-time, data needs to be interoperable especially when dealing with cross-border healthcare, the origin of the data should be made clear for accountability purposes, data should be machine-actionable, and since healthcare deals with sensitive data, the proper authorization measures should be implemented. How this can be achieved

will be covered in section 5.2. Discussed next are digital health intervention studies that have been done in the EAC.

4.3.1 Digital Health interventions in the EAC

Digital health can provide immense support for areas that the EAC health systems are deficient. Firstly, by using health data, digital health can provide faster, effective, and efficient healthcare (Stroetmann, 2018). The data allows better decision making, is time efficient, and lowers the chances of duplicated efforts i.e. running similar tests in health facilities (Stroetmann, 2018). Secondly, rural and remote areas can be able to access healthcare through avenues such as telemedicine whereby patients, CHW, nurses and doctors can connect virtually (Stroetmann, 2018). Thirdly, the high penetration of mobile phones into society has made it easier to collect and report data, easing the communication between the various health parties (Stroetmann, 2018). Lastly, digital health tools can be used to empower patients and HCW by educating them. An example of this is an eLearning platform used in Tanzania to educate HCW and nurses on maternal and perinatal healthcare in rural areas (Stroetmann, 2018). This section discusses digital health intervention studies done in the EAC. The outcomes from these studies will provide insight on what affects the success of newly introduced digital health systems and what factors to consider before introducing them. In the end, an overall picture of whether digital health provided the EAC the advantages mentioned above and what the reception was to the interventions and the perceived usefulness and perceived ease of use according to TAM (Venkatesh & Bala, 2008). The outcomes will be useful to identify what is needed for digital health tools to be effectively implemented to improve the current state of cross-border health in the EAC. Digital health encompasses eHealth and mHealth (WHO, 2015a). The interventions are divided into eHealth interventions and mHealth interventions.

eHealth interventions

eHealth is described as: *"an enhanced way of the delivery of health services and information through the internet and related technologies*"(Eysenbach, 2001). eHealth consists of Telehealth, electronic patient records, and areas of health informatics. Figure 8 illustrates the different forms of activities defined under the eHealth and there will be three eHealth interventions discussed in this section (Khandpur, 2017).

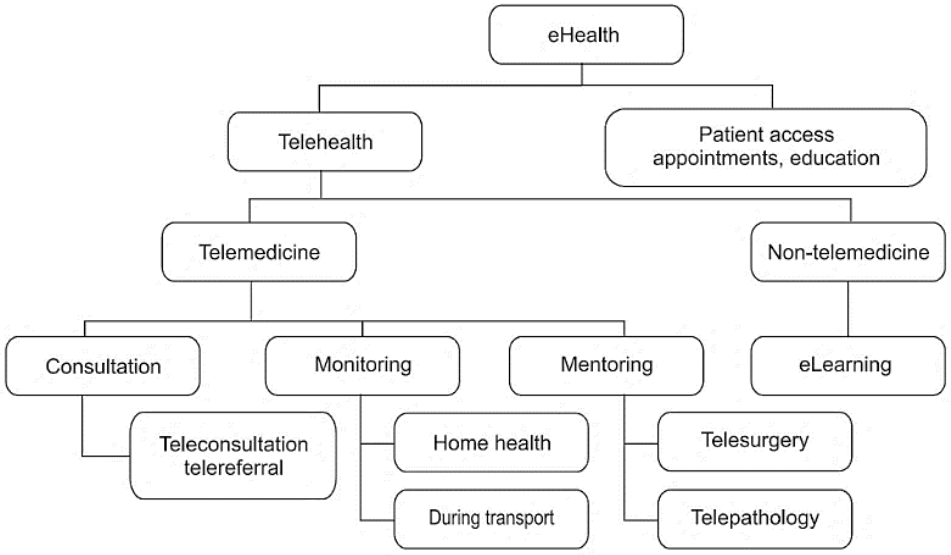


Figure 8: Subsets of eHealth (Khandpur, 2017).

Table 2

Overview of eHealth studies (n=3)

	Author	Year	Methods used	Country	Type of intervention	Application	Condition	Results
Pilot (n=1)								
1.	Qin et al	2012	Quantitative	Kenya	Telemedicine	Increase health access for patients in rural areas	General healthcare	Feasible
Post-trial (n=2)								
2.	Nyamtema et al	2017	Qualitative	Tanzania	Teleconsultation	Provision of healthcare in remote and rural areas	Maternal healthcare	Feasible
3.	Namageyo-Funa et al	2017	Qualitative	Kenya	Electronic Health Information Systems (EHIS)	Immunization	Maternal and child healthcare	Variable results

Pilot (n=1) The quantitative study (1) was of a store-and-forward telemedicine system that aimed to improve access to healthcare in the rural areas. "*It quantified the accuracy and appropriateness of remote diagnoses in the current health infrastructure*" (Qin et al; 2012). The process involved CHW travelling with a telemedicine system, to enable patients to connect with a consulting nurse via the internet. The system collected medical history, vital statistics, i.e. weight and blood pressure which was sent to the nurse who would further respond with advice by internet, text message, or phone. The system did not act as a replacement but as an enhancement to the current system in place, to improve the availability and access to primary healthcare to patients who may not be able to travel to the nearest health centres. The conclusion was that, the telemedicine system was reliable since it was able to provide the same results in 90% of the consultations as if the patient had gone to consult a nurse face-to-face. It was also both economically and socially valuable to the rural community. The obstacles faced were, the nurse and the CHW received different complaints from 1 in 5 patients. There were two probable causes for this, one being the varying levels of the patients trust between

the CHW and the nurse. The assumption was that this was due to the levels of experience as perceived by the patient because the nurse was more educated, she was trusted more. The other cause was because of the patients' misconceptions about the whole consultation process. These are things to take into consideration when launching a new digital health tool. The last obstacle was the systems limits to do tests, i.e. blood and malaria tests (Qin et al., 2013).

Post-trial (n=2) Both the post-trial studies used qualitative methods. The first one (2) was of a teleconsulting platform aiming to improve services provided to mothers who were expectant. Through the platform, healthcare providers were able to communicate with skilled obstetricians in the case of emergencies where they required assistance. This enabled them to learn and apply the new skill while making better decisions. The study showed real potential for use in the rural areas even though the effectiveness on the health outcomes was not assessed. Nevertheless, the health providers were equipped with more skills and knowledge. In order to scale up such a system, the infrastructural and technical challenges need to be addressed (A. Nyamtema et al., 2017; A. S. Nyamtema et al., 2016). The second study (3) compared a standardised paper-based immunization system used in Kenya to an Electronic Immunization Information System (EIIS) to see if the EIIS could potentially be a replacement. However, the EIIS had incomplete data compared to the standardised paper-based system to be a substitute or function alone. Possible solutions could have been the use of a hybrid or the use of both systems, but this possibility remains unknown. The study also highlighted the issue of not having an immunization specific standard for EIIS nationally. This restricted the systems functions i.e. exchanging information with various national level Health Information Systems (HIS). This caused the study to have inconsistent results between health facilities involved in the study (Namageyo-Funa et al., 2018). This stresses the need for the health delivery systems to be interoperable.

In conclusion, out of the three eHealth studies, two had positive results in terms of feasibility. The telemedicine intervention (1) showed great potential for primary healthcare delivery in the rural areas and can be scaled up to include other components i.e. taking tests or administering medicine (Rosie Qin et al; 2012) and as for the teleconsulting intervention (2), it enabled better decisions to be made regarding patients and equipped the health workers with immediately acquired skills (A.

Nyamtema et al., 2017). For the last study, it proved not to be feasible due to the data incompleteness on the EIIS and highlighted the importance of having immunization-specific standards and interoperability between the health systems which could have improved the results of the intervention (Namageyo-Funa et al., 2018).

mHealth interventions

Ryu (2012) defines mHealth as: "*medical and public health practice that is supported by the use of mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices"* (Ryu, 2012). Mobile phones are becoming significant in public health and delivery of healthcare due to the growth of their computing power and their high penetration (Khandpur, 2017). In the EAC, the growing number of people owning mobile phones may be the reason why most of the digital health interventions have been of mHealth compared to eHealth, especially Short Message Service (SMS) based health interventions. This is because the basic mobile phone supports SMS, SMS is also cheaper to finance for the implementors of the SMS mHealth platforms (Nugroho Sujatmiko, 2015).The following section will discuss thirteen studies of mHealth interventions in the EAC.

Table 3

Overview of mHealth studies (n=13)

	Author	Year	Methods used	Country	Phone use	Application	Condition	Results
Pilot (n=6)								
1	Asiimwe, et al.	2011	Quantitative	Uganda	SMS	Real time information access	Malaria	Feasible
2	Githinji, et al	2013	Quantitative	Kenya	Text	Real time information access	Malaria	Feasible, advise given
3	Barrington, et al	2010	Quantitative	Tanzania	SMS	Drug supply management	Malaria	Feasible

4	Rassi et al	2018	Mixed	Uganda	Receiving text messages	Health workforce training	Malaria in pregnancy	Positive feedback from health workers and feasible
5	Keane et al	2017	Quantitative	Kenya	Tablet Application	Provision of accurate and timely data	Malnutrition	Feasible
6	Ngabo et al	2012	Quantitative	Rwanda	SMS	Communication	Maternal and children's health	Feasible, but advise given
Post-trial (n=7)								
7	Toda et al	2016	RCT	Kenya	Text	Tracking of a disease outbreak	Various	Significant, but with challenges
8	Chang et al	2011	Mixed	Uganda	Text and Call	Information gathering	HIV/AIDS	Positive feedback but no statistics to back it up - various challenges experienced
9	Tumusiime, et al	2014	Quantitative	Uganda	SMS	Communication and provision of timely information	Children's Health	Feasible
10	Shao, et al	2015	Qualitative	Tanzania	App	Healthcare training and diagnosis guidance	Children's health	Positive feedback
11	Odeny, et al.	2015	RCT	Kenya	Two-way-text	Communication	HIV/AIDS	Significant
12	Wexler et al	2018	RCT	Kenya	SMS	Sending alerts to patients	HIV/AIDS	Feasible despite challenges experienced
13	Kabakyenga et al	2016	Mixed	Uganda	Mobile system	Communication and real time data collection	Children's health	Feasible

Pilot (n=6). Out of the five pilot studies, five used quantitative methods while one used mixed methods. The first one (1), was of an SMS based platform used to monitor Malaria cases in areas distant to the capital city of Uganda, Kampala. The HCW used the platform to send weekly reports via SMS that were stored in a database and from the database, reports could be printed out. The result of the project was that it is feasible for real time healthcare related data to be acquired from remote areas so that monitoring Malaria in terms of diagnosis and treatment is efficient, synchronizing it with the supply of Malaria tests and drugs needed. However, the extent of using SMS to improve on drug stocks was not properly assessed in Uganda since there was shortages of Rapid Diagnostic Tests (RDTs) and Artemisinin Combination Therapy (ACT) stocks nationwide during the intervention. It is important to note that there were no incentives provided to the HCW (Asiimwe et al., 2011). This can be compared to the other studies done in Kenya (2) and Tanzania (3) that used SMS technology to ensure accuracy and real-time information regarding Malaria drug stocks except for the fact that Kenya used incentives. The study in Kenya, was done in five districts in rural areas, in 87 public health facilities. HCW used mobile phones to text the number of stocks that were available in the respective health facility after receiving a weekly data request. Thereafter, the figure from the text would be reported on a web-based system. Each time the HCW sent a text, they were rewarded airtime of 50 Kenyan shillings. The study showed high response rates of the HCW compared to Uganda which could be credited to the incentives provided. The conclusion was that further studies should be done on a *"larger scale"* without the use of incentives (Githinji et al., 2013). The Tanzanian study (3) was replicated as well but without the use of incentives. The management of malaria drug stocks was more efficient, increasing the number of health facilities having a full stock. This showed the potential health facilities in the rural areas have in maintaining their stock levels to ensure the drug is always available without incentives (Barrington et al ., 2010). The fourth quantitative study was of a tablet application used to support HCW dealing with malnourished kids (5). It was used in forty health facilities in Wajir county, Kenya and managed to provide access to accurate real-time data that was stored in the cloud. The data was then used for decision making. Compared to the paper-based system used in the area, the application lessened the data errors due to the error prompter tool it had embedded in the app and decreased the time the data would normally take to reach the management teams. The application managed to achieve the intended purpose and illustrated that it had the potential to do more i.e. detecting operational bottlenecks (Keane et al ., 2017). Lastly, is

the study on the Rapid SMS system (6) used to facilitate communication between CHW and ambulances, health facilities, district hospitals, and central level care. The aim was to improve the antenatal and postnatal care delivery at health facilities and emergency obstetric care, to minimizing the problems in communication that lead to mothers and new-borns dying. CHW would have a chance to register their expecting mothers via the Rapid SMS system, monitor them throughout the process, and report in case of a dangerous situation. The system also had a built-in reminder system that would remind the mothers for clinic appointments and delivery. The findings were that mobile phones have the power to assist with timely access to medical care especially in the case of emergencies, but the lessons learnt were that a strong government and dedicated private sector are key to have a sustainable system (Ngabo et al., 2012).

The mixed method study, (4) was designed to provide educational text messages to HCW after health training in a classroom, to assess the effectiveness of the intervention comparing it to training in a classroom alone without the additional text messages. The reception from the HCW was notable and the study showed feasibility and potential for the application to be used to increase the HCW knowledge (Rassi et al., 2018).

To summarise, the pilot studies show positive outcomes on feasibility and acceptability. The ability for the HCW to use their normal mobile phones was effective and illustrates how cost effective these interventions can be. The importance of a strong government in collaboration with committed private sectors was also recognised to ensure the sustainability of the mHealth systems (Ngabo et al., 2012). The aspect of compliance according to TAM can be seen in the case where incentives had a role in determining the outcome of the introduced digital health system (Githinji et al., 2013; Venkatesh & Bala, 2008).

Post-trial (n=7) Regarding the post-trial studies, three of them were Randomized Control Trials (RCT), two used mixed methods, one was quantitative, and the last one was qualitative. One of the RCT studies (7) was concerned with tracking disease outbreaks. The purpose of the study was to use SMS to ease communication between HCW and MOH managers. SMS was used together with a web-based portal. In the case of a disease outbreak, texts were sent to the web portal by HCW. HCW also

added health events that needed to be reported within 24 hours and checked if there had been any responses from the health managers. The main goal was to assess time taken to report a case that needed to be urgently reported. Indeed, there was substantial improvement however, the responses were to a substandard level. The challenges experienced during the intervention were regarding training of the HCW, lack of *"supportive supervision"* and lack of incentives (Toda et al., 2016). Venkatesh and Davis (2000), mention that factors such as rewards, in this case incentives and having support when using IT, influence the acceptance of newly introduced IT systems (Venkatesh & Davis, 2000). The second RCT (11) evaluated how a personalised two-way SMS and call setup between a nurse and different patients (mothers with HIV) could improve the process of maternity; from clinical visits when women are pregnant to when they give birth. The objective was preventing HIV spreading from the mother to child by reminding them to visit the clinic. The study produced noteworthy results improving the number of kids being tested for HIV however, the total percentage of women's attendance at the clinics when they were at their postpartum period was low. (Odeny et al., 2014). The last RCT (12) aimed at differentiating the service between standard Early Infant Diagnosis (EID) systems versus HIV Infant Tracking System (HITSystem) from a provider point of view to understand what factors may hinder its sustainability and acceptance. The HITSystem differed from the typical EID system because it had the ability to notify the clinic and lab providers when a patient had not attended an important EID service and also used SMS to inform mothers when test results were ready. The EID service providers observed that the HITSystem enhanced the communication between the patients, the clinicians, and laboratories. As a result, the EID services were efficient and delivered on time, the clinicians also noted that the patients were pleased to be notified for their test results, and the HITSystem's ability to track patients simplified the procedure compared to the manual tracking being done before. Despite the challenges such as internet access and supply shortages, HITSystem illustrated how useful it can be for process tracking and was able to facilitate communication between patients, clinicians, and the laboratory. The providers of the systems were also able to observe the challenges first hand (Wexler et al., 2018). Such a system can be useful for cross-border healthcare delivery where there is an issue on communication between cross-border health facilities.

Both studies (13) and (8) used mixed methods. The purpose of (13) was to measure the use of mobile phones as a supportive tool for CHW dealing with children. Using integrated Community Case Management (iCCM) as a guide, CHW used their mobile phones as a data entry tool and the data entered was compared to paper-based reports. The advantage mobile phones had was that the accuracy and completeness of the records could be checked and in case of errors, they could be corrected unlike the paper records. Additionally, it facilitated communication between the CHW and their bosses regarding drug stocks. The supply of drugs was efficient as they didn't need to travel to get them, just a call away and they would be delivered. The end results were that mobile phones improved the provision of real time data for better decision making, especially with drug stocks and one thing to note was the CHW acceptance of using mobile phones in their work place but with training (Kabakyenga et al., 2016). According to TAM2, if individuals feel supported while using new IT, it will affect their perceived ease of use and they will be more likely to accept it as can be seen in study (13) (Kabakyenga et al., 2016; Venkatesh & Davis, 2000). For study (8), mobile phones were used to support community-based Peer Health Workers (PHW) to report on clinical data and adherence of patients after home visits via text messaging. The data was then stored in a central database. The clinical staff would also guide the PHW or if the case needed higher level care, they would be sent. Patient care improved, logistics, and communication were made better and there was support for using mobile phones. The results were significant qualitatively but not on the quantitative analysis side due to systematic challenges from the implementors. Other challenges faced were of phone maintenance with restricted access to electricity and not every patient being able to access a phone. The results were positive showing support and the advantages of having such an intervention in rural areas (Chang et al., 2011).

The purpose of the last qualitative study (10) was to gain insight into what influences the sustainable adoption of two different mobile technologies; tablets and smartphones as decision support systems in six health facilities in Tanzania. These technologies were used to measure the usage of drugs in children illnesses as an effort to have evidence-based medicine. An algorithm was developed for the tablets and smartphones to facilitate this and the HCW were trained and supervised while using them. The intervention had positive results from the HCW stating that the use of the applications did not affect their rational decision making and the patients' trust, they made their work easier, helped them

make the correct diagnosis, give the correct treatment, and prescribe the precise dosage. The factors affecting the acceptance of the applications were; despite the majority of the HCW finding the applications easy to use, there were few that found it difficult to type. There were also concerns raised regarding the increase in the time spent in consultation of a patient as a result of the use of the applications. Other reasons were due to the limits of the health system; being short-staffed, lack of motivation for the HCW because they received no compensation for using the applications, increased paperwork resulting from the normal duties the HCW had to perform, and drug shortages. The conclusion was that mobile technologies are capable of enhancing the management of childhood illnesses however, the contextual factors that were mentioned need to be addressed to ensure sustainability (Shao et al., 2015).

