Journal of HyoJeong Academia

*Article*

# Ownership of Health Data as the new Frontier for the Future of VODAN-Africa

**Reginald Nalugala[1,*] and Mirjam Van Reisen[2]**

[1] Tangaza University College, Nairobi, Kenya
[2] Tilburg University and Leiden University, Netherlands
*Correspondence: reg.nalugala@tangaza.ac

**Abstract:** The Covid19 situation created a state of unequal use of data to produce vaccines. Africa was not in control over sovereign decision-making relating to the health of its citizens and to access of the data pertaining to it. The available digital architecture in Africa health facilities allowed data to be siphoned to Europe and the US at will. The purpose of the research is to argue why medical data once created should be held in ownership of the facility where the data is produced under the regulatory framework of the county and national state jurisdiction. This is referred as data that is Findable, Accessible (under well-defined conditions) Interoperable and Reusable (FAIR). The study inventories the additional benefits of FAIR data for health purposes as means to assist Africa generate (self-)employment benefits to many unemployed youths based on the value that data holds in the digital economy. The study was carried out using a case study approach with four health facilities in Kenya, to help identify the contribution of the FAIR data concept to producing a sustainable outcome for health data management in Kenya. The paper discussed the potential challenges which should be overcome to realize the full potential of FAIR data for a sovereign management of the health data in Kenya. Health data remained as an asset for the health facility for providing improved health at point of care. The findings show digital health data has an economic value and health benefit if well managed at point of production.

**Keywords**: Digital architecture, FAIR Data asset, improved health and sustainable outcomes

**Citation:** Reginald Nalugaka and Mirjam Van Reisen. Ownership of Health Data as the new Frontier for the Future of VODAN-Africa. *JHJA 2(2)*, **2024**.

Received: April 14, 2023
Accepted: November 16, 2023
Published: August 8, 2024

**Publisher's Note:** JHJA stays neutral with regard to jurisdictional claims in published maps and institutional affiliations.



## 1. Introduction

The state of the post Covid-19 pandemic in Africa calls for new paradigms of thinking around data ownership. Data ownership is now an emerging key contributor to country specific economic development and sustainability. The report from World Health Organization [1] estimated that global spending on health was reaching US $8.3 trillion between 2020 and 2018, which is about ten percent of global GDP. It underlines why there is a growing need for an organized system of health data collection and storage. Research by Royal Bank of Canada [2] shows that data generated by the health care industry is growing faster than manufacturing, financial services, media and the entertainment sector. Thirty percent of the world's data is generated by the healthcare industry and during the Covid-19 pandemic the demand for data continued to grow [2]. The RBC research teams [2] and Financial Times at the same time revealed that Big Tech companies have seen an opportunity to harness the ever-growing amount of information in advance from various

countries to champion and pioneer new innovations and light up the health care revolution. RBC research calculated that by June 2021, the venture capital divisions of Amazon, Apple, Facebook, Google and Microsoft had invested more than $7 billion in healthcare start-ups. Africa Private Equity and Venture Association [3] (AVCA, 2021) agrees with the RBC statistics by adding that funding African start-ups is growing fast with venture capital deals reaching $3.5 billion by mid-2022 [3].

This is to challenge the commercial imperatives and charitable efforts where vaccines continue being the exclusive control of private companies through intellectual property and manufacturing capacity monopolies, resulting in fatal vaccine inequity [4]. The fierce competition by wealthy countries to buy up the vaccines even before they were product buy up all vaccines and deny poor countries access can be avoided when respective countries of Africa control their own health data and agree to enter strong equal partnerships with the rich nations and private donors.

To make a point for this future investment agreement, the IMF has evaluated existing agreements focusing on 2025 where US $50 billion has been put aside from donors and national governments to strengthen existing mechanisms, with attention put on ACT-A and including vaccine purchase and distribution facility COVAX, which could generate US $9 trillion of additional global output. IMF estimates that sixty percent (60%) of gains would benefit developing countries, especially Africa [5].

The World Health Organization (2020) report on Global Vaccine Market Report reiterates the lack of resilience and limited geographic spread to manufacturing infrastructure before the pandemic where ninety percent (90%) of all vaccine production was concentrated with four companies, GSK, Pfizer, Merck and Sanofi. In terms of volume the Serum Institute of India was the lone largest producer with 28% of estimated 5.5 billion vaccines produced by 2020 [6, 7].