Lastly is the quantitative study (9), that was based on mobile phones being used as a tool to allow generation of weekly and monthly reports, to enable real time tracking of the work the CHWs were doing, for feedback by the supervisor, for performance checks, and to monitor referrals of patients (children) with the facilities they had been referred to. Through training of CHWs and partnering up with private bodies i.e. the MOH, community partners and academic partners to ensure network connectivity and facilitate the development of user-friendly tools, the results were positive. Despite the challenges faced of varying education levels within the CHWs, basic mobile phone instruction requirements for first time mobile users and security issues i.e. theft, the intervention was a success and proved to be feasible. The CHWs were able to master using the technology at hand despite it being the first time for some to hold a mobile phone, the data gathered was of better quality than the paper records that was in use and the intervention showed how it is possible for different bodies to come together to create a tool to provide assistance to CHW to help children in their rural communities (Tumusiime et al., 2014).

In summary, the post-trial studies illustrate that the interventions had significant results in terms of feasibility and acceptance. The studies also showed the importance of the system providers examining the functionality of their systems to identify problems and possibly implementing them faster once identified (Wexler et al., 2018). Various interventions resulted in timely availability of data to assist decision making, improved communication between HCW amongst themselves and patients,

improved reporting of clinical data, showed the capability mobile phones have in ensuring evidence-based medicine, and enhanced the methods of supervising CHWs (Chang et al., 2011; Kabakyenga et al., 2016; Odeny et al., 2014; Shao et al., 2015; Toda et al., 2016; Tumusiime et al., 2014; Wexler et al., 2018).

The digital health interventions have illustrated what factors affect the acceptability of newly introduced digital tools which include incentives, supportive measure such as training, misconceptions, infrastructure i.e. electricity, access to mobile phones, and the inclusion of different sectors in solving a problem. Before the acceptance of digital health tools especially for the case of cross-border health, there are governing concerns that need to be agreed on beforehand which may discourage the use of digital health systems. This may be due to the amount of work involved, due to the lack of preparedness, due to some countries not being well equipped to deal with the issues at hand among others. The following section discusses on matters to do with governing cross-border digital health and what needs to be considered.

4.4 Digital Health governance

There are several obstacles that may be faced while governing digital health. This section will cover the obstacles regarding Telemedicine, a digital health practice. World Health Organization (WHO) defines Telemedicine as: *"the use of ICT to improve patient outcomes by increasing access to care and medical information"* (WHO, 2010). Telemedicine has been attractive to Africa as it can deliver timely access, cost-effective, high quality healthcare services across borders, and has potential in resolving HCW shortages (European Union, 2009; Jack & Mars, 2008; Kekana, Noe, & Mkhize, 2010; Lareng, 2002, 2013). It is also able to connect a patient and a HCW or two HCW together for example, in the case of teleconsultation which was discussed in Section 4.3.1. For populations that are frequent travellers, nomads, long distant travellers etc., such services can ensure they access healthcare services (EAC, 2015). These services are also important, for tracking, detecting, monitoring, and responding of diseases regardless of their location (European Union, 2009; fhi360, 2018). However, the delivery of patient care over a distance and perhaps from another country presents a set of challenges that may hinder its optimum performance that may bring hesitation in terms of adopting it, and may make governing difficult. The obstacles that may be faced are discussed below and have

been divided into four categories: (1) Legal factors, (2) Sustainability factors (3) Cultural and language factors and (4) Contextual factors (Mars, 2013; Saliba et al., 2012)

1. Legal factors

1.1. Liability and jurisdiction: regarding the legal responsibility for the patient, there is often confusion and uncertainty over who, between the referee and the one to whom the patient has been referred, should be liable for the patient (Mars, 2013; Saliba et al., 2012). This may have negative implications on the legal proceedings, thus it is recommended that there should be more clarity on who holds the legal responsibility of patients prior to any medical care being given (Mars, 2013; Saliba et al., 2012).

1.2. Clinical governance: sustaining the quality of care between cross-border services can be a difficult task (Saliba et al., 2012). Specific standards for various disciplines need to be developed to ensure that quality is maintained and that there is no negligence from HCW (Kekana et al., 2010; Saliba et al., 2012). For example, radiologists based outside of the UK, providing their services to the patients in the UK, are supposed to apply the same standards of service as the UK (Saliba et al., 2012). The contracts signed between the two countries should include requirements that need to be adhered to such as: "*quality and assurance systems, justification of procedures, and data quality"* (Jarvis & Stanberry, 2005; Saliba et al., 2012). However, this can be difficult because the legislation varies in different countries and they may not be able to ensure this (Jarvis & Stanberry, 2005; Saliba et al., 2012). The question then becomes: Will patients in developing countries be denied health services if the standards are not met? Is it better to provide services that may not be up to standard in areas where there are non-existent forms of healthcare? (Jack & Mars, 2008).

1.3. Informed consent: when dealing with low- or middle-income countries, where the illiteracy is high and the population has limited exposure to ICT, informed consent is important but can be challenging to enforce (Ferguson, Doarn, & Scott, 1995; N. et al., 2007). The patients' medical records should be shared with their knowledge and this

should be explicitly referenced in a contract (Ferguson et al., 1995; Geissbuhler, Ly, Lovis, & L'Haire, 2003; Jarvis & Stanberry, 2005; N. et al., 2007; Williams, Mullick, Butler, Herring, & O'Leary, 2001). However, explaining that sophisticated ICT will be used and how their data will remain secure is a difficult task even for computer-literate patients (Jack & Mars, 2008).

1.4. **Data security and confidentiality:** this is related to the issue of informed consent (Jack & Mars, 2008). Medical data is very sensitive and needs to be protected (Saliba et al., 2012). Thus, a physician should ensure secure measures are taken to keep patients' data confident (Jack & Mars, 2008). This can never be guaranteed with the internet due to likelihood of unauthorised access such as cyber-attacks (Saliba et al., 2012). Over 49 million cyberattacks occurred in Africa within the first three months of 2014, mostly in Algeria, Egypt, South Africa, and Kenya according to a report by Kaspersky (Jean Shiloh & Amzath Fassassi, 2016).

2. Sustainability factors

2.1. **Financing and scale:** poor funding and lack of long-term commitment affects the success of cross-border telemedicine services which in the end cannot be scaled up (Richard Wootton, 2008). They limit the assessment of why some telemedicine interventions succeeded and why some failed (Richard Wootton, 2008). This can impact the future development of telemedicine in that area because lessons cannot be learnt (Richard Wootton, 2008).

2.2. **Cost:** The argument used to campaign for telemedicine for cross-border health is that the costs will go down (Brandling-Bennett et al., 2005, Martínez Álvarez, Chanda, & Smith, 2011). However, the cost-effectiveness of this has not yet been determined because of lack of evaluation (Brandling-Bennett et al., 2005, Martínez Álvarez, Chanda, & Smith, 2011). This ties back to the point of lack of assessments and evaluations mentioned in financing and scale above. Such valuable insight defines whether or not telemedicine can be sustainable or not (Richard Wootton, 2008).

2.3. **Integration:** integration of cross-border services with the existing infrastructures can help achieve sustainability such as the healthcare facilities alongside its HCW and patients (Richard Wootton, 2003). However, there can be instances where HCW are not comfortable using the digital health systems and need familiarisation or training programmes to get acquainted with the digital health tools, which may cost time and money (Jack & Mars, 2008; Richard Wootton, 2003).

2.4. **Top-down vs bottom up approaches:** the approach used in agreements made between two or more countries for cross-border health services is usually top-down and has been viewed as the more sustainable method for executing cross-border health services (Martínez Álvarez, Chanda, & Smith, 2011). However, local community empowerment though the bottom-up approach is quite powerful and necessary institutions such as healthcare centres and MOH need to provide more support for such initiatives (Bagayoko, Müller, & Geissbuhler, 2006).

3. Cultural and language factors

3.1. **Language:** working with different cultures and languages is inevitable so there needs be measures in place that can overcome challenges that arise from dealing with multilingual health professionals and patients (Geissbuhler, Bagayoko, & Ly, 2007, Ross et al., 2010). For example, in Africa there are over 2000 languages, South Africa having 11 official languages and in the EAC, a total of 308 languages (Eberhard, Simons, & Fennig, 2019; Jack & Mars, 2008). Communication between the patient and the health professionals can be difficult (Asiedu & Commentary, 2018; Jack & Mars, 2008).

3.2. **Trust and acceptability:** establishing trust between patients and HCW from different countries can prove to be difficult. Patients may prefer local interpretation over foreign ones (Lester, Durazzo, Kaye, Ahl, & Forman, 2007). They may be more free to be in consultation with a HCW who they share the same language and or culture (Lester et al., 2007; Mucic, 2008). Regarding acceptability, in low and middle income countries patients may be sceptical of 'western medicine' due to cultural reasons or religious beliefs

(Ferguson et al., 1995). These two factors may hinder the uptake of digital health systems for cross-border health.

3.3. Resistance: this is a human factor whereby health professionals may resist change in the way they work and shift their mindset on the use of technology to provide health services (Kalyanpur et al., 2004). It can also prove difficult for health professionals from different cultures to work together which may build up the resistance to the adoption of the digital cross-border health service (Qaddoumi et al., 2008).

4. Contextual factors

4.1. Resources: the healthcare services in Africa face various obstacles i.e. shortage of workers let alone skilled workers, health inequalities, drug stock-outs among others that may hinder the uptake of cross-border services or limit its sustainability (Mars, 2013). For example, if a patient is using a teleconsultation service and is not able to access or afford the medicine, the health inequality problem trying to be solved will still exists. Therefore, the service will not be of benefit to the patient nor the doctor (Ferguson et al., 1995, R Wootton et al; 2004).

4.2. Infrastructure: infrastructure challenges range from poor electricity, internet connection and bandwidth etc. An example of this can be identified from the digital health interventions in the EAC in Section 4.3.1, which had issues with accessing electricity to charge their mobile phones (European Union, 2009). These may affect the stability of the services provided (Bagayoko et al., 2006).

These are the factors to consider before digital health can be used to improve the current state of cross-border health. The legal aspect regarding the patient and the quality of care need to be factored in, the costs, the incorporation of digital health with the existing infrastructure, the approach behind the initiative, language, trust, acceptability, and resistance of the digital health tools, lastly, if there is enough resources and infrastructure to support the digital health system. However, there are issues to do with data management and data governance that should be discussed. Findability, accessibility

and interoperability of data is an important issue for cross-border health to enable real-time flow of information while ensuring there is provenance details in the data for accountability purposes and that there is adequate provisions that ensure data is protected. Chapter 5 discussed the various data management and data governance issued the EAC faces and how they can be tackled.

5 Findings on data management and governance in the EAC

This chapter contains the findings on the data-related problems in the EAC. Firstly, the data-related problems will be discussed which have been categorized under two topics data management and data governance. Following that is how FAIR can be applied to solve these problems which addresses the third research question of is FAIR data can solve data-related problems in the EAC.

5.1 Data-related problems in the East African Community

1. Data management problems

Data users often require real time available data that is accessible and reliable (Galetto, 2016). Data users can be governments, citizens, researchers, donors, among others. Data management is the procedures involved in collecting, validating, storing, securing, monitoring, and processing data to ensure the requirements of the data users are fulfilled (Galetto, 2016). This section discusses data problems that relate to data management.

1.1 Data collection and use

Reports by the African Population Health Research Center (APHRC), the Center for Global Development (CGD) and MO Ibrahim foundation have highlighted four main data problems relating to data management in Africa (African Population and Health Research Center (APHRC) & Center for Global Development, 2014; Mo Ibrahim, 2015) discussed below.

1.1.1 Lack of autonomy and unreliable budgets

The foundation behind data production and data management in the majority of African countries are the NSO (APHRC & CGD, 2014). They provide expert services to generate official statistics and support other national offices with their data activities, their end goal being to produce accurate and timely data to inform policies (APHRC & CGD, 2014). Due to unreliable budgets and lack of autonomy, NSO are exposed to intimidation from political and interest groups and may end up misreporting data (APHRC & CGD, 2014). The NSOs in twelve out of fifty four countries in Africa are regarded as

autonomous, including Tanzania, Rwanda, and Uganda from the EAC (APHRC & CGD, 2014). The NSO in the forty two countries left are managed by other government agencies and are often not in charge of their budgets and receive insufficient funding from the government (APHRC & CGD, 2014; Mo Ibrahim, 2015). Consequently, these NSO become dependant on donors for their most essential tasks, various African countries receiving 80% of their entire budget from donors (APHRC & CGD, 2014; Mo Ibrahim, 2015). The NSOs are also not able to perform their data management activities including managing other ministries that produce data (APHRC, 2014). A result of this may be duplication of data and variable methods of data collection and management which decreases the quality of the data and wastes resources (APHRC, 2014).

1.1.2 Misalignment of incentives

Misaligned incentives contribute to inaccurate data (APHRC & CGD, 2014; Mo Ibrahim, 2015). For example, in decentralised governments such as Tanzania and Rwanda, the various regions in the country are assigned local governments. These local governments are formed to deal with the education, health and agriculture among other needs of that particular region. They are allocated funds from the national government and also from donors to cater to these needs (APHRC & CGD, 2014; Mo Ibrahim, 2015). For instance, in order to get more funding, the local governments may increase the number of registered students in a local school to get more funds or in agriculture manipulate the yields to get subsidies from the national government (APHRC & CGD, 2014; Mo Ibrahim, 2015). This leads to publishing distorted data nationally and internationally (APHRC & CGD, 2014; Mo Ibrahim, 2015).

1.1.3 Donor priorities over national priorities

Donors devote millions for projects in Africa and they generate substantial amount of revenue for NSO and NSO staff (APHRC & CGD, 2014). The staff earn per diems which are more than their monthly salaries (APHRC & CGD, 2014). They earn them from attending donor-funder workshops, training, and fieldwork (APHRC & CGD, 2014; Mo Ibrahim, 2015). This creates a dependency on donor funding and takes the needed resources away from the NSO (APHRC & CGD, 2014; Mo Ibrahim, 2015). Consequently, the NSO lose motivation to improve the statistics nationally or the other national

offices concerned with building data which affects the data collection and management activities (APHRC & CGD, 2014).

1.1.4 Data accessibility

Accessing data in an African environment can be hard due to a considerate amount of data being unavailable publicly (Steele & Orrell, 2017). Data such as land ownership, census data, and agricultural data (Van Belle et al., 2018; Willem Heemskerk et al., 2017).This can be attributed to the lack of culture in data use, data hidden in old archives, data not being centralised, and resource constraints such as experienced workers and internet (Beguy, 2016; Mo Ibrahim, 2015; Snow, 2017; Willem Heemskerk et al., 2017). NSO may not want to publish their data due to their incapability in publishing and analysing data in ways that match international best standards (APHRC & CGD, 2014; Kiregyera, 2015; Mo Ibrahim, 2015). The data may also be in hardcopies or formats that can be problematic to use (Lowry & Wamukoya, 2016; Ojok, Mukhone, & Enywaru, 2018). In a data collection project in Uganda, Anderson and Sabiti (2015) came to the realization that the government may not purposely resist transparency rather, the data is not in user friendly format and that they also do not want the data to be misused (Bill Anderson & Bernard Sabiti, 2015).

1.2 Interoperability

Interoperability brings together communities of 'data holders' in an effort to improve the way data is used and collected (Steele & Orrell, 2017). Interoperability can lessen the time, effort, and cost spent on data collection and improve inconsistency and incomplete data (Steele & Orrell, 2017). However, data needs to be readily available for this to happen in the first place, suitable standards for interoperability need to be developed, and the necessary infrastructure such as electricity and internet need to be in place (Steele & Orrell, 2017). In Africa, such items are not guaranteed especially in rural areas where some residents do not even have electricity (Adebesin, Foster, Kotzé, & Van Greunen, 2013). For the urban areas that can afford to have these items, issues such as unsuitable standards, fragmented information systems, use of different vocabulary, privacy, security, and confidentiality of personal data arise (Adebesin et al., 2013).

1.3 Poor data quality

Incorrect data, data incompleteness, missing data, data duplication and no real-time availability are the various problems experienced in EAC health systems (Gourlay et al., 2015; Namageyo-Funa et al., 2018; Tumusiime et al., 2014) . As expected, these data problems consequently lessen the quality of the available data which then leads to inefficient decision making, overload on HCW work and incorrect statistical reports (Gourlay et al., 2015). Additionally, constructive monitoring and assessment of interventions cannot be made (Beguy, 2016).

2. Data governance problems

Data governance is concerned with supervising the way data resources are administered, by asserting authority and control together with enforcing policies that ensure the data resources are managed properly (Ladley, 2012). This section discusses data problems that relate to data governance.

2.1 Data protection laws

The data problems discussed under this section are a result of lack of or in some cases weak data protection laws.

2.1.1 Personal data usage

In a society that is increasingly being driven by data, it is imperative to have data protection laws (Mutabazi, 2018). In the EAC however, the standards of protection around data processing are not being adhered to in the face of data breaches such as, surveillance of citizens and interference by government and private agencies (CIPESA, 2018). On the 25th of May 2018, the European Union (EU) enforced the General Data Protection Regulation (GDPR) to apply rules that protect the personal data of its citizens (European Union, 2016). These rules outline the way in which citizen data should be accessed, processed, and handled, and highlight the need for consent prior to using citizens' data (EU, 2016). Following the allegations made against the company Cambridge Analytica for exploiting peoples' data to influence elections in Kenya and Nigeria, the formation of GDPR set precedence for Africa to enforce their own data protection laws as a collective (Abdi Latif Dahir, 2018; Maggie Fick & Alexis Akwagyiram, 2018). However, the laws on personal data and cybersecurity set by the African Union (AU) are yet to be enforced since only eleven members out of fifty five signed them since 2014,

none from the EAC members (Abdi Latif Dahir, 2018; African Union (AU), 2014). The absence of these laws has left the citizens data exposed to misuse by companies without them facing any consequences (Abdi Latif Dahir, 2018). An example of this is when voters in Kenya were sent political messages on their mobile phones by politicians that they had not subscribed to (Abdi Latif Dahir, 2018; Muthuri, Monyango, & Karanja, n.d.). These messages were deeply worrying due to the fact that they contained personal information such as names and addresses, information that was obtained from Safaricom, the biggest mobile service company in Kenya which was an infringement on their privacy (Abdi Latif Dahir, 2018; Kenyanito, 2014).

2.1.2 Data privacy

The low trust of citizens during elections in Africa have led to African countries implementing biometric technologies in the electoral process (Muthuri et al., n.d.). Biometric technologies have been identified as potential methods for building the trust and confidence in the election process and that ensure efficient processes (Muthuri et al., n.d.). These biometric systems use cross-referenced information obtained from a database to verify someone's identity (Privacy International, n.d.). Without strong data protection laws, this technology may be used to socially profile people, discriminate in the basis of tribes or ethnic group and can be used to conduct mass surveillance (Muthuri et al., n.d.; Privacy International, n.d.).

Mass surveillance has been used before by the Ugandan government to intrude on the opposition leaders' privacy (Privacy International, 2015). By using malware attached to their phones and computers, the sitting government was able to spy on them and acquire personal information used to blackmail them (Privacy International, 2015). This is a clear violation of the *"right to privacy of person, home, and other property"* stated in the 1995 Ugandan constitution (Government Of Uganda, 1995). The power in this case lies with the government, and if in the same case sophisticated biometric technology was used, the government could do so much more (Muthuri et al., n.d.; Privacy International, 2015).

2.1.3 Data gathering

In an effort to improve the management of citizens data that is stored in heterogenous sources and enhance security, the Government of Kenya (GOK) wants to introduce an integrated system that will centralize the citizens' data, from national identification cards to drivers licences (Mercy Muendo, 2019; Victor Kiprop, 2018). This is a risky move considering the regulatory frameworks in Kenya do not have adequate provisions for handling cases such as fraudulence, data breaches, and misuse of data (Abdi Latif Dahir, 2018; CIPESA, 2018). For example, when there is a data breach, they often go undocumented and the users are not informed (CIPESA, 2018).

In 2018, Facebook delivered Wi-Fi services to Kenya allowing Facebook users to access the platform for free without knowing their personal data is the price to pay (Business Daily (The East African), 2018). With the Wi-Fi operations under Internet Service Providers (ISP) in Kenya and not Facebook, Facebook is not licenced to collect any data (Business Daily (The East African), 2018; Luesby, 2018b). However, Facebook confirmed that it is indeed collecting personal information from the Wi-Fi access points stating that the data is used to enhance the experience of their customers; to make sure the Wi-Fi hotpots are functioning properly, and to monitor the traffic use (Luesby, 2018b; Maggie Fick & Alexis Akwagyiram, 2018). The Communication Authority of Kenya (CA) who oversees the communication sector in Kenya and who govern the national cyber security framework providing licences to industries like ISPs, was not aware of Facebook's activities of collecting data directly (Communication Authority of Kenya, n.d.; Luesby, 2018b). This presented a possible breach of the Kenyan law (Luesby, 2018b). Even though it was a possible breach, CA stated that there are no overarching rules on data collection and use by 3rd parties without consent from users (Luesby, 2018a).

2.1.4 Data sovereignty

The lack of data protection laws can lead to the misappropriation of data as seen from the example above (Abdi Latif Dahir, 2018). Safaricom is 40% owned by Vodafone, a telecommunications company based in the UK (Kenyanito, 2014). Vodafone is able to provide user information to other governments, taking advantage of the inadequate data laws in Kenya (Kenyanito, 2014). The data can be misused and transferred to 3rd parties without consent from the data owners and have no repercussions (Kenyanito, 2014). This happened in 2013 where it was reported that researchers in

the UK, obtained location data of fifteen million Kenyans to study Malaria transmission by tracking their movement without their consent, despite it being a violation of the Kenyan constitution; Article 31 which claims that *"Every person has a right to privacy"* (Kenyanito, 2014; Privacy International, 2019).

2.2 Data provenance

Data provenance is the provision of metadata that details the origin and the history of the data, where the data came from, the processing it has undergone if any, and if it contains someone else's work (GO FAIR, n.d.-b; Marinescu, 2018). The two issues discussed under this section are the lack of provenance in government and global health data.

2.2.1 Lack of provenance in government data

African government agencies websites usually contain data from various institutions (Van Belle et al., 2018). However, the data in the websites lack provenance which makes them unverifiable when one wants to use it (Van Belle et al., 2018). For example, in Tanzania, researchers were unable to find the origin of census data that consisted of geographic information on *"administrative boundaries and markings of water stretches"* (Van Belle et al., 2018). The data was published by the National Bureau of statistics but did not include where the data came from (Van Belle et al., 2018). This lack of traceability of data can lead to publishing data that is inaccurate or incomplete, the efforts used to analyse and compile the data going to waste (Lowry & Wamukoya, 2016). This can lead to stakeholders, citizens, and governments using unreliable data to make decisions (Lowry & Wamukoya, 2016).

2.2.2 Lack of provenance in global health data

Global health is referred to as the research practice that puts the need on improving health and ensuring that health is equitable for all the people in the world (Koplan et al., 2009). This can involve various students, researchers or health professionals from High-Income Countries (HIC) coming to work or do research in Low- and Middle-Income Countries (LMIC) to study diseases, assist in the creation of solutions for the challenges experienced with the healthcare systems, or to offer their professional services to the people (Calland, Petroze, Abelson, & Kraus, 2012).

In LMIC, the research environment can be difficult for local researchers due to insufficient or lack of funding, poor infrastructure i.e. labs and computers, lack of research expertise, and restricted or no access to equipment that is expensive (Kumwenda et al., 2017; Leonelli, Rappert, & Bezuidenhout, 2018). For the researchers that break through the hurdles, it can be a difficult experience for them when they need support (Dale Peters, 2017). There are instances where African researchers collaborate with international researchers from HIC collecting purely African data but, the African researchers don't receive the credit they deserve such as peer recognition and publication benefits since it is analysed and published in HIC since that's where the funding came from (Chu, Jayaraman, Kyamanywa, & Ntakiyiruta, 2014; Dale Peters, 2017). The African researchers also lose out on re-using the data because it is not owned by them (Dale Peters, 2017).

5.2 FAIR principles for data Management and data Governance

The following section identifies the ways in which the FAIR principles can be applied to solve the problems mentioned in the section above.

Findability

The Findability principle can facilitate the discovery of datasets (Wilkinson et al., 2016). Through assigned metadata and metadata ID of data items, data users who want to find data will use the information on the metadata to locate it (Wilkinson et al., 2016). The metadata of a document may contain the location where a file is stored or may contain information of a contact person or email (Luiz Olavo Bonino(Document Owner), 2016). For machines, the location could be a MAC address. The data item is discovered and found without the actual values known so, if the data user for example finds that the data is in a format that they do not want, they can save time acquiring data that they will not be able to access (Bicarregui, 2016).

In another instance, the metadata ID could be associated with a FDP. The data items could contain the metadata ID and the FDP would use this to discover the files, then find them and later make them available which will be illustrated in Chapter 6. For fragmented systems, this method can ensure data

are made available via the FDP and ensure real time availability (Luiz Olavo Bonino(Document Owner), 2016).

The Findability principle also encourages the registration of (meta)data in a location that enables exploration of the (meta)data (Wilkinson et al., 2016). This can combat duplication of data items, enhance the findability process and in the case of availability, the (meta)data can inform data users if the data item is available or not (Wilkinson et al., 2016). The issues with duplication of data incomplete data, and unavailability of data the EAC experiences can be improved with this principle. The Findability principle can also ensure that the data stays where they are so that the EAC can have ownership of their own data.

Accessibility

The accessibility principles states that when data users want to access a data item, the (meta)data ID should enable them to do so in a standardised method that can be applied anywhere in the world (Wilkinson et al., 2016). This facilitates accessibility of decentralised data items, that may be located in different databases or in different parts of the world (Wilkinson et al., 2016). The accessibility principles also ensure that authorised access to data items is granted and authentication is provided if the need be, before entry to and retrieval of the data (Wilkinson et al., 2016). For data governance in the EAC such provisions can be placed to govern centralised data locations where sensitive and personal data are stored, guaranteeing that only official access is granted. However, the data does not need to be centralized. The FAIR principles are based on finding data that is distributed since centralization of data is not sustainable. This principle can go further into the government using this to empower citizens to have control over their own data whereby, the (meta)data contains the contact details of the data owner. If anyone wants to use their data, they can contact the owner, or the owner can also provide the necessary permissions in the (meta)data beforehand similarly to the PHT (DTL, et al., n.d.).

Interoperability

Interoperability aims to ease the communication between various modes of information and communication technologies (Asuman et al., 2006). This enables precise use of exchanged information to achieve effectiveness and consistency in the act of the exchange (Asuman et al., 2006). The interoperability principle facilitates this process by advocating for utilization of commonly recognizable and accessible language in (meta)data and in *"knowledge representation"* that are FAIR (Wilkinson et al., 2016). It also ensures that (meta)data are properly referenced (Wilkinson et al., 2016). The use of common languages allows different systems to communicate with ease and encourages re-use of existing tools rather than creating new ones that may bring complications (Steele & Orrell, 2017). In the fragmented information systems, this principle can be applied for them to share information with each other more effortlessly (Wilkinson et al., 2016). The EAC suffers from this complexity of having various health systems where the health data is not interoperable and if the systems share the same language, they can be able to have mechanisms that facilitate the exchange of data amongst each other. Interoperability can also reduce duplicated efforts and advance innovation and development of knowledge (Wilkinson et al., 2016). For example, if the data has been produced before, it can be built upon instead of being re-created various times (Wilkinson et al., 2016).

Reusability

The FAIR principles highlight the importance of re-usability of data; (meta)data should be described with the significant characteristics that provide the user who would like to re-use the data with enough details (Wilkinson et al., 2016). Also, the need for (meta)data to have detailed provenance accompanying it (Wilkinson et al., 2016). Firstly, this principle can be applied to solve the issue with government data. It can contain well detailed (meta)data such as the origin, date of production, and the processing it has undergone if any (Wilkinson et al., 2016). In the case of restricted data items or for data items that need a licence to access, the (meta)data will contain the requirements needed (Wilkinson et al., 2016). As a result, the data item's reliability will increase.

For global health, research articles will have (meta)data stating the origin and the processing it has undergone. With the origin provided, credit can be given where it is due, and the researchers can be

recognised for the work they have done (Wilkinson et al., 2016). Overall, this can benefit the African research community as well as the rest of the world since there can be collaborations where there is an underlying understanding of the data at hand and who it belongs to, what processes it has been through, and the provision for re-usability can be applied (Wilkinson et al., 2016).

Machine actionability

The FAIR principles also denote the importance of data to be machine actionable (Wilkinson et al., 2016). This enhances the ability for machines to discover, find, read, and access data (Wilkinson et al., 2016). In this era of machines and big data, this is most important for interoperability as well as the other FAIR principles (Wilkinson et al., 2016). The limits humans present compared to the fast growth of data; machines need to be able to do what the humans do with processing data (Wilkinson et al., 2016). With the problem of data not being centralised, if the data is transformed into machine actionable data formats, the process of discovering the data can be made faster to make the data available, accessible, and interoperable (Wilkinson et al., 2016). In systems that have issues with connectivity, a machine can be made aware of a certain server being online at a particular time i.e. 3PM through the metadata and will go access the server at that time which facilitates flexibility of the application of the FAIR principles.

The FAIR principles have shown the potential to tackle the data-related issues faced by the EAC. However, data-governance problems such as personal data protection and data gathering will require efforts from the government to put the necessary measures in place to ensure they are tackled. The FAIR principles are not a standard but are guidelines aimed at improving the way data is managed and governed. This gives the FAIR principles the ability to be tailor-made to suit the environment in which they operate in i.e. in areas which have limited resources such as the internet. The following chapter illustrates how stock and reports datasets can be made Findable through a FAIR data point, and how it can be used to tackle cross-border health problems.

6 Development of a FAIR data-based model

This chapter contains the design of a FAIR data-based model for the cross-border health challenges the EAC faces. Detailed process steps alongside figures will be presented on how the FAIR principles were modelled, and the end result of the design and the visualization of how it would be in the EAC. This chapter will address the fourth research question of what a suitable FAIR data-based model would be to address the challenges of cross-border health in the East African Community.

6.1 Eldoret FAIR data-based model

To visualise how a FAIR data-based model may look like in the context of the EAC, a FAIR Data Point (FDP) model was developed as a proof of concept. The FDP created was named Eldoret after one of the major cities in Kenya. Eldoret is home to one of the main referral hospitals in Kenya called Moi Teaching and Referral Hospital (MTRH). MTRH provides its services not only to Kenyans but to Ugandans and South Sudanese (Moi Teaching and Referral Hospital (MTRH), 2019). Identified in Section 4.2 were cross border health challenges faced in the EAC. Two of the challenges were on drug stock outs and real time availability of data. Due to the poor flow of information between health systems and different healthcare professionals, optimum decisions cannot be made (Asiimwe et al., 2011; Bamenyekanye & Bigirimana, 2015; Barrington et al., 2010; fhi360, 2018; Githinji et al., 2013; MEASURE Evaluation, 2017; Nditunze et al., 2015; Vital Wave Consulting, 2009; WHO, 2016). As part of the policies of the EAC, availability and accessibility of medication, and real time information for decision making are objectives that are shared amongst the EAC (MOH (Kenya), 2013; MOH (Rwanda), 2015; MOH (SouthSudan), 2016; MOH (Uganda), 2010; MOHCDGEC (Tanzania), 2017). Therefore, the Eldoret FDP model was developed to show how these challenges can be tackled and illustrate how it would be in relation to the healthcare delivery systems in the EAC since there were no other prototypes. In the public policy agenda setting, policy entrepreneurs can push their solutions to problems identified when the political climate is good and take a window of opportunity to ensure a policy is enforced(John Kingdon, 1995). The Eldoret FDP model can be a proposed solution that the Africa IN can advocate for. However, it is important for the potential users to see it as being useful and practical to them for their data needs so that they can accept such a solution (Reisen & Stokmans, 2019).

Objective and scope of the Eldoret FDP

The objective of the Eldoret FDP was to illustrate how stock of medication and reports on illnesses datasets can be assigned machine-readable metadata, to enable them to be discoverable through the Eldoret FDP by applying Findability of the FAIR principles. Table 4 contains the Findability principles.

Table 4:

Findability Principles (Wilkinson et al., 2016).

Findability principles	Code
"(Meta)data should have a unique and persistent identifier" (Wilkinson et al., 2016).	**F1**
The data should be represented by sufficiently detailed metadata.	**F2**
The metadata should consistently contain the identifier of the data.	**F3**
(Meta)data are enlisted in a location that allows exploration of the (meta)data.	**F4**

The Eldoret FDP was not meant to serve as a cross-border health service but as part of the health services provided in the EAC. It was supposed to be incorporation with FDPs designed for Masvingo, Zimbabwe and Kampala, Uganda to test cross-border discoverability between the FDPs. However, the Mazvingo and Kampala FDPs were not ready for the testing phase. Nevertheless, Eldoret was modelled as a single unit and the limitations of this will be discussed further on in the chapter.

There is a limited prototype (http://136.243.4.200:8086/fdp/) of a FDP developed by the DTL which uses Swagger as the API however for the Eldoret FDP, Onadata API was used. Onadata is a data tool that is already in use in Kenya and it was selected to illustrate how a digital tool can achieve discoverability of data through a FDP. The difference between the FDP of the DTL and the Eldoret FDP is that it uses a CSV file format containing the metadata to assign to datasets which makes it easy to use and assign, it contains different kinds of datasets (drug stocks and reports of illnesses) and it is designed to interact with other FDPs.

6.2 Development process of the Eldoret FDP according to the Findability principles

The Findability principles are listed in section 6.1. The steps taken to develop the Eldoret FDP model according to these principles were as follows:

a. Creating the stock and reports datasets that will be represented by metadata.

Initially the stock and reports datasets were supposed to be created by Microsoft Access but that was not going to be retrievable in real time thus, a web platform by the name of Onadata which collects, analyses and makes data available in real time was selected to host the datasets. The stock and reports datasets were created using Xforms- used to create web forms and were uploaded in the Onadata API (Application Programming Interface). Once the forms were uploaded, stock and reports web forms were created via Enketo ready for data submissions. The fields for the stock data were: Medicine name, Code, Description and Quantity and for the reports were: Illness name, illness year, description and file location.

b. Identifying the metadata standard to use.

Metadata standards have been developed to maintain a consistent method of classifying and structuring data (Smith, Breytenbach, & Groenewald, 2007). The metadata standard used in the Eldoret FDP is Dublin Core (DC) which used to describe simple texts (Smith et al., 2007). DC contains fifteen descriptors of metadata and can be categorized into three: descriptive metadata, intellectual property metadata, and physical assets metadata as illustrated in Figure 9. Thirteen of these were used for the metadata of the stock and reports datasets.

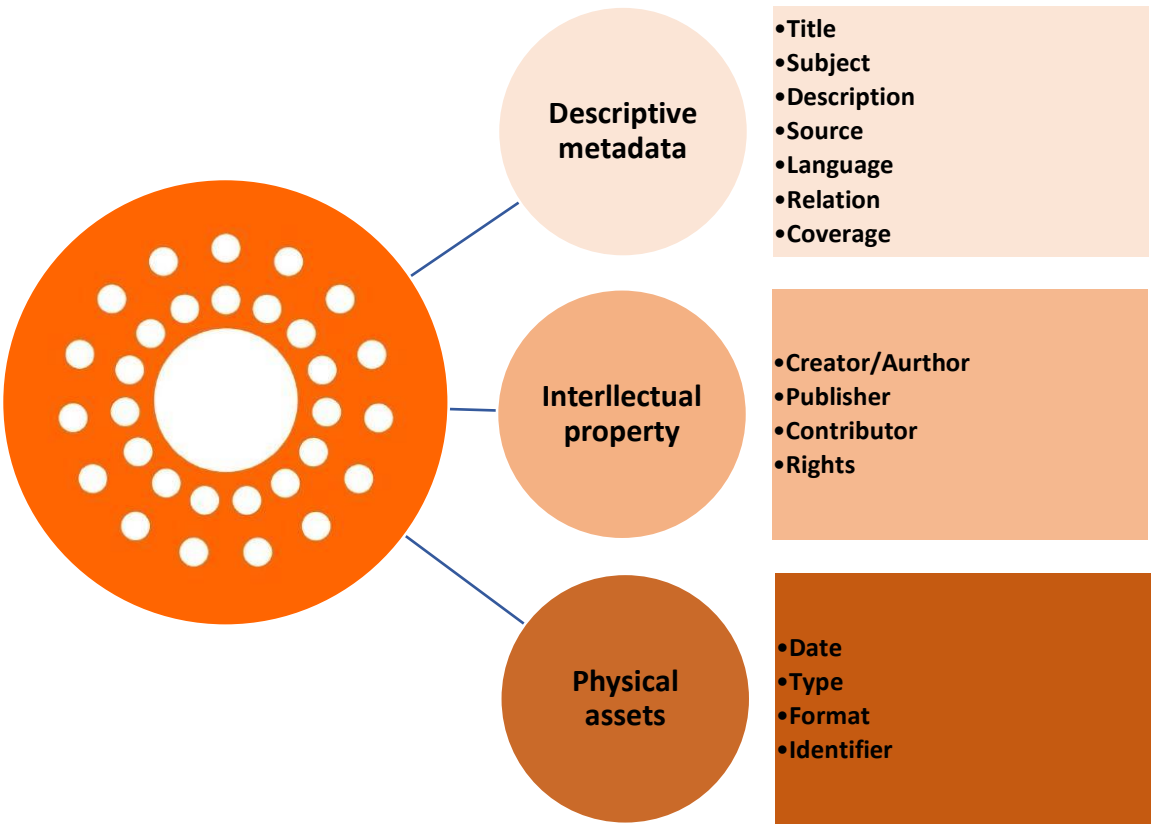


Figure 9: Dublin Core Metadata Standard (DCMI Usage Board, 2012; Smith et al., 2007).