The demand for vaccine manufacturing capacity for Covid-19 vaccines has shown limitations to global manufacturing infrastructure, with relatively little vaccine capacity able to produce at large scale outside of major vaccine corporations and SII, and a high dependency on a very limited number of producers [8]. WHO (2021) reports that 99% of its vaccines are imported. The United Operation Warp Speed alone has invested over US $10 billion in the R&D of six promising vaccines and US $2.5 billion for Moderna and US $1.5 billion for Johnson & Johnson [9]. The German Government invested US $450 million to BioNTech [10, 11]. WHO (2021) reports that 97% of financing to develop the AstraZeneca/Oxford Vaccine came from public funds including the European Union and Governments of United Kingdom and Northern Ireland [1, 9, 12, 13, 14, 15]. Mazzucato et al [16] have criticized this approach and suggested COVID-19 patent rights should be mutually binding among collaborating nations.

In another study by Salient Advisory, cited by Thabiso Foto [17], states that while the pandemic itself had a negative effect, healthcare infrastructure development has come out as a significant opportunity, for ensuring equitable access to quality healthcare among all the 54 countries of Africa. The pandemic created this necessity for accelerated development of healthcare solutions by tech entrepreneurs. In another study by Salient Advisory, cited by Thabiso Foto, states that while the pandemic itself had a negative effect on ordinary health of millions of people, Africa is home to 1,276 health tech start-ups that are supporting health care delivery and distribution. By 2020 over 60% health tech start-ups had already been founded in Africa. In 2020 alone over 22% of the companies were founded as the pandemic surged. The question arising from this data is who owns and controls this sensitive health data. Once tech start-ups take control of data there is the big privacy question and security challenge to individual health data. Therefore, African governments can find worthy investors in their own data production and data infrastructure systems if they have ownership over the data. With available data, Africa will be able to produce its own vaccines and compete among emerging global players in vaccine production alongside China, Russia to help diversity the global manufacturing.

Hence, health data are a critical resource for development of products in health. Peter Clardy, the senior clinical advisor at Google, was able to demonstrate that patient data infrastructure development would have a comparative advantage when data is collected and curated at respective country specific health facilities. The East African Health Research Commission [18] had started working on digital health innovation policy by 2017 by acknowledging the potential of patient data as Findable, Accessible (under well-defined conditions, Interoperable and Reusable (FAIR) [19]. The Virus Outbreak Data Network (VODAN)-Africa research reveals that countries of

Africa have developed capacity and technological advancement in the development of health data infrastructure to make sure data is in residence of its collection point, within health facilities where patients are treated from.

Vodan Africa was founded by leading researchers in Africa in 2020 at the height of covid 19 pandemic. The goal was the use of data as a value contribution to containing and treatment of covid 19 pandemic. The leading universities in Africa included Mekelle University and Addis Ababa University (Ethiopia), Kampala International University (Uganda), Tangaza University (Kenya), Olabisi Onabanajo University (Nigeria), Ibrahim Badamasi Babangida University Lapai (Nigeria)University of Sousse (Tunisia), Great Zimbabwe University and East African University, Mogadishu, (Somalia). Today, 2024, VODAN now translates to value driven ownership of data and accessibility network. The East African Health Research Commission fell short of incorporating a VODAN-Africa type of infrastructure to make their data FAIR. The potential of a FAIR-based data infrastructure for Kenya is investigated in this paper. This is referred as data that is Findable, Accessible (under well-defined conditions) Interoperable and Reusable (FAIR). GO-FAIR Leiden refer to Wilkinson by describing FAIR data principles as the contribution of information to gaining access to that data and making it compatible with other data with the aim of reusing it [19].