Dublin Core Metadata for the stock and reports datasets

Table 5 contains the metadata terms used in the Eldoret FDP model, the Uniform Resource Identifier (URI), the description and comments regarding the metadata terms used for the stock and reports files.

Table 5:

Dublin Core Metadata Descriptors (DCMI Usage Board, 2012).

	Name	Uniform Resource Identifier (URI)	Description	Comment
1	Title	http://purl.org/dc/terms/accessRights	A term assigned to the data resource.	This is what the data will be known as by all the data users.
2	Identifier	http://purl.org/dc/terms/identifier	The assigned identification of the data resource.	The identifier is an important term to have. This is used to distinguish the data from other data globally and enable machines to interpret the data. In the stock and reports datasets, the identifier should be uniquely assigned and visible in the data they represent.
3	Description	http://purl.org/dc/terms/description	Describes the content of the data.	Provides the user a description on the data.
4	Subject	http://purl.org/dc/terms/subject	The subject of the data resource.	This will provide the user an indication of what the data is about.
5	Format	http://purl.org/dc/terms/format	Presents the format of the data resource.	This is used to provide the users information regarding the format so that they know the software or hardware to use when they seek to access the data.
6	Created	http://purl.org/dc/terms/created	The date the data was created.	These date elements inform the user when the data was created and when it was modified. It should conform to a set standard. The data applied for the stock and reports metadata uses the YYYY-MM-DD format according to ISO 8601 [W3CDTF] (Quiballo, 2018).
7	Modified	http://purl.org/dc/terms/modified	The date the data resource was altered.	
8	Creator	http://purl.org/dc/terms/creator	The party responsible for creating the data.	This is assigned to know who made the data.
9	Publisher	http://purl.org/dc/terms/publisher	The party responsible for the data.	This metadata provides the user the details of who is

				responsible for the data. This can be a government or an individual person.
10	License	http://purl.org/dc/terms/license	A permit requirement for the data.	The license detail is used to indicate what a data user is permitted to do with the data i.e. not use it for monetary value.
11	Access rights	http://purl.org/dc/terms/accessRights	Information regarding the permissions set for accessing the data resource.	This informs the user about the access options. If it is open access or requires special permission. The stock dataset is open access and will enable users to access the data without any permissions but the reports dataset it restricted access and only authorized people can access the dataset.
12	Language	http://purl.org/dc/terms/language	The language of the data.	This is used to define the language the stock and reports data is in. The language metadata comes in form of a link that indicates the language standard followed.
13	Coverage	http://purl.org/dc/terms/coverage	The geographical location where the data is applicable.	This metadata item specifies the location the data is applicable. When working with multiple systems in a particular geographical context, the coverage metadata ensures that the users knows this.
14	Source	http://purl.org/dc/terms/source	Specification of the related source of the data.	These last two metadata descriptors were not used because the data was not sourced from any resource and related data was not used due to time constraints. In the event of large sources of data from multiple streams related to different resources, the source and relation metadata would be important to include.
15	Relation	http://purl.org/dc/elements/1.1/relation	Specification of related resources.	

c. Creating and assigning the metadata to the stock and reports datasets

The next step after identifying the metadata standard to use, was to assign the metadata to the stock and reports datasets. Onadata was used to host the stock and reports forms (datasets) and the advantage of Onadata was that each dataset was assigned an automatically generated unique identifier. The unique identifier was used as the metadata ID in the stock and reports dataset metadata to ensure consistency (F1, F3). Figure 10 contains the allocated metadata for the stock and reports datasets (F2).

Stock dataset metadata	**Reports dataset metadata**
Title: Eldoret medication stock MetadataID: 422358 Description: This contains medication stock Subject: Essential medicine Format: CSV Created: 2016-09-15 12:00 Modified: 2019-02-25 12:00 Creator: Kidero Publisher: Keleni pharmacy License: https://creativecommons.org/licenses/by-nc-nd/3.0/ Access Rights: Open Access Language: http://id.loc.gov/vocabulary/iso639-1/en Coverage: Eldoret, Kenya	Title: Eldoret Patient illness reports MetadataID: 428223 Description: This contains reports of patient illnesses Subject: HIV/AIDS & Malaria Format: CSV Created: 2016-09-25 12:00 Modified: 2019-02-27 12:00 Creator: Jidenna Publisher: Eldoret hospital License: https://creativecommons.org/licenses/by-nc-nd/3.0/ Access Rights: Open Access Language: http://id.loc.gov/vocabulary/iso639-1/en Coverage: Eldoret, Kenya

Figure 10: Stock and Reports metadata

Metadata can be stored in different ways. They can be in independent files in formats such as XML or HTML, contained in documents, embedded in web pages, or be contained in a database (Smith et al., 2007). The metadata in this case used a CSV file to assign the datasets the metadata. The CSV file was created containing the metadata, and using the **CURL post** command, the metadata was posted to the datasets in Onadata.

d. Retrieving the metadata

The Onadata API provides a method in which one can search the database for a particular dataset using an ID (F4). The ID used in this case is the metadata ID assigned to the datasets above. The method used involved making an HTTP GET request to the Onadata database. First a connection was established to the Onadata database by using an authorization token. This is sent in the header of the HTTP GET request. The metadata is retrieved and is presented as a json text file.

The value for the **data_file** property in the json text represent a link to the dataset. Another HTTP GET request was made to the Onadata server to retrieve the dataset. The response of the request is a CSV (Comma-Separated Values) data format corresponding to the metadata of the respective dataset.

e. Assigning the Eldoret FDP metadata

This step involved allocating the Eldoret FDP metadata. The objective of the Eldoret FDP model was to make the stock and reports datasets discoverable through the Eldoret FDP. For that reason, the Eldoret FDP needed metadata and in the case of a human/ machine discovering the Eldoret FDP, the metadata will enable them to know about the FDP and what data it holds. The Eldoret FDP metadata is presented in Figure 11 below and was created using HTML.

Eldoret FDP metadata
Identifier: AFR12345 FDP Name: Eldoret Referral Hospital Description: FAIR data point for Moi referral hospital. Contains medicine stock datasets and illnesses reports datasets. Publisher: Kenya Health Care Coverage: Eldoret, Kenya Contact: khc@go.ke

Figure 11: Eldoret FDP metadata

f. Creating the Eldoret FDP GUI

Lastly, for the data users to interact with the (meta)data, a Graphical User Interface (GUI) was needed. The GUI's purpose was to present the metadata of the FDP itself, and that of the stock and reports datasets to data users. Once a data user discovers the Eldoret FDP, they are informed about the FDP and its datasets via the metadata presented in the GUI. The metadata assigned in step 5 was presented in the GUI and links to the reports and stock datasets were added as illustrated in Figure 12. Once the Stock link is clicked, the Stock metadata is presented similarly case for the Reports link.

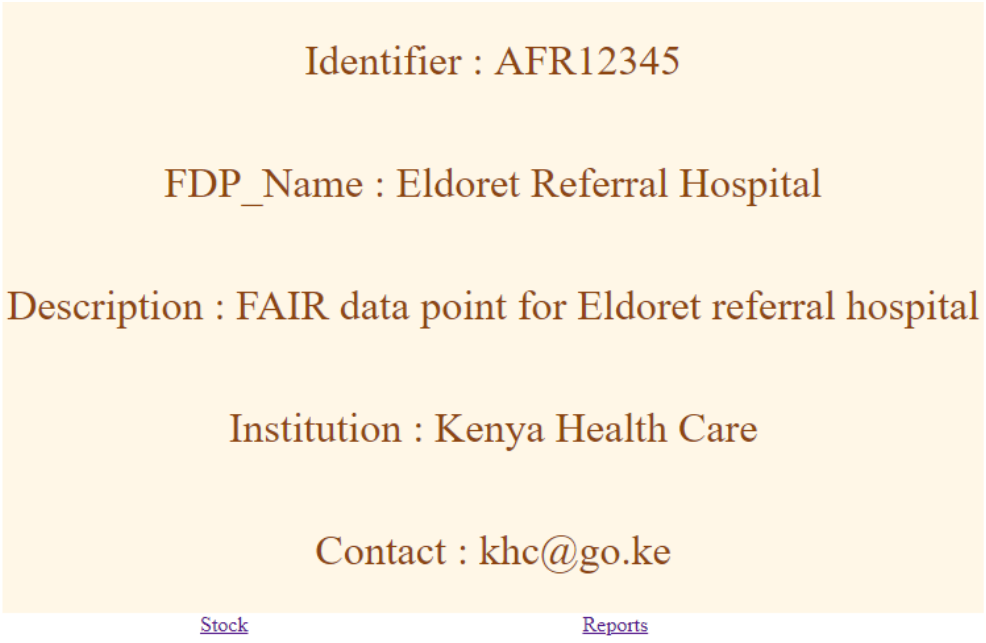


Figure 12: Eldoret FDP GUI (http://130.89.221.193:82/ELDFDP/).

The Eldoret FDP flow diagram

Figure 13 contains the overall process of Findability modelled by the Eldoret FDP and illustrates the flow into the Accessibility principle of the FAIR principles. The first interaction involves a user/machine interacting with the Eldoret FDP's API/GUI through a web browser, the FDP's metadata is presented and enables entry into the metadata of the datasets it has via the provided links. If the user/machine is allowed access, they can access the datasets.

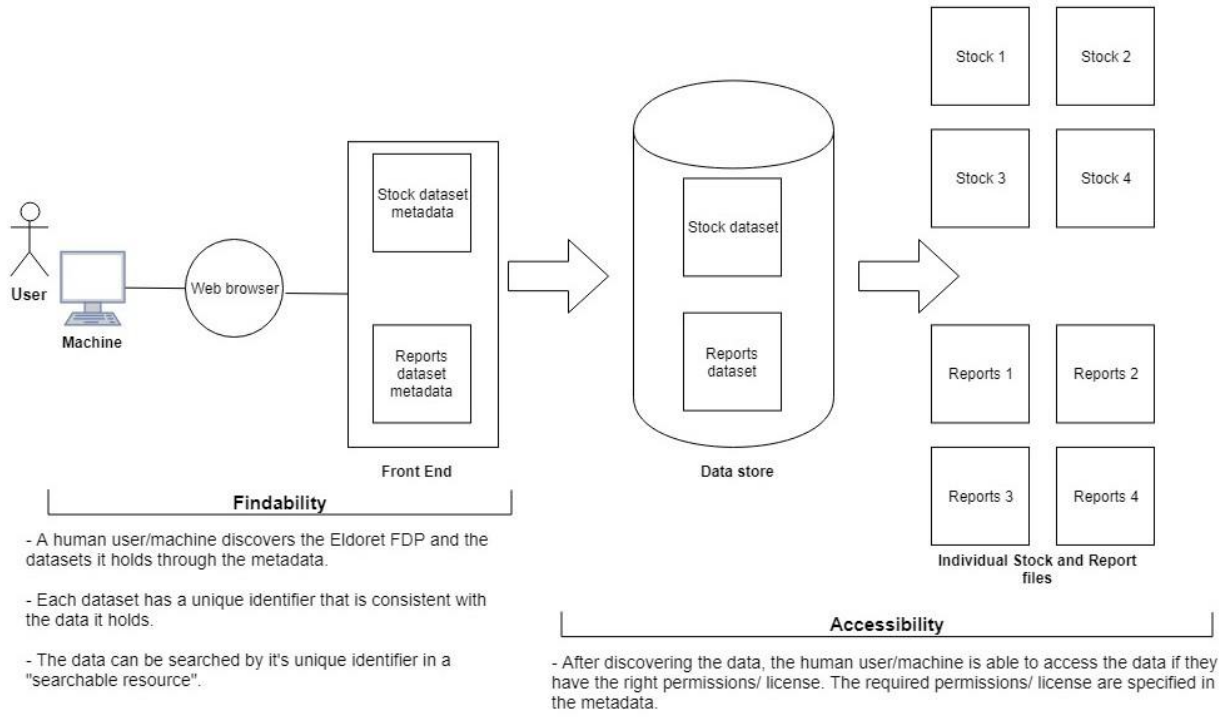


Figure 13: Eldoret FDP flow diagram

6.3 Data structure of proposed solution

The Eldoret FDP model was supposed to show how a FDP can help with discoverability, availability and findability of data. The FDP was modelled as a single unit and in this section the data structure of the solution the Eldoret FDP within the context of cross border health in the EAC will be presented which addresses the fourth research question. Figure 14 contains the data flow between the Eldoret FDP and that of the other countries in the EAC in the realization of the solution. It models the FDPs interacting with the healthcare delivery systems (referral hospitals, health centres, and district hospitals) and the NSO as well.

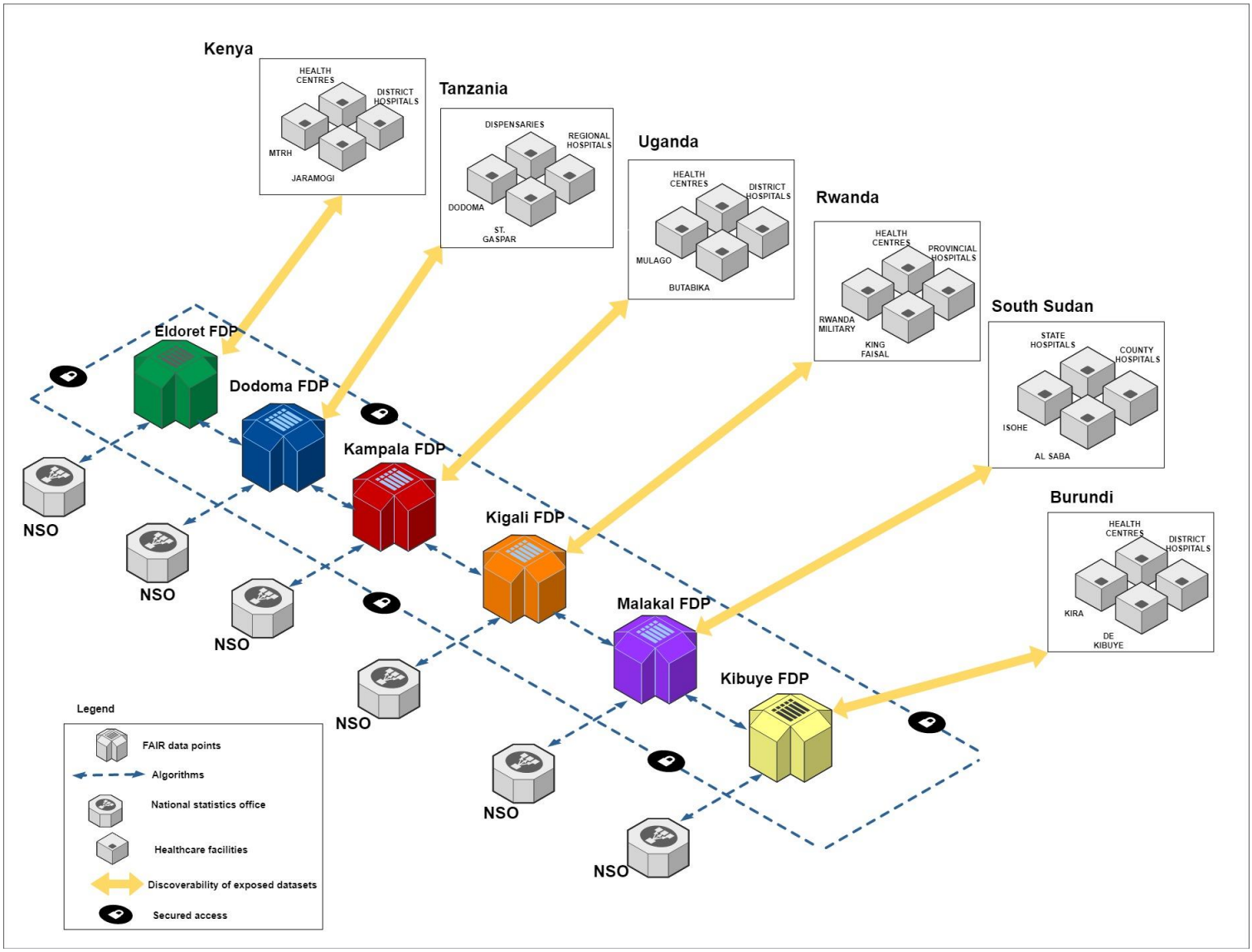


Figure 14: Data structure of solution

The FDP hosts metadata of datasets of the health delivery systems in this example, the MTRH of Eldoret, Kenya. The Eldoret FDP can store the metadata of its datasets. The Eldoret FDP can be the focal point for Jaramogi referral hospital to discover the MTRH datasets and vice versa, as well as other FDP belonging to the other EAC countries if the datasets are exposed. Kampala FDP could be storing metadata of stock and reports datasets belonging to Mulago and Butabika referral hospitals. Since the metadata is in a machine-readable format, a specific algorithm seeking stock datasets from Dodoma FDP can be sent to discover the datasets in the Eldoret and Kampala FDP. Once the algorithm has interacted with the (meta)data and it has the correct permissions, it is able to access the distributed datasets. For the organizations such as the NSO, they may be only interested in stock data for example, after interacting with the metadata and the stock datasets have no access restrictions, they are able to access the stock data.

In another instance, the Dodoma FDP could only be interested in a particular reports dataset from all the FDPs. An algorithm is sent to collect this dataset interacting with the distributed (meta)data of all the FDPs. If licence/access permissions are granted to all FDPs but the Kibuye FDP, Dodoma FDP gets access to all the datasets but Kibuye.

Once datasets are discovered, found, and accessed, they can now be interoperable and reused in a FAIR manner. The FDPs provides a solution to distributed data. Instead of attempting to gather data in a central location, you provide the metadata and thereafter, a user can be able to locate the data they need. By providing metadata that details the distributed data, a data user is able to know what data it is, if it is useful to them and how they can access it by providing details such as format, licence, and access details in the metadata. The EAC governments could want the stock of Malaria medication regional wise to make budgetary plans and the FDPs can be a way of producing such details. If a certain dataset has special permissions set, the algorithm will realize this from the metadata provided. The NSO may want the Malaria medication reports and the algorithm visiting the FDP can read the data it needs if it has the permission.

The challenges identified from Chapter 4 regarding drug stock-outs and real-time availability of data can be solved through FDPs. By having discoverable data, the FDPs from other countries can be able to seek the data and make them available in their FDPs. For example in a scenario of an event of a drug stock-out of an essential drug in Tanzania, if Kenya has enough stock they can be able to communicate and share where there is need through the information provided in the FDPs. This can facilitate timely decision making and can be incorporated with the DHIS that the EAC has implemented and other digital tools they are using. However, this will depend of how the FDP is presented to the potential users and their perceived usefulness and perceived ease of use. For example, for the NSO who are easily influenced due to their lack of autonomy can accept the FAIR principles if they are paid to use them. This concurs with the compliance aspect of perceived usefulness of TAM (Venkatesh & Bala, 2008). The Africa IN should acknowledge the motive behind such organizations. But, the issue of accessing real-time information addressed in the health policies of the EAC and the perceived usefulness by healthcare professionals may be acknowledged. The GO Change can further instil the value of the FAIR principles and the GO Train and GO Build can affect the perceived ease of use of the users of FAIR. Both affecting the acceptance of the FAIR principles (Reisen et al., 2019).

7 Discussion and conclusion

7.1 Discussion

The EAC experiences various challenges with cross-border healthcare delivery such as scarcity of human resources, no interoperability between other cross-border health facilities, and poor information flow which leads to health supply shortages. Digital health can potentially solve or provide support to help alleviate these problems such as using telemedicine to help with the scarcity of HCW. However, digital health systems can be difficult to govern, and they need proper management and governance to safeguard data being produced such as the FAIR principles. This can help improve the traceability of data within the digital health systems in the EAC and can make data available and accessible in a secure way. This chapter discusses the findings of this research. Firstly, the sub-research questions are discussed, and the main research question will be addressed.

What is the current state of cross-border health in the EAC?

The EAC countries have various health delivery systems such as referral hospitals which offers a range of health services, health centres that deal with minor illnesses, and health posts that are in charge of reporting in the case of a suspected disease outbreak within a community. The regional integration in the EAC has enabled cross-border movements between the member countries however, this movement carries risks of the spread of CD which the healthcare systems are inadequate to deal with. Especially in the wake of Ebola in the Democratic Republic of Congo (DRC), which is seeking to join the EAC, which is a disastrous situation waiting to happen (Aggrey Mutambo, 2019; Godfrey Olukya, 2012). The inadequacy comes from issues such as insufficient number of HCW, poor information flow, and health supply shortages i.e. drug stockouts (fhi360, 2018). The EAC health policies address these issues and they aim to improve the situation around the health workforce, to make evidence-based decisions for health interventions and finance, to improve the systems around disease outbreaks to respond faster, and to ensure citizens access quality medicine. The EAC has acknowledged that these issues will need regional, national, and international bodies involved to ensure there is proper flow of information on a real time basis to improve communication and provision of accurate information across the borders. To prevent and control CD and NCD, they have set up units that have strategies

to develop the methods used for the detection and treatment of CD and NCD regionally, and to ensure that the EAC citizens have access to quality food and medicine. In Kingdon agenda setting, problems must be attention grabbing to the decision makers (John Kingdon, 1995). The issues to do with lack of evidence-based information, insufficient numbers of HCW, and health supply stock-outs was recognized by decision makers and thus policies were formulated on how they can be tackled.

To what extent can digital health improve the current state of cross-border health?

Digital health shows the potential to tackle the issues faced with cross-border health. The various digital health interventions in the EAC have had a majority of positive results with a few limitations. The interventions have shown to have great potential in tackling matters on data collection and monitoring, tracking of disease outbreaks, health workforce training, communication between patients and HCW, and drug stock management. However, the systems continue to suffer from data incompleteness and the unavailability of real-time data which is important for decision making. These limitations resulted in the interventions to not be fully optimised due to the lack of access to sufficient data. In regard to TAM2, for the users of the newly introduced interventions, the factors that influenced the outcome were; how they were able to get more skills (result demonstrability), if they were being paid to use the new systems (compliance), if they had support during the interventions i.e. training (ease of use), and if they were apprehensive on using the new systems (ease of use) (Venkatesh & Bala, 2008). Also exhibited in these interventions, was the importance of the 'community approach', involving different parties such as MOH, academic partners, and community partners when tackling an issue due to the value each one adds. Another positive result highlighted was the use of eHealth systems in coordination with an already functioning health system offering support instead of replacing it. Also, mHealth was preferred over eHealth since mobile phone, especially SMS based interventions, were more cost effective and that the HCW could use their own mobile phones. The challenges experienced with mHealth however, were the maintenance of areas that do not have electricity and the lack of usability for the health professionals who don't own mobile phones.

Apart from the factors highlighted above, implementing digital health systems for cross-border services can be problematic. This is due to factors such as, the regulatory and legislative measures

which are in place within different countries on matters to do with quality of care, liability of the patient, informed consent, and governing patients data to guarantee security and confidentiality. Furthermore, there are sustainability concerns such as costs and financing of the systems as well as integration with the existing healthcare system, cultural and language differences between the different geographical borders, and lastly contextual factors such as resources i.e. skilled workforce and inadequate infrastructure. These factors may hinder the adoption of cross-border digital health tools. Also, digital health needs backing from the seven digital health ecosystem enablers; good leadership and governance, effective and efficient strategies, effective legal mechanisms, right policies and compliance terms, trained and appropriately allocated workforce, suitable standards and interoperability of systems, adequate infrastructure and supportive services and applications to digital health. Effective leadership and governance are needed to ensure the right strategies are employed for cost- effective successful implementation of digital health tools (EARHC, 2017). Additionally, this can help to maintain the quality in the standard of care, to increase accountability for data breach cases and to provide easily accessible legal measures for patients to take. This can result in the effective execution of cross-border digital health systems. But of course, the perceived usefulness and perceived ease of use from the perspective of the users of the digital health system will determine whether they will accept them or not (Venkatesh & Bala, 2008).

Can FAIR data solve data-related problems in the EAC?

The FAIR principles have the potential to solve the data management and governance problems the EAC experiences however, there are various systematic challenges that cannot be tackled by FAIR and require systematic changes such as the issue of donors' involvement in the data collection and lack of autonomy for the NSO. Donors playing a big role on the data production for the national statistics offices in terms of budget and the kind of data that is being collected leads to misaligned incentives and priorities being set to what the donors demand (APHRC & CGD, 2014; Mo Ibrahim, 2015). Due to unstable budgets and lack of autonomy, the NSO are not able to perform their tasks optimally which affects the quality of data being produced, leads to inaccessible, and unavailable data (APHRC & CGD, 2014; Mo Ibrahim, 2015).

In regards to data governance, in a data-driven society, the EAC members need to recognise that personal data can be exploited and have damaging effects to the subjects involved and take necessary

measures to ensure personal data is protected (Internet Society (ISOC) & African Union (AU), 2018). For example, for the new system being introduced in Kenya discussed in Section 5.1, Kenyans need the assurance that their data will be protected and in cases where there has been a data breach, that they will be informed (Victor Kiprop, 2018). They should also be empowered to hold the government accountable in the face of mismanagement or misuse of their data (Mercy Muendo, 2019). Additionally, there is the lack of provenance in data. Government data can be more trusted if the history and origin of the data is attached to it. Data can be published when it is incorrect or incomplete and mislead decisions being made(Lowry & Wamukoya, 2016). When it comes to global health data, African researchers need to be equally involved in data publishing and be recognised for it. Historically, there have been exploitation of the African researchers where they do not hold power when it comes to data analysis rather, they just perform the data collection due to a lack of resources i.e. funding and proper infrastructure for analysing the data and in some cases, they do not get recognised for taking part in the data collection process. As a result, they are not able to re-use the data because it is not owned by them(Chu et al., 2014; Dale Peters, 2017; Ellen & Plewes, 2015). This can create a bias in the data that is collected and a lack of recognition for the efforts put in by the African researchers.

The FAIR principles can ensure real-time discoverability, availability, and findability of data through the provision of metadata that has been registered and identified as belonging to that data (Wilkinson, et al., 2016). In regard to data protection, data sovereignty, and data governance, management and processing of data, FAIR can ensure that there is more responsibility around data protection and data re-usability, research by African researchers can be cultivated by the provision of proper metadata attached to the data produced by them thereby, improving the citations and recognition worldwide (Wilkinson, et al., 2016). However, the EAC needs to form policies for this to happen. The data related issues that can be solved by the FAIR principles will require a policy change on the government and management of data in the EAC. The policy change will need the people in power or near power, people close to the decision makers to advocate for these issues, to ensure that it has caught the decision makers attention (John Kingdon, 1995). In this case it is the EAC governments. Secondly, it will also need proposals for these solutions to be ready, proposals of feasible solutions such as the one developed in this thesis, and lastly, it will require the policy making

body to be involved which in this case is the EAC (John Kingdon, 1995). The coupling of these three by a group of determined people, such as the Africa Implementation network who are interested in the implementation of the FAIR principles in Africa, can ensure that when an opportunity presents itself, they are ready with the solutions applied to the data government and management problems (John Kingdon, 1995).

In addition to the policy change, the FAIR principles need to be accepted by the users. The GO Change, GO Train, and GO Build agendas will be key to ensure acceptability of the FAIR principles through training, making the users more aware of the usefulness, as well as providing support for the users in the issues regarding data management and governance (Reisen et al., 2019). These factors will affect the acceptance of the FAIR principles in the EAC.

What would be a suitable FAIR data-based model to address the challenges of cross-border health in the East African Community?

The Eldoret model illustrates how datasets can be assigned metadata to facilitate discoverability of data through a FDP. After discoverability, the datasets are found and made available and can therefore be accessed by data users if the necessary permissions are granted. The metadata provision allows for users to identify the data they want to access, and the necessary requirements needed to access it. Due to the various health deliver systems, centralization of data may not be the optimum option. The Eldoret FDP suggests that the metadata should be stored linked to the datasets of the health delivery systems and safeguard the data access where only authorized people/ machines can be allowed entry. In the case of data that doesn't have restrictions, smooth data discoverability can be ensured by machines. The Eldoret FDP can be replicated in the other countries of the EAC to enable cross-border discoverability of the data within the region. This will improve the accessibility and availability of data to improve the information flow which is currently an issue being faced. However, for the realization of this solution, policy and political will are required to solve a public problem (John Kingdon, 1995). The public problem needs to be well articulated to the decision makers, and entrepreneurs that are determined to change the policy such as the Africa IN (John Kingdon, 1995; Reisen & Stokmans, 2019). They should couple the well-articulated problems to solutions and ensure there is a good political climate to take a window of opportunity that will lead to policy change (John Kingdon, 1995; Reisen & Stokmans, 2019).

How can the FAIR principles be incorporated in digital health systems in the East African Community to improve cross-border access to health?

This is the main research question of how the FAIR principles can be incorporated in digital health systems. They can be integrated through a FDP as illustrated in Chapter 6. The Africa FAIR IN as a policy entrepreneur group can advocate for the use of FAIR principles, and can promote certain solutions such as the use of FDPs to tackle problems that they have set the attention to by decision makers such as the challenges of finding data. However, it is important for the users to accept them by their perception of the usability and ease of use of FAIR-based digital health and also policy is key for the solution to be realized. Policy that would make every country in the EAC will agree to implement the FDPs. By bringing all these items together when the political climate is good, and if the opportunity to change the policy around data to be governed by the FAIR principles is taken, they can form policies where the digital health systems use the FAIR principles. Once this is tackled, the FDPs can be tailor-made to suit each of the countries needs and can coordinate with other FDPs designed as an effort to improve the cross-border access to health through the provision of real-time discoverability of data. As expected, there can be some form of resistance due to lack of understanding, lack of trust especially since this is an idea from the 'west', among other reasons. The GO Change will be by far the most challenging task.

7.2 Conclusion

In order for the FAIR principles to be a reality in the EAC, different organizations need to come together such as governments who are in charge of making important decisions, researchers, and entrepreneurs to make it possible and form public policies based on FAIR. The opportunities the FAIR principles present to the EAC cross-border health are abundant. The acceptance of the use of FAIR principles will be affected on how they view these opportunities in relation to how easy it will be to use, the effects they will have on their job and if they will see the benefits. The acceptance factors and public policy formulation can ensure FAIR is incorporated in the digital health systems where it can improve the cross-border access to health.

Limitations

There are several limitations to this research. Firstly, regarding the data collection method used which was interviews. The interview results did not contribute to the research since they were only two people interviewed and there was little information extracted on the relevant topic discussed due to the limited knowledge on the FAIR principles. The number could also not lead to any generalizable results. The research would have benefitted from interviews if there were more people to interview and who had knowledge on the topic. Secondly, regarding the model design, the Eldoret FPD discoverability function by other FDPs was not tested due to the Masvingo and Kampala team not being ready for testing. Thus, the result could not be tested. Despite the model being designed and working as a single unit, the solution proposed for the EAC was not tested. Additionally, there were several cross-border health challenges but only two were addressed for the Eldoret FDP due to time constraints. Also, the FAIR principles consist of three other principles yet the Eldoret FDP only covered Findability. The solution of cross-border health will need accessibility, interoperability, and reusability to tackle the issues they have. Lastly, the FAIR principles are based on something that should be used on the internet. However, there are kinds of data that cannot transcribe to such forms and are equally important to healthcare systems meaning they will be left out of the FDP.

Recommendation for Future Research

The Eldoret FDP only modelled Findability of the FAIR principles, future research can explore all the FAIR principles and how they would be implemented in a FDP that tackles a similar issue on cross-border health. Interviews can be conducted to find out the perceived usability and perceived ease of use of the FAIR principles around the EAC especially with people dealing with data such as the MOH, NSO and HCW. A fully established FDP can be tested on Findability, Accessibility, Interoperability, and Reusability especially with machines. Lastly, a study could be done on the areas the FAIR principles will leave out and the likely impact.

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9 Appendix

9.1 Abbreviations

API: Application Programming Interface

CD: Communicable diseases

CHW: Community Health Workers

CSV: Comma-Separated Values

Digital (REACH): Regional East African Community Health Initiative Towards

DOI: Digital Object Identifiers

DTL: Dutch Techcentre for Life Sciences

EAC- East African Community

EAOSCH: East African Open Science Cloud for Health

FAIR: Findable, Accessible, Interoperable, Reusable

FDP: FAIR Data Point

GUI: The Graphical User Interface

HCW: Health Care Worker(s)

HIS: Health Information System(s)

HIV/AIDS: Human Immunodeficiency Virus infection/ Acquired Immune Deficiency Syndrome

HTTP: Hypertext Transfer Protocol

ICT: Information Communication Technology

IFDS: Internet of FAIR Data and Services

NCD: Non-Communicable diseases

NFC: Near Field Communication

NSO: National Statistics Office(s)

PHT: Personal Health Train

RDF: Resource Description Framework

RDT: Rapid Diagnostic Tests

UHC: Universal Health Coverage

URL: Uniform Resource Locator

VCT: Voluntary Counselling and Testing

XML: eXtensible Markup Language

9.2 Definition of terms

Communicable diseases: Infectious diseases i.e. Tuberculosis (WHO, 2017a).

Community Health Workers: people who voluntarily get chosen by their communities and are trained by the Ministry of Health (MOH) and medical staff (Leuchowius, 2014).

eHealth/ E-health: *"This refers to an enhanced way of the delivery of health services and information through the internet and related technologies"*(Eysenbach, 2001).

FAIR data point (FDP): A FDP contains a software that enables data owners to make their data discoverable by both humans and machines, using data formats that are machine-interpretable and that use widely-accepted vocabulary to enhance interoperability, complying with the FAIR data guiding principles (Bonino da Silva Santos et al., 2016; Wilkinson et al., 2017). If the license permits, the data can be accesses through the properties it holds referred to as metadata (Luiz Olavo Bonino(Document Owner), 2016).

Genomic Revolution: genome sequencing coupled with the technological advances to provide valuable insight on the DNA of organisms (Joanna Lynne Kelley & (Contributor), 2013).

Malaria Rapid Diagnostic Tests (RDTs): tests used to see if someone's blood contains the Malaria parasite (WHO, 2015b).

mHealth/ M-health: *"is a component of digital health where medical and public health practice is supported by the use of mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices"* (Ryu, 2012).

Mpesa: mobile money service <https://www.safaricom.co.ke/personal/m-pesa>.

Near Field Communication (**NFC):** NFC is *"a wireless communication technology that enables the transfer of data over distances of up to 10 centimetres"*(Halaweh, 2013).

Non-Communicable diseases: Diseases that can't be spread from one person to the other. i.e. Cancer.

RDF: *"a globally-accepted framework for data and knowledge representation that is intended to be read and interpreted by machines"* (Wilkinson, et al., 2016).

Store-and-forward telemedicine: *"is collecting clinical information and sending it electronically to another site for evaluation. Information typically includes demographic data, medical history and documents such as laboratory reports"* (NZTelehealth, n.d.).

The East African Community: *"The EAC is inter-governmental organization"* consisting of 6 countries: Burundi, Kenya, Rwanda, South Sudan, Tanzania and Uganda (East African Community, 2017).

Metadata

Metadata is 'data about data' (lac group, n.d). The lac group have identified 5 categories of metadata below:

1. **Descriptive metadata:** used to identify and locate an item. For example, a user can distinguish the item by searching for the author (lac group, n.d., lac group, 2018)
2. **Technical metadata:** information regarding the technical process behind the creation of a digital item and what is required to use it (lac group, 2018).
3. **Structural metadata:** gives a description about how the item is layered internally i.e. Table of contents (lac group, n.d).
4. **Administrative metadata:** information on the administrative aspects such as intellectual property rights (lac group, 2018).
5. **Preservation metadata:** contains the methods that have been used to preserve a digital resource and ensure quality is maintained i.e. Changing servers (lac group, 2018).

9.3 FAIR Articles

Table 7:

FAIR Articles and FAIR citations

		Inventory of FAIR articles (A) and citations (C):	**Topic**	**Location**	**Links:**
1	**A**	The FAIR Guiding Principles for scientific data management and stewardship	FAIR principles	Europe	http://www.nature.com/articles/sdata201618
2	**A**	A design framework and exemplar metrics for FAIRness	FAIR metrics	Europe	https://www.nature.com/articles/sdata2018118#t1
3	**A**	FAIR Data Points Supporting Big Data Interoperability	Big Data Interoperability	Europe	https://www.researchgate.net/publication/309468587_FAIR_Data_Points_Supporting_Big_Data_Interoperability
4	**A**	Evaluating FAIR-Compliance Through an Objective, Automated, Community-Governed Framework	FAIR-Compliance	Europe+USA	http://dx.doi.org/10.1101/418376
5	**C**	A Global Data Ecosystem for Agriculture and Food	Agriculture and food	Europe	https://www.godan.info/sites/default/files/documents/Godan_Global_Data_Ecosystem_Publication_lowres.pdf
6	**A**	Interoperability and FAIRness through a novel combination of Web technologies	Interoperability and FAIRness	Europe+USA	https://peerj.com/articles/cs-110/#conclusions
8	**C**	The Semantic science Integrated Ontology (SIO) for biomedical research and knowledge discovery	Semantic science Integrated Ontology	Canada+Europe+USA	https://jbiomedsem.biomedcentral.com/articles/10.1186/2041-1480-5-14
9	**A**	Cloudy, increasingly FAIR	EOSC	Europe	https://content.iospress.com/download/information-services-and-use/isu824?id=information-services-and-use%2Fisu824

10	**C**	The health care and life sciences community profile for dataset descriptions	Healthcare and life science	Europe	https://peerj.com/articles/2331/
11	**C**	Reproducible and reusable research: are journal data sharing policies meeting the mark?	Data sharing	USA	https://peerj.com/articles/3208/?utm_source=TrendMD&utm_campaign=PeerJ_TrendMD_0&utm_medium=TrendMD
12	**C**	MOLGENIS Research: Advanced bioinformatics data software for non-bioinformaticians	Bioinformatics data software	Europe	https://www.researchgate.net/profile/Salome_Scholtens/publication/327346428_MOLGENIS_Research_Advanced_bioinformatics_data_software_for_non-bioinformaticians/links/5b94254e299bf147392a590e/MOLGENIS-Research-Advanced-bioinformatics-data-software-for-non-bioinformaticians.pdf
13	**A**	How FAIR Can you Get? Image Retrieval as a Use Case to Calculate FAIR Metrics	FAIR metrics	Europe	https://ieeexplore.ieee.org/abstract/document/8588646/references#references
14	**A**	FAIR principles and the IEDB	Immune Epitope Database	USA	https://academic.oup.com/database/article/doi/10.1093/database/bax105/4877121
15	**C**	Conceptualization of Methods and Experiments in Data Intensive Research Domains	Research Domains	Russia	https://link.springer.com/chapter/10.1007/978-3-319-57135-5_1
16	**C**	Linking Health Web Services as Resource Graph by Semantic REST Resource Tagging	Linking Health Web Services	Europe	https://www.sciencedirect.com/science/article/pii/S1877050918318441
17	**C**	Reproducibility of studies on text mining for citation screening in systematic reviews: Evaluation and checklist	Text mining	Europe	https://www.sciencedirect.com/science/article/pii/S1532046417301661#bi005

18	C	An integrative systems bioinformatics approach of the environmental, genetic and molecular factors regulating sleep	Systems bioinformatics	Europe	https://serval.unil.ch/resource/serval:BIB_F83443750AF0.P001/REF.pdf
19	C	Meaningful Data Interoperability and Reuse among Heterogeneous Scientific Communities	Data Interoperability and Reuse	Russia	http://ceur-ws.org/Vol-2277/paper05.pdf
20	C	Transparent to whom? No algorithmic accountability without a critical audience	Algorithms	Europe	https://www.tandfonline.com/doi/full/10.1080/1369118X.2018.1477967?scroll=top&needAccess=true
21	A	FAIR Data Based on Extensible Unifying Data Model Development	Canonical Data Model	Russia	http://ceur-ws.org/Vol-2277/paper04.pdf
22	A	Ready, Set, GO FAIR: Accelerating Convergence to an Internet of FAIR Data and Services	Convergence to an IFDS	Europe + USA	http://ceur-ws.org/Vol-2277/paper07.pdf
23	A	FAIR science for social machines: Let's share metadata Knowlets in the Internet of FAIR data and services	Sharing metadata	Europe	http://www.data-intelligence-journal.org/static/publish/B5/D1/28/A85A05492CA4E681827A4F8BF7/0511-Barend_Mons.pdf
24	A	FAIRsharing: working with and for the community to describe and link data standards, repositories and policies	Reporting data and metadata	Europe	https://www.biorxiv.org/content/biorxiv/early/2018/01/17/245183.full.pdf
25	A	Advancing Discovery Science with FAIR Data Stewardship: Findable, Accessible, Interoperable, Reusable	Discovery science	Europe	https://www.tandfonline.com/doi/abs/10.1080/0361526X.2018.1443651?needAccess=true#aHR0cHM6Ly93d3cudGFuZGZvbmxpbmUuY29tL2RvaS9wZGYvMTAuMTA4MC8wMzYxNTI2WC4yMDE4LjE0NDM2NTE/

					bmVlZEFjY2Vzcz10cnVlQEBAMA==
26	**C**	Navigating the unfolding open data landscape in ecology and evolution	Biology	Europe	https://www.nature.com/articles/s41559-017-0458-2#Bib1
27	**A**	How to make research information FAIR: DSpace-CRIS and best practices in open research information	Research information management	Europe	https://dspacecris.eurocris.org/handle/11366/657
28	**A**	The FAIR guiding principles for data stewardship: fair enough?	Data Stewardship	Europe	https://www.nature.com/articles/s41431-018-0160-0
29	**C**	NOMAD: The FAIR Concept for Big-Data-Driven Materials Science	Materials science	Europe+USA	https://arxiv.org/ftp/arxiv/papers/1805/1805.05039.pdf
30	**C**	Enhancing Reuse of Data and Biological Material in Medical Research: From FAIR to FAIR-Health	Medical research	Europe	https://www.liebertpub.com/doi/pdf/10.1089/bio.2017.0110
31	**C**	A Conceptual Enterprise Framework for Managing Scientific Data Stewardship	Scientific Data Stewardship	USA	https://datascience.codata.org/articles/10.5334/dsj-2018-015/
32	**C**	Four simple recommendations to encourage best practices in research software	Research software	Europe	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5490478/
33	**A**	Fair design jam: a case study on co-creating communication about fair data principles	Data management	Europe	https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2932831
34	**C**	Minimum Information for Reusable Arthropod Abundance Data (MIReAAD)	Diseases	Europe+USA	https://www.biorxiv.org/content/biorxiv/early/2018/10/17/429142.full.pdf
35	**C**	From Historical Handwritten Manuscripts to Linked Data	Linked data	Europe	http://liacs.leidenuniv.nl/~plaata1/papers/TPDL2018.pdf

36	**C**	Building and sustaining data infrastructures: putting policy into practice	Data infrastructure	Europe	https://wellcome.ac.uk/sites/default/files/building-and-sustaining-data-infrastructures-oct16.pdf
37	**C**	Social sciences and humanities research data and metadata: a perspective from thematic data Repositories	Thematic data Repositories	-	http://eprints.rclis.org/30054/
38	**C**	InChI As a Research Data Management Tool	Research data and metadata	Europe	https://www.degruyter.com/view/j/ci.2016.38.issue-3-4/ci-2016-3-408/ci-2016-3-408.xml?format=INT&intcmp=trendmd
39	**A**	FAIRDOM: Reproducible Systems Biology through FAIR Asset Management	Biology	Europe	https://www.research.manchester.ac.uk/portal/files/57033545/NETTAB_2016_paper_22.pdf
40	**C**	FAIR approaches applied to unravelling Plant-Pathogen Interactions Data and RNA Processing Evolution	Biology	Europe	https://dialnet.unirioja.es/servlet/dctes?codigo=114571
41	**C**	Open data and the publishing landscape	Open data	Europe	http://pastglobalchanges.org/download/docs/magazine/2018-2/PAGESmagazine_2018%282%29_52-53.pdf
42	**A**	DSA and FAIR: The best guarantee for the open and long term accessibility of research data	Research data	-	https://pure.knaw.nl/ws/files/3998562/SciDataCon53.pdf
43	**C**	Data Citation in Neuroimaging: Proposed Best Practices for Data Identification and Attribution	Data Citation	USA	https://www.frontiersin.org/articles/10.3389/fninf.2016.00034/full

44	**C**	An Ecosystem for Linked Humanities Data	Linked data	Europe	https://link.springer.com/chapter/10.1007/978-3-319-47602-5_54
45	**C**	Improving the discoverability, accessibility, and citability of omics datasets: a case report	Biology	USA	https://academic.oup.com/jamia/article/24/2/388/2631485
46	**C**	Water, Water, Everywhere: Defining and Assessing Data Sharing in Academia	Data Sharing	USA	https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0147942
47	**C**	Publishing FAIR Data: An Exemplar Methodology Utilizing PHI-Base	Diseases	Europe	https://www.frontiersin.org/articles/10.3389/fpls.2016.00641/full
48	**C**	Identifying ELIXIR Core Data Resources	Biology data resources	Europe	https://pdfs.semanticscholar.org/8d34/738f73bdb4e340843a6487b8375ef8925606.pdf
49	**C**	Making sense of big data in health research: Towards an EU action plan	Health research	Europe	https://genomemedicine.biomedcentral.com/articles/10.1186/s13073-016-0323-y
50	**C**	GAP Data Management Plan	Research data	Europe	http://gap-project.eu/wp-content/uploads/2016/10/GAP-D1.1-Data-Management-Plan.pdf
51	**C**	Developing a data sharing community for spinal cord injury research	Data Sharing	USA	https://www.sciencedirect.com/science/article/pii/S0014488617301371
52	**C**	National plan open science	Open science	Europe	https://repository.tudelft.nl/islandora/object/uuid%3A9e9fa82e-06c1-4d0d-9e20-5620259a6c65?collection=research
53	**C**	Fair data for next-generation management of multiple sclerosis	Diseases	Europe	https://journals.sagepub.com/doi/full/10.1177/1352458517748475

54	**C**	Discovering and linking public omics data sets using the Omics Discovery Index	Biology	Europe	https://www.nature.com/articles/nbt.3790.pdf?origin=ppub
55	**C**	Identifiers for the 21st century: How to design, provision, and reuse persistent identifiers to maximize utility and impact of life science data	Life science data	Europe+USA	https://journals.plos.org/plosbiology/article?id=10.1371/journal.pbio.2001414
56	**C**	A metadata-driven approach to data repository design	Meta data	Europe	https://link.springer.com/article/10.1186/s13321-017-0190-6
57	**C**	Supporting FAIR Data Principles with Fedora	Open source repository	-	https://www.liberquarterly.eu/articles/10247/print/
58	**C**	FAIR national election studies: How well are we doing?	Election studies	Europe	https://link.springer.com/content/pdf/10.1057%2Fs41304-018-0194-3.pdf
59	**C**	A nomenclature and classification for the congenital myasthenic syndromes: preparing for FAIR data in the genomic era	Diseases	Europe+USA	https://ojrd.biomedcentral.com/track/pdf/10.1186/s13023-018-0955-7
60	**C**	From Open Access to Open Data: collaborative work in the university libraries of Catalonia	Open science	Europe	https://www.liberquarterly.eu/articles/10.18352/lq.10253/
61	**A**	FAIR: A Call to Make Published Data More Findable, Accessible, Interoperable, and Reusable	Biology	USA	https://www.cell.com/molecular-plant/fulltext/S1674-2052(18)30239-9
62	**C**	The RD-Connect Registry & Biobank Finder: a tool for sharing aggregated data and metadata among rare disease researchers	Diseases	Europe+USA	https://www.nature.com/articles/s41431-017-0085-z
63	**C**	Research data management in the French National Research Center (CNRS)	Research data management	Europe	https://www.emeraldinsight.com/doi/abs/10.1108/DTA-01-2017-0005

64	C	Project Tycho 2.0: a repository to improve the integration and reuse of data for global population health	Global population health	USA	https://academic.oup.com/jamia/advance-article/doi/10.1093/jamia/ocy123/5132125
65	C	Preparing healthcare delivery organizations for managing computable knowledge	Healthcare and life science	USA	https://onlinelibrary.wiley.com/doi/full/10.1002/lrh2.10070
66	C	FAANG, establishing metadata standards, validation and best practices for the farmed and companion animal community	Animal genomes	Europe+USA	https://onlinelibrary.wiley.com/doi/full/10.1111/age.12736
67	A	Testing the FAIR metrics on data catalogs	FAIR metrics	Europe	https://peerj.com/preprints/27151.pdf
68	C	The radiation oncology ontology (ROO): Publishing linked data in radiation oncology using semantic web and ontology techniques	Linked data	Europe	https://aapm.onlinelibrary.wiley.com/doi/full/10.1002/mp.12879
69	C	How to reach a wider audience with open access publishing: what research universities can learn from universities of applied sciences	Open access	Europe	https://www.liberquarterly.eu/article/10.18352/lq.10237/
70	C	Recommendations for Improving the Quality of Rare Disease Registries	Diseases	Europe+USA	https://www.mdpi.com/1660-4601/15/8/1644/htm
71	C	Quality Assessment of Biomedical Metadata Using Topic Modelling	Biomedical Metadata	Europe	http://ceur-ws.org/Vol-2112/sewebmeda_paper_2.pdf
72	C	The international nucleotide sequence database collaboration	Nucleotide sequence database	USA	https://academic.oup.com/nar/article/46/D1/D48/4668651
73	C	The CEDAR Workbench: An Ontology-Assisted Environment	Meta data	USA	https://link.springer.com/chapter/10.1007/978-3-319-68204-4_10

		for Authoring Metadata that Describe Scientific Experiments			
74	**C**	Fostering effective data management practices at Leiden University	Data management	Europe	https://www.liberquarterly.eu/articles/10185/print/
75	**C**	Early career researchers want Open Science	Open science	Europe	https://genomebiology.biomedcentral.com/articles/10.1186/s13059-017-1351-7
76	**C**	Experiences with DERIVA: An Asset Management Platform for Accelerating eScience	eScience applications	USA	http://isrd.isi.edu/downloads/deriva-experiences.pdf
77	**C**	Aztec: A Platform to Render Biomedical Software Findable, Accessible, Interoperable, and Reusable	Biomedical research software	USA	https://arxiv.org/ftp/arxiv/papers/1706/1706.06087.pdf
78	**C**	Medical Image Data and Datasets in the Era of Machine Learning—Whitepaper from the 2016 C-MIMI Meeting Dataset Session	Medical data	USA	https://link.springer.com/content/pdf/10.1007%2Fs10278-017-9976-3.pdf
79	**C**	BioSharing: curated and crowd-sourced metadata standards, databases and data policies in the life sciences	Life science data	Europe	https://academic.oup.com/database/article/doi/10.1093/database/baw075/2630435#47329888

USA

Europe

Russia

Europe +USA

Canada+Europe+USA

9.4 FAIR principles

FAIR principles (Wilkinson et al., 2016)

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

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

Interoperable:

I1. (meta)data use a formal, accessible, shared, and broadly applicable language for knowledge representation.

I2. (meta)data use vocabularies that follow FAIR principles

I3. (meta)data include qualified references to other (meta)data

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

9.5 Expert interview transcript

FAIR data use in digital health systems in Africa

Date of Interview: 12th September 2018

Interview between:

- **Ronald Manhibi (Project Manager at SolidarMed)**
- **Albert Mulingwa (National Coordinator- Training and Clinical Mentorship Programmes, Ministry of Health and Child Welfare, Harare)**
- **Annastansia Ochuku Master student at Leiden University**

Beginning of interview:

Annastansia Ochuku: I'm gonna briefly introduce my research area, what I'm researching on is- we have an issue in East Africa (EA) or Africa in general of accessing health care and this is in Urban areas, in rural areas wherever you are because also in urban areas we have poor people, we have rich people, we have all sort of people, middle class, low income people and they also have a problem accessing health. So, what I've done is since there is an organization called Digital Reach, I think Mirjam touched on it and its main focus is on improving the healthcare, one of the focus areas is improving the healthcare in EA and as EA comes together, the trade becomes easier, travel becomes easier and why not health-accessing health? And so, my focus is on- my thesis is on how we can use digital systems to help in cross border health care but not only that, but- implementing the FAIR principles in those systems. How can we find if the systems are put in place? Let's ensure that the data is Findable, Accessible, Interoperable and Reusable- Yeah so that's my main research focus. Right now I've just done the literature review, what I've done is I've just gone through the- mostly its mHealth that have been implemented around Africa, maybe due to the mobile penetration-high mobile penetration in-

Ronald Manhibi: You say it's mostly m- uh?

Annastansia Ochuku: mHealth- mobile health using- different systems, different applications to support or to help with HIV or specific diseases but not overall healthcare, just as a support system or like uh- just to help the workers or something like that- that have been implemented so far- according to my literature and yeah-so I'm not really focused on other eHealth, web-based applications so yeah that's where I'm at currently and yeah maybe you can talk about your- just briefly talk about your expertise.

Albert Mulingwa: I'm a medical doctor by profession with special interest in health systems management and quality management systems. I hold a national portfolio responsible for capacity building, for eHealth workforce in the country, for provision of HIV and TB services according to set standards and guidelines and also improvement of quality of services provided in Zimbabwe.

Ronald Manhibi: My name is Ronald Manhibi, I'm a computer science- I'm a computer scientist by profession and for masters I did masters in Ecommerce and information systems and for undergraduate I was looking at artificial intelligence, how I could use artificial intelligence to connect farmers to use natural medicine to- these herbs to help cure diseases like (Inaudible) then there was- for masters I was looking at mobile- we call it mobile learning. Since I have been involved in the implementation of information systems, in businesses looking at how they align the business of ICT to the business depending on which type of business you will be looking at and I have been a consultant with non-governmental organizations, right now I've got a particular interest in electronic health because I am now a project manager with SolidarMed that is into public health and I believe that-(Inaudible) I don't know if you need any more?

Annastansia Ochuku: No that's enough. So maybe we can- I can summarize some of the problems I experienced in East Africa and maybe you can summarize the problems- main problems you have experienced in Zimbabwe and what we can do is like how we think eHealth systems will help such problems although there is a lot of literature but it's always good to see from a personal perspective how'd you think or how'd you think it will maybe extend the problem and make it even worse than

solving the problem. So, for me what I've- the main problems experienced in East Africa, in Kenya specifically is- what I've realized is monitoring- the drug-monitoring if people are taking drugs, overall access to healthcare-some people you will find that they travel so far to- because the capital is where the health is- health systems are the best per se so you find people travelling all the way from rural to the urban areas to access health care- within the urban areas, we find that there is poor people who cannot afford their healthcare- to access healthcare in hospitals and stuff like that and also problems like- I'd say like adherence as well, like you are given something you have to- I dunno if I can say report it or you don't adhere to- for example if you are given TB medicine, you reach half way and you are like I'm done with this I don't feel like doing it anymore, so such problems. I can say monitoring, accessing health care and- those are the main issues that are backed up with data that I can think of right now and what about you?

Albert Mulingwa: When I look at our program, our national response to the HIV pandemic and also throw in TB there- we have come quite a long way and we note some success stories, these days we are talking about the UN 909090 targets for HIV- you are familiar with that?

Annastansia Ochuku: I think I've heard- yeah

Albert Mulingwa: Okay, yeah so like the targets set by the UN that we should have 90% of our people knowing- that are living with HIV knowing their status and of those 90% that know their status, that are positive are put on treatment and 90% of those who got treatment are (Inaudible)-the target by 2020 as we move towards ending AIDS by 2030 as a public health problem. So, every country, specifically Zimbabwe we are using the same targets and we've made quite significant progress towards the 909090 targets so much that we are looking at ourselves as we are in the last mile in our fight against HIV and what that simply means is we are left with fewer people to look for that are living with HIV that we should put in treatment meaning we have to make sure that those we find are maintained on treatment meaning we have to be clear of the numbers, we have to be clear of the data, we have to be clear of the quantification of our treatment and so on and with those that are on treatment, we need to help them retain treatment and finally be suppressed- what that means is we also need to make sure that our data is telling us the correct story and the collection of our data is

giving the accurate story on the ground. So, across this spectrum, we note the both ends of connecting data that is accurate, we note the importance of making use of the data that we get for programming, we also note the importance of improving systems for collecting data for disease surveillance, for treatment and retaining patients in care, we have had most of our data or strategic information related interventions paper based for a long time, it has come again as a burden to the health care worker who is already overburdened by the bigger numbers of patients that they are dealing with- so we are at a time where we have to look at innovative ways to manage our data, manage our information and we are in that era where we are looking at systems that we can use for patient monitoring, systems that we can use for- you know electronic health records for patients, that is the era where we are in and that comes with a lot of issues that we need to make sure that are put in place so that there is a good buy in from the relevant authorities and we do it correctly and we protect our patients and our people and our data, yeah. This is where the issues of governance, ownership accountability and protection of our data comes in-And maybe one day if we push for this data Govpower thing that we brought up today- Because that becomes the basis of our- it's quite a critical component of making use of ICT In Health, health is one sensitive area in terms of confidentiality issues and so forth and in some places they might actually look at this as security risks in one way or the other for a country to be exposed when their data is not protected enough you know- and yeah, that's where I see eHealth coming in and doing it properly is critical.

Annastansia Ochuku: I can- personally I can see how such problems also relate to Kenya or any I'm not sure about the other East African countries but yeah that really relates to Kenya because I mean they have digitalized to a certain extent they are still using paper- their systems are paper-based. Although, like the last time I checked they were using- maybe you can say half paper, half systems Like this still have not really fully moved to using computers or digital systems yet but yeah I can see the paper-based methods and the issue comes back to FAIR you try and find data like in 1990 the sickness that you had in 1990, Can you really find it in those papers? You have to and we are in 2018 can you really find the data it needs to be Findable and Accessible anything to add with the problems?

Ronald Manhibi: Problems that are being faced? well I would say you need with the healthcare and ICT implementation of ICT in health well they're quite a lot and I would start by saying that mostly

when you get to the training of healthcare workers most of them are not very computer literate. I would say one of the days about a fortnight ago we had a talk with a county director Dr Janneke van Dijk for SolidarMed we went to one of the referral hospitals called Masvingo hospital in Zimbabwe and what we found is that there is some equipment that was donated to these health care workers and they were trained but they were not using it, and you know what they said they are given an apple laptop like this one and they said I think it had been there for something like 2 years and they said no we're safe keeping it, it will get damaged and you know it's really quite a challenge but we are still having a such an high number of computer literate people and not conscious because maybe after you may have been given such a gadget you would think that maybe they would utilise it to make their work easier, and then you also talked about you know the other problem that we spoke about in the other meeting (expert meeting 1), they still expect allowances to such an extent that some players that want to help and are not having that much money to give them allowances might actually have challenges coming in let's see maybe you want to teach them about HIV you want to teach them about something else but your budget is something like 50,000 for the allowances and their budget is 50,000 but you have got something like 10,000 or 15,000 just to book the teams and so on and you can actually get the facilitators but you can't just come in because they expect you to pay them for just sitting and training it's just some of those big thing then you would also look at the fact that there are certain services that are still a challenge. I'm back there in Zimbabwe like the cost of the bandwidth, the internet connectivity there is a very notable nonexistence of- or should I say poor telecommunications infrastructure in some of the most remote areas or in some parts that are rural in Zimbabwe and that alone actually constricts or should I say restricts limits where eHealth can be in any one given point. So, we are talking of something like cloud computing and so on here in Europe or in other parts of the world you can speak about that in that area because we at one point were looking there- we saw that they pay about €60 to get something like a connection of about 300 megabytes per second I think you understand here in Europe. But back home to get such a connection you might be paying something like 20,000 30,000 dollars per month so if you compare 20,000 to 60 euro yeah I think you can actually see why it's a not being were not able to implement it. In those areas part of the problem it's been that the Taxes are quite high you would be looking at something like 25 to 30% of that going towards Taxes of that amount or if you say you've got a bill of 20,000 at least 6,000 is going towards the taxes so these are still- as much as there are no players on the ground

to help with this regulator is something to do with this because and I think it should actually come from the government going down, so you would find that the government has challenges like through the information of ICT they have challenges noting this because maybe someone has not been able to they've not been able to be on the same table to understand this so it would still remain a challenge. As long as maybe we don't have something like that or they may be knowing but they might not yet be having the budget to make it right. We have a- we also have another issue to do with maybe people in the healthcare because some of them have not been exposed to the power of ICT- what myself and Dr Mulingwa here is been exposed because we have travelled places when do we know that eHealth is the in thing and is changing lives, is changing how things are so based on that they can't have that drive to say that we want to change we want it to look like this And it is that resistance to change that actually is the problem in a way and then you also look at the list goes on and on.

Annastansia Ochuku: so maybe what I can say for internet costs yeah I think it's too high for you guys but I think what I can speak for Kenya, what Kenya has done, they have this mobile provider they have this one mobile provider called Safaricom and it's made it like so that at least everyone can have internet but at least the cheapest you can get internet for is 5 shillings which is like you can say it's like 5 euro cents.

Ronald Manhibi: For how much data?

Annastansia Ochuku: 35 mbs. Yeah but it's something you know- and you have it the whole day and then you can renew it so it's five shillings per day, so at least it's trying to help people access- even when I went I was surprised to access my internet back in my rural area where there's like- let me tell you where I live is an island of no development, no electricity, no roads, nothing but now at least it's coming up but I was surprised to access my Safaricom in my area so maybe if they come up with such things of making it easier for people access internet you know…

Albert Mulingwa: yeah in our setting it's more of our Private sectors and our public private partnerships that are beneficial that are mutually beneficial to the people that we are serving I'm

just thinking about people like Econet,(inaudible) and so on they are private players but they have the interest of the people at heart and we can meet somewhere like private mix.

Ronald Manhibi: well like in my experience education there was one point where we engaged them and you know I was part of a commission from the Ministry of higher education so it was a 6 member band representing universities so I was like a member the other guys (inaudible). So, we went there and asked what would it take for you guys to actually help and then they said no, we're actually we are prepared to help but it is you guys you have to go back to the ministry and ask them to lower the taxes because we can't do business as long as a taxes are that high. So, it was actually the shock of our life- we ended up trying to come up with what you call an NREN(national research and Education Network) where we would want the government would say that the internet that is imported or that comes through the NREN Is zero rated if it costs something like $100 and the admin costs the administration costs and so on costs about $5 then it supposed to be given to anyone doing education at $105 sharp and then it means that you would not need these players because what their argument is that you have been- you guys we own this equipment the infrastructure like Econet is where in some of the most remote areas they have put their infrastructure so they are kind of putting some money they invested there back to the consumer saying that we really want that money to come back because we invested and if you would like to lower this you do the investment yourself and then you lower the- knowing it would take 5 years to get that money back so that has been argument and that has been the discussion with these players and you know when someone has got that kind of leverage against you or that power you have very little to argue with them especially in public health it is one of the most affected.

Annastansia Ochuku: So I was talking to you and you were saying it would be amazing if you a Zimbabwean and can be able to access your data or information in Zambia-

Albert Mulingwa: oh yeah what were talking about earlier- what I would say would be a common problem, I look at our setting in Zimbabwe where we boarder South Africa, Botswana, Mozambique and our neighbouring partners who maybe performing better in one or two areas that are of interest in terms of trade and collaboration with- economic collaboration with Zimbabwe. In such contexts

we are finding quite a lot of cross border trading and in the context of infectious diseases that have become a public health problem control of such is- becomes complex and requires you know cross-border collaborative and the countries to come together and look at innovations that makes sure that people access services when and where they need them and making that easy would include making sure that access to patient information or patient data is made accessible but of course with confidentiality and with respect and protection that it deserves but for the benefit of the patient you need such information to be accessible in the right context. We're not talking of these problems specifically HIV, as a chronic illness you don't want to break the continuum of care, we're also talking of differentiating services- there is days where our services have to be patient centred I'm a cross-border trader that's the way I live my life my accessing health should not deter me from my economic activities because I may prioritise this more than my health- you know as they speak of differentiating services we also need to look at these special populations that are across borders and making sure that service is a differentiated for them or with them in mind and we could hear more from them how we can do it better because I always believe that solutions come from the affected people from the affected community so probably through engaging them, engaging those that are providing services to them and respective authorities we can come up with solutions that helps them it's not a secret that technology can help with that it's not a secret that internet can help with that but like I said earlier this is sensitive information we also want to protect our patients and some problems that we are having around retention in care have to do with disclosure and stigma and so what we want to do is tread carefully, we know overally it's important for them and for everyone- if you don't do it properly in Zimbabwe, if you don't do it well in South Africa or Botswana it becomes a problem in Kenya and here in Netherlands.

Annastansia Ochuku: And I feel like it's also important the patients who don't know they have this right to be informed so that also comes into education- like are they aware that they have this right.

Albert Mulingwa: Yes definitely, it's not just access of Healthcare, it's access to information building their capacity to understand that there are patient rights and so forth, make them the centre of the services they need and also find ways to get feedback from them- Mike from the previous idea get

feedback from them on how we can improve services to them that's where we can use all these ICT informations to assist and improve systems.

Ronald Manhibi: Actually to access the health information is another problem as well- I would like to compliment what he said that I think we could also engage these big corporates or any corporate in helping with the training or helping with the distribution of information if we've got let's say a cholera Outbreak for instance, You know we could engage Vodafone Netherlands to actually send an SMS to everyone, send an email to everyone yes it could be deemed as spam or something like that, spam email but in a way to some extent it's informative in helping- it could work in a way that is like- you know what they call location-based advertising, the one that is used by, mostly used by Google and Facebook, it could be like that let's say there's a problem in a certain area like Nairobi, you can locate everyone who is there and then that advertisement just goes there if your phone is located around there then algorithm just sends a message there, so we would need that kind of technology to actually help in public health and so on. They had maybe to pre-empt this, I don't know if you would permit me to me to speak about planet learning.

Albert Mulingwa: Sure

Ronald Manhibi: They are implementing nationwide in Zimbabwe a system that works offline, that is based on tablets maybe I'm just going to give you a snippet and he may comment on that where they say like we have those self-test kits who HIV and AIDS and maybe you might actually instead of having a Healthcare worker do that do the testing and maybe do the counselling you just have that information accessed somehow the person can actually be counselled then after that counselling session he or she is taught how to self-test and then he or she tests himself and then the training goes on even to the health care workers let's say instead of having so many people spending so much money on the training that normally goes on to 2 weeks and so on and having spoken about the issue about allowances that is- not that if I was going to be a health worker I wouldn't want to such allowances, I would like them but maybe looking from the policymakers point of view, it's not sustainable and it's not really feasible because in the developed world they're not looking at that that makes them a little bit different from the developing countries because they are actually taking that

into consideration so it's one of the systems that they are using mobile learning or electronic learning to have a tablet to be with pre-recorded instructions to help the Healthcare workers, to help their patients, to help all the other people around that. so that goal of eradicating HIV and AIDS by 2020 can actually be a thing of the past if it is a success.

Annastansia Ochuku: Yeah yeah and if they stay- is they are actually used. so let's move on to fair data, so in terms of a data, I briefly explained, I think you understand what FAIR data is by now. so how do you think?- the model, if we can model this fair data based approach to healthcare in Africa, how would you think it would look like?

Albert Mulingwa: No doubt we need, it is a good concept, FAIR data we want our interventions these days to be guided by evidence, we want our policies To Be guided by evidence, we want to research to be guided by data, we want to speak to all that, most of our interventions through correct accurate data that is accessed by the relevant systems and institutions for use in the respective communities and so forth. How this can come into play is a very important discussion question why because in the era that we are in especially first speak about my context we are getting used to ICT quite a bit slowly, we're taking each step quite carefully, change management has not been an easy thing for any intervention that comes through, the capacities that we have are at different levels are also an issue of concern yeah in the era of ICT and use of data so I would model it in a way that initially allows for penetration of the systems that matter in a careful manner that shows the different systems that matter, the importance of it that we share the vision with the powers that matter, we have buy in from different governments and sectors that have the power to make the decisions to implement this. it important and critical for us to have buy in for these stakeholders but can then make the difference in their own context. once we have the buy in of the different stakeholders and institutions that have the powers that we need to make use of it may then become easier for them to run with it in their different areas of influence. So think it's a matter of approaching those either buying- if you're speaking at an international level then you're engaging the different regions appropriately people or institutions that have the powers to influence the different regions having those different regional representatives influence the next level from the nations and then after that make sure that the different national systems buy in and then they take the responsibility and the buy in to cascade

that further to their countries because we all understand at its important and critical and it would be of benefit to everyone in terms of our responses to our health issues quality of services and further research and so forth.

Annastansia Ochuku: In Zimbabwe do you have like a Central health system or its just private, private, private, public? or how is the health Dynamics in Zimbabwe?

Albert Mulingwa: We have the ministry of health as the custodian of health and health interventions in the country and within the country there's a public system and private-sector system but the accountable institution remains the ministry of health so the ministry of health would set the different regulation that guide the different sectors and programming in the public sector is also done through the established structures in the ministry and at national level provision level, down to the lowest level facilities and even some of the community interventions are programmed through the ministry of health. We also have quite high-end helpful number of strategy partnership, we have some non-profit organisations working with the ministry and the public system in what the government would have prioritise these areas of concern within the country. We also work very closely with the recipient's themselves of the service, that's the patients so the patient's networks that also helps as part of the system, with their feedback, with their assistance on how we should structure our responses, we also work with lobbyists and other activists that also assists in shaping how the Healthcare should be at the different stakeholders at different levels using the various platforms that are in existence in the country. private sector has also it structures when organised to speak to the clients that they serve. there are several opportunities of course that exists in trying to improve the whole system at large because what if there might be a problem that's in the private sector that's not been taken care of well becomes a public health problem so there are some areas that we're still need to work on in terms of public private partnerships and also accessing all knowing what thing or data that is being collected by the private sector visa vie what we see the national picture and so forth.

Annastansia Ochuku: And you? anything on the fair data, how do you think the best type of healthcare would look like

Ronald Manhibi: Complimenting what he said, the question would be what is involved, what is needed to make it a reality what kind of mechanisms are required especially on the part of Africa and states what is whose role? what is her role? what his role? the government's role, what is the healthcare providers role and so on. so there might be a need for some kind of universal standard, universal framework to actually dictate to guide how it's going to be like and from that framework, you might be in a position to know what kind of hardware, what kind of software you need, what kind of funds do you need what kind of training is needed? so in a way it could be in a way an audit of some sort an audit of the healthcare workers and the Healthcare systems so that even its glad the policies to see if the fair data policy won't have any conflicts or with the legislations or some of the regulatory frameworks that exist in the various African countries like for instance you know ever since the Red Cross and the WHO thing, you would find that- you know when they banned opium in the 1950s and so on? it has been like everyone in The Consortium UN supporting Red Cross and so on, everyone just up in arms against that and they said no. you don't want this thing because of what it does to us. even though it still exists but it's now a little bit more controlled and more manageable. So we need such stance especially on the part of the Nations and it is these mechanisms that would actually help or determine its success or failure because they- even if you go from the bottom up you might still have the problem because the up will always have a challenge if it doesn't start most of the times so so it's more of a policy.

Annastansia Ochuku: I mean fair- it has an expounded version, I'm just summarising it But they have- it can be a standard- each acronym F, A has its own explained bits, if implemented , it would be beneficial to health care and it would be I feel like if you have it in mind, if the systems have it in mind it will be easier for them to think of this is like a let's say foundation so that in the future you don't run into these problems because right now Europe is going through- they have systems in place and they have these challenges and before they didn't have to think about this thing when they were making their systems but now they do have to think about it but if before- for us before we do this, let's think of this is so that we don't run into problems in the future.

Annastansia Ochuku: So that's it anything else to add? those are all the questions I had if I have any more questions, I will contact you and thank you very much.

9.6 State of digital health

Table 6:

State of digital health

EAC member countries		Uganda	Rwanda	Kenya	Tanzania	Burundi	South Sudan
State of Digital health	**Formulated strategies (EARHC, 2017).**	-National eHealth Strategy	-Smart Rwanda Smart Plan 2020.	- eHealth Policy 2016 – 2030	- eHealth Strategy 2013 – 2018	-National health policy.	-National Health Policy 2016 – 2025.
			-ICT Security Policy.		-ICT Policy Guideline for Health	- National Development Plan on Health Informatics.	
		-National eHealth Policy	-eHealth Policy and Strategic Plan.	- Has plans to implement Unique ID	- Digital Health Investment Roadmap 2017 – 2023	-National plan for the development of eHealth.	
		-eGovernment Policy Framework	-Rwanda eHealth Framework.				
	Digital health infrastructure in use (EARHC, 2017).	DHIS2.					-DHIS2 partial implementation
		EMR (Open MRS) (EARHC, 2017; Waithera, Muhia, & Songole, 2017).			-iHFeMS (ERP) -EMR	-Open Clinic -Open Pharmacy -eHealth -Open RBF System	

		- MTrac (essential medicines monitoring). - Lab. Information System (LIS). - Pharmacy Information Portal (PIP).	-ERP. -Alert system (Rapid SMS). -Health resource tracking tools.		- Open Health Information Exchange (HIE)- ongoing process		
		- Open Health Information Exchange (HIE)- ongoing process	-Open Health Information Exchange (HIE).				
	Challenges (EARHC, 2017)	-Hiring and retaining eHealth and IT Professionals -Interoperability and standardisation between systems -Data management, security & privacy	-Fragmented systems and interoperability -Poor support and maintenance of ICT infrastructure in remote areas - Computer illiteracy		-Infrastructure and unreliable connectivity		-Political instability -Poor infrastructure -No clear eHealth strategy in place
		-Infrastructure and unreliable connectivity	Electricity and ICT infrastructure		-Insufficient funding	-Inadequate technical skills -Lack of ICT coordination by MOH	
					-Fragmented pilot projects	- Computer illiteracy	
						-Fragmented initiatives	

eHealth plans

Similar health systems

Similar health challenges related to digital health implementation

9.7 Eldoret FDP

a. Stock and reports Xforms

type	name	label
text	medicine_name	Medicine Name
integer	code	Code
text	description	Description
integer	quantity	Quantity

Figure 15:Stock Xform

type	name	label
text	illness_name	Illness name
integer	illness_year	Illness year
text	description	Description
text	file_location	File Location

Figure 16:Reports Xform

b. Stock and reports Webforms

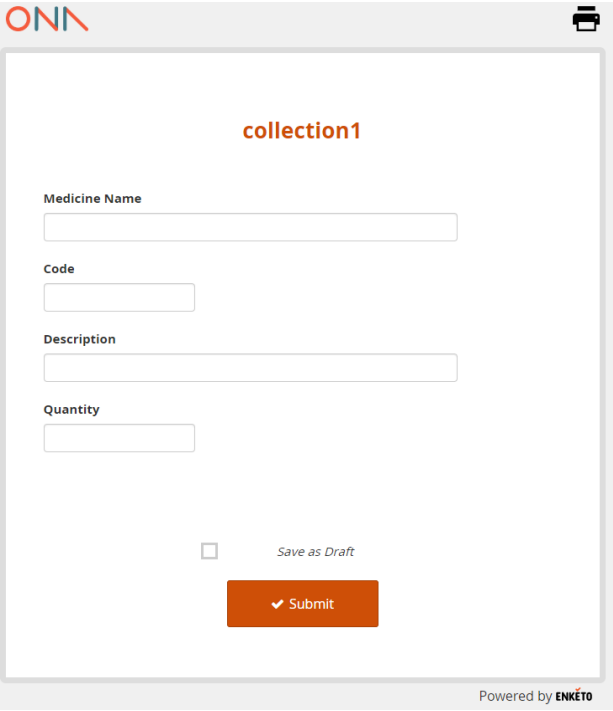

Figure 17:Stock webform

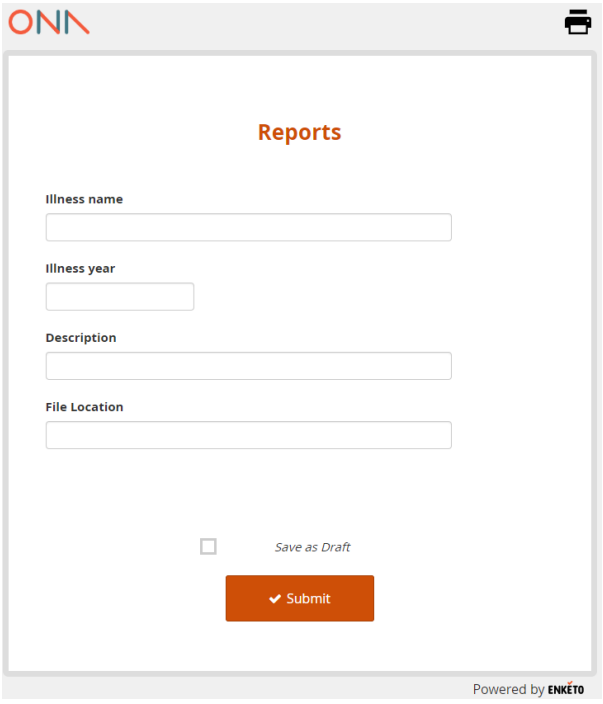

Figure 18: Reports webform

c. Data entries

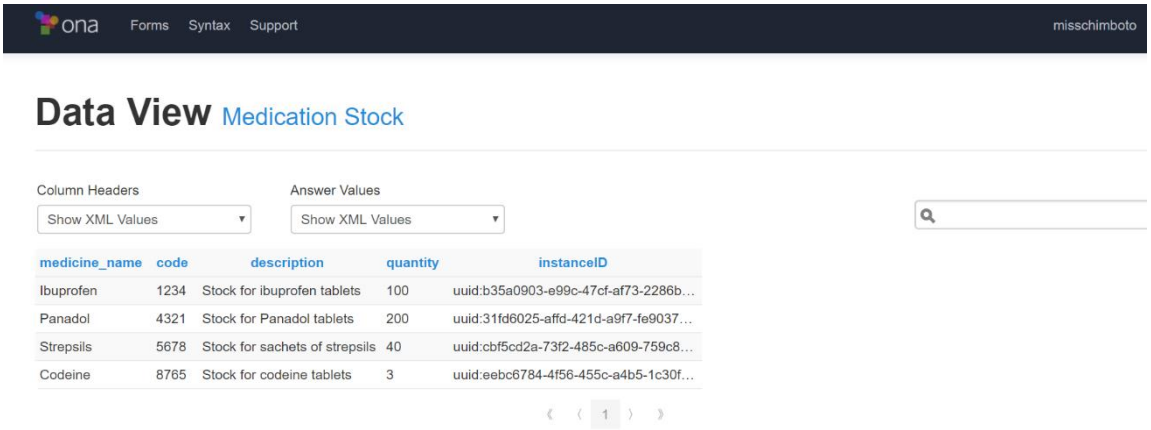

Figure 19: Stock data

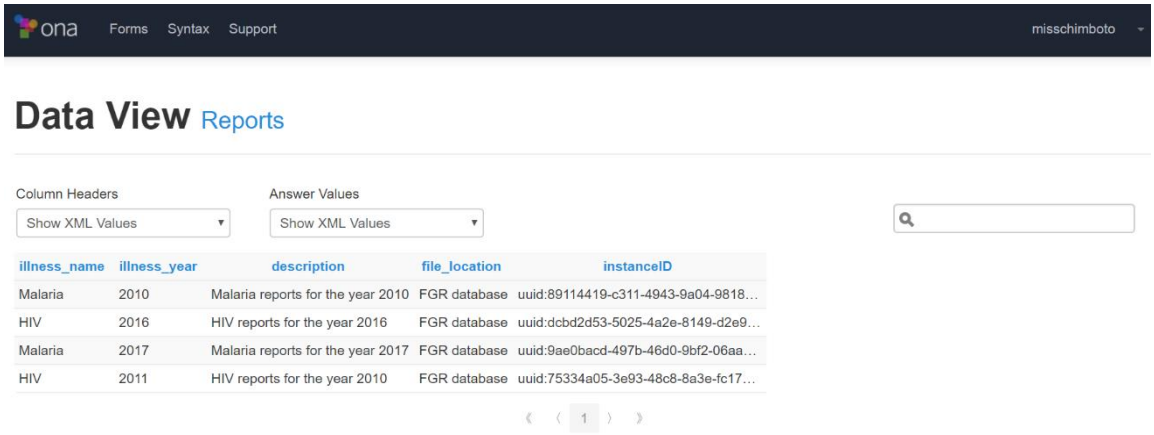

Figure 20:Reports data

d. Published Stock and reports forms in Onadata API

The two forms (Stock and Reports datasets) were published in Onadata and dummy data was added into the forms. Each dataset had four data entries, and this concluded the datasets.

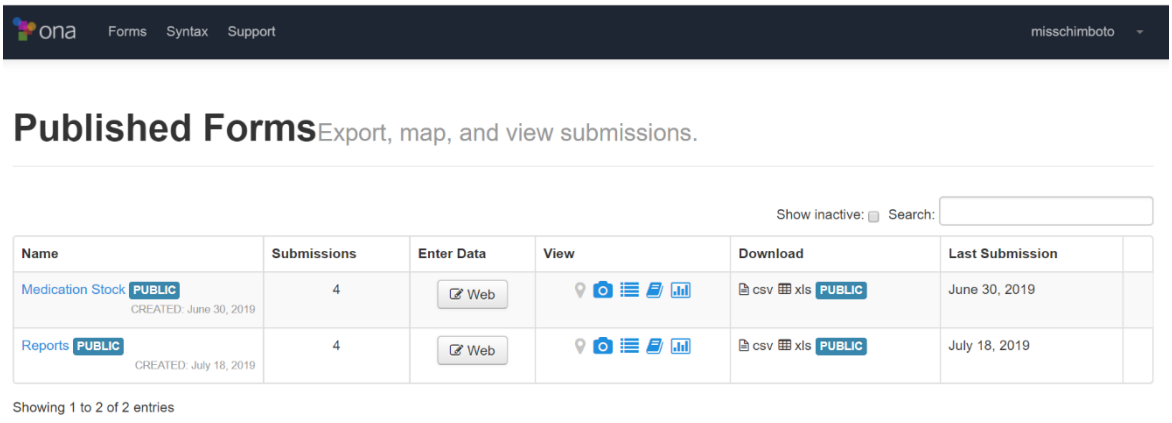

Figure 21: Stock and Reports forms

e. The assigned identifier of the reports and stock forms(datasets)

The text below represents the stock and reports forms (datasets) that were published in Onadata. The highlighted text are the unique identifiers allocated by Onadata for each of the forms (datasets) and their titles.

1. [{"url": "https://api.ona.io/api/v1/forms/422358", "formid": 422358, "owner": "https://api.ona.io/api/v1/users/misschimboto", "created_by": "https://api.ona.io/api/v1/users/misschimboto", "public": true, "public_data": true, "require_auth": false, "tags": [], "title": "Medication Stock", "users": [{"is_org": false, "metadata": {"zebra": {"tos-pp": {"2018-03-30": {"date": "2019-06-30T14:33:59.626Z", "accepted": true}}, "eu-citizen-consent": {"date": "2019-06-30T14:31:18.050Z", "eu-citizen-data": false}, "hide-home-walkthrough?": true, "hide-data-view-walkthrough?": true, "hide-share-modal-walkthrough?": true, "hide-project-view-walkthrough?": true}}, "first_name": "", "last_name": "", "user": "misschimboto", "role": "owner"}], "enketo_url": "https://enketo.ona.io/x/#CyvWuvk4", "enketo_preview_url": "https://enketo.ona.io/preview/::0ULgd3E7", "num_of_submissions": 4, "last_submission_time": "2019-06-30T15:24:09.361383+00:00", "data_views": [], "description": "", "downloadable": true, "allows_sms": false, "encrypted": false, "sms_id_string": "collection1", "id_string": "collection1", "date_created": "2019-06-30T10:35:17.073509-04:00", "date_modified": "2019-07-16T19:03:25.568969-04:00", "uuid": "207884a02aff4137ba3c2711f5e5ce71", "bamboo_dataset": "", "instances_with_geopoints": false, "instances_with_osm": false, "version": "201906301435", "has_hxl_support": false, "last_updated_at": "2019-07-16T19:03:25.568990-04:00", "hash": "md5:5bd1e48bcfe60a200587ec427a3a8c38", "is_merged_dataset": false, "project": "https://api.ona.io/api/v1/projects/91320"},{"url": "https://api.ona.io/api/v1/forms/428223", "formid": 428223, "owner": "https://api.ona.io/api/v1/users/clts", "created_by": "https://api.ona.io/api/v1/users/clts", "public": false, "public_data": false, "require_auth": true, "tags": [], "title": "Reports", "users": [{"is_org": false, "metadata": {"zebra": {"tos-pp": {"2018-03-30": {"date": "2019-06-30T14:33:59.626Z", "accepted": true}}, "eu-citizen-consent": {"date": "2019-06-30T14:31:18.050Z", "eu-citizen-data": false}, "hide-home-walkthrough?": true, "hide-data-view-walkthrough?": true, "hide-share-modal-walkthrough?": true, "hide-project-view-walkthrough?": true}}, "first_name": "", "last_name": "", "user": "misschimboto", "role": "owner"}], "enketo_url": "https://enketo.ona.io/x/#fcJg8VrG", "enketo_preview_url": "https://enketo.ona.io/preview/::JKeREi8y", "num_of_

submissions": 4, "last_submission_time": "2019-07-17T21:59:42.756425+00:00", "data_views": [], "description": "", "downloadable": true, "allows_sms": false, "encrypted": false, "sms_id_string": "Reports", "id_string": "Reports", "date_created": "2019-07-17T17:55:33.646365-04:00", "date_modified": "2019-07-18T14:50:12.206817-04:00", "uuid": "368350de442f45ada740fcdb6f3f8229", "bamboo_dataset": "", "instances_with_geopoints": false, "instances_with_osm": false, "version": "201907172155", "has_hxl_support": false, "last_updated_at": "2019-07-18T14:50:12.206837-04:00", "hash": "md5:c307b3c7dadd904220ebde42f25cb82e", "is_merged_dataset": false, "project": "https://api.ona.io/api/v1/projects/2821"},{"url": "https://api.ona.io/api/v1/forms/428504", "formid": 428504, "owner": "https://api.ona.io/api/v1/users/misschimboto", "created_by": "https://api.ona.io/api/v1/users/misschimboto", "public": true, "public_data": true, "require_auth": false, "tags": [], "title": "Reports", "users": [{"is_org": false, "metadata": {"zebra": {"tos-pp": {"2018-03-30": {"date": "2019-06-30T14:33:59.626Z", "accepted": true}}, "eu-citizen-consent": {"date": "2019-06-30T14:31:18.050Z", "eu-citizen-data": false}, "hide-home-walkthrough?": true, "hide-data-view-walkthrough?": true, "hide-share-modal-walkthrough?": true, "hide-project-view-walkthrough?": true}}, "first_name": "", "last_name": "", "user": "misschimboto", "role": "owner"}], "enketo_url": "https://enketo.ona.io/x/#2Cejovna", "enketo_preview_url": "https://enketo.ona.io/preview/::WQARUgAb", "num_of_submissions": 4, "last_submission_time": "2019-07-18T18:54:44.981829+00:00", "data_views": [], "description": "", "downloadable": true, "allows_sms": false, "encrypted": false, "sms_id_string": "Reports", "id_string": "Reports", "date_created": "2019-07-18T14:53:57.268703-04:00", "date_modified": "2019-07-18T15:48:16.892129-04:00", "uuid": "39b1f0ade9344e07b9ae40072e0f4643", "bamboo_dataset": "", "instances_with_geopoints": false, "instances_with_osm": false, "version": "201907181853", "has_hxl_support": false, "last_updated_at": "2019-07-18T15:48:16.892144-04:00", "hash": "md5:7a5abf576db7fd0f88a63b4d830b9109", "is_merged_dataset": false, "project": "https://api.ona.io/api/v1/projects/91320"}]

Figure 22: Reports and Stock details

f. CURL post commands

The commands are presented below whereby, **metadata1.csv** and **metadata2.csv** are the metadata files posted to the stock and reports datasets respectively.

Metadata for Stock

curl -X POST -F 'data_type=media' -F 'xform=422358' -F 'data_file=@**metadata1.csv**' -F 'data_value=metadata2' https://api.ona.io/api/v1/metadata -u MissChimboto: *******

Metadata for Reports

curl -X POST -F 'data_type=media' -F 'xform=428223' -F 'data_file=@**metadata2.csv**' -F 'data_value=metadata3' https://api.ona.io/api/v1/metadata -u MissChimboto: *******

g. HTTP GET request and response

```
token = "9f9aa72a5fcd8957cd9268e435fc07f9645be86b"
formid = "2687714"
headers = {
   'Authorization': 'Token %s'% (token),
}

response = requests.get('https://api.ona.io/api/v1/metadata/%s'%(formid), headers=headers)

jsonData = json.loads(response.text)
```

Figure 23: HTTP GET request


```
{"id":2687714,"xform":422358,"data_value":"metadata1.csv","data_type":"media","data_file":"https://onadata.s3.amazonaws.com/misschimboto/formid-media/metadata1.csv?AWSAccessKeyId=AKIAI4F57PFP6OPEQ4WA&Signature=aEIVisuzisY6ap658KcraeJ%2Ftn0%3D&Expires=1565732645","data_file_type":"text/csv","media_url":"https://onadata.s3.amazonaws.com/misschimboto/formid-media/metadata1.csv?AWSAccessKeyId=AKIAI4F57PFP6OPEQ4WA&Signature=aEIVisuzisY6ap658KcraeJ%2Ftn0%3D&Expires=1565732645","file_hash":"md5:46d33d747487c599ea1ab37b0da5c5b1","url":"https://api.ona.io/api/v1/metadata/2687714","date_created":"2019-07-16T12:27:59.182218Z"}
```


Figure 24: HTTP GET response

h. Eldoret FDP metadata html script

```
<html>
  <head>
    <title>Eldoret FAIR Data Point</title>
    <meta charset="UTF-8">
    <meta name="viewport" content="width=device-width, initial-scale=1.0">
    <link rel="stylesheet" href="main.css" type="text/css"/>
  </head>
  <body>
    <div>
      <table class="start-div">
        <tbody>
          <tr>
            <td>Identifier : AFR12345</td>
          </tr>
          <tr>
            <td>FDP_Name : Eldoret Referral Hospital</td>
          </tr>
          <tr>
            <td>Description : FAIR data point for Eldoret referral hospital</td>
          </tr>
          <tr>
            <td>Institution : Kenya Health Care</td>
          </tr>
          <tr>
            <td>Contact : khc@go.ke</td>
          </tr>
        </tbody>
```

```
        </table>
        <span class="stock-span">
          <a href="stock_metadata.html">Stock</a>
        </span>
        <span class="reports-span">
          <a href="report_metadata.html">Reports</a>
        </span>
      </div>
    </body>
  </html>
```

i. Stock and Reports metadata in the Eldoret FDP GUI

Title : Eldoret medication stock

MetadataID : 422358

Format : CSV

Description : This contains medication stock

Coverage : Eldoret

Date Created : 2019-07-16T12:27:59.182218Z

Last Modified : 2019-02-25 12:00

Modified by : Kidero

Access rights : Open Access

License : http://rdflicense.appspot.com/rdflicense/cc-by-nc-nd3.0

Language : http://id.loc.gov/vocabulary/iso639-1/en

https://api.ona.io/misschimboto/forms/collection1

Figure 25: Stock metadata (http://130.89.221.193:82/ELDFDP/stock_metadata.html).

Title : Eldoret Patient illness reports

MetadataID : 428504

Format : CSV

Description : This contains reports of patient illnesses

Coverage : Eldoret

Date Created : 2019-07-18T19:23:21.052749Z

Last Modified : 2019-02-27 12:00

Modified by : Jidenna

Access rights : Restricted

License : http://rdflicense.appspot.com/rdflicense/cc-by-nc-nd3.0

Language : http://id.loc.gov/vocabulary/iso639-1/en

https://api.ona.io/misschimboto/forms/Reports

Figure 26: Reports metadata
(http://130.89.221.193:82/ELDFDP/report_metadata.html).