### *1.1. The limitation of the study*

The study looked generally on the past experiences of losing data collected during the Ebola endemic and felt the same situation should not happen again during the covid-19 pandemic. The selected countries as points of reference to data ownership, were seven in total from Africa namely Ethiopia, Kenya, Somalia, Tanzania, Zimbabwe, Nigeria and Tunisia. Selecting health facilities from these countries was more of a demonstrative sample of the challenges Africa was facing compared to developed nations of the west. In 2020, UN Secretary General, Antonio Guterres, while addressing the UN Security Council on equitable distribution of vaccines. He fell short of suggesting that while the G20 would form the task force, Africa too should be well represented in the task force. He had observed that while, "The rollout of COVID-19 vaccines is generating hope," the 15-member council chaired by Kenya then, the injustice was in vaccine equity. He is quoted saying, "At this critical moment, vaccine equity is the biggest moral test before the global community." It implies that Africa should not be reduced to a perpetual emergency only continent without structures in place to speak, discuss, compliment and ask for the necessary resources to produce and own its own vaccines [20].

Therefore, the selected seven countries and the four health facilities in Kenya may not fully give specific details of challenges in the 54 countries in Africa. However, the discussion helps the reader to develop a general overview on the situation of four health facilities in Kenya cuts across the experience of losing data to the west in Africa.

### *1.2. Statement of Contribution*

VODAN-Africa has identified a gap in the digital architecture development in Africa. It makes a strong point that while Africa has been open to improving its digital health infrastructure, most donors and sponsors for advanced technology do not respect basic interests for data ownership in the continent. Most of the digital health data collected is easily siphoned to Europe and the US, thus creating a situation in which Africa is not in control over sovereign decision-making relating to the health of its citizens. The unjust and poor centralized control of data has denied subjects access to data as a resource for information, knowledge and development.

VODAN-Africa is making a strong case for health data to be controlled by the government under the Ministry of Health and curate who accesses this data. To do so, requires an organized and updated health data infrastructure system to realize the full potential of Findable, Accessible, Interoperable and Reusable (FAIR)-data for a sovereign management of the health data in Kenya.

This article explores the potential for advanced new methodologies for enhancing health data as a public good that can contribute to improved health outcomes in Africa, and how such potential can be unlocked to contribute to the development potential of the continent. The study was carried out using a case study approach with four health facilities in Kenya, to help identify the contribution of the FAIR-data concept to producing a sustainable outcome for health data management in Kenya, while also discussing the potential challenges that may need to be overcome to realize the full potential of FAIR-data for a sovereign management of the health data in Kenya.

The paper concludes by showing why digital innovations, are key to data collection and storage but also creating room for economic advantage unlike the past when data could be siphoned out to the developed world.

The main question is an investigation of the current data handling and value of the health data in Kenya to demonstrate how VODAN-Africa is offering an alternative architecture for handling health data by using four health facilities in Kenya as case studies, with extended data produced across 88 health facilities across Africa. The rationale is that advanced FAIR-based systems for data collection, storage and curation within the facilities under the Ministry of Health can contribute to data sovereignty, ethical data curation for the production of valuable data, and the creation of job opportunities for a sound economic development in Africa in the digital era.

To answer the research question, the paper discusses the key problem area, a methodology to investigate the current data handling and value of the data, the health data policies in Kenya. The study then discusses the implementation of an alternative architecture in four health facilities by VODAN-Africa.

## 2. Materials and Methods

The research included (i) a desk study analysis of the current health data infrastructure in Kenya; (ii) an investigation of an implementation of an architecture to curate patient data as FAIR. The desk study was carried out in a systematic desk review involving all relevant policy statements of the Government of Kenya. The study referred journal papers from WHO and policy statements by the Kenya Government on health data and infrastructure development. The paper identifies policy directions proposed to realize the full potential of data for a better management of the health data in Kenya. The different government policy papers around FAIR facets constituting core principles showed equivalency with the ambition of the Kenyan government, and it demonstrated the available potential in making sure health data is secure at locality of access and under the arm of the Ministry of Health as discussed in Ester Thea Inau et al [21].

In order to carry out the second purpose of this study, case study in four health facilities in Kenya was carried out. These were (1) Zambezi Hospital (private hospital) and (2) Pumwani Hospital (under Nairobi County Ministry of Health) and (3) Beacon of Hope (private an in Kajiado County). (4) Kenya Medical Research Institute was also involved in the study to assess the outcomes. The research followed a case study approach implementing the innovation in a natural setting. The assessment included participation of the various stakeholders and took an interdisciplinary approach involving all stakeholders, including the ICT technical teams, electronic and computer network engineers, medical doctors, nurses, social scientists, policy makers, social workers and health data stewards.

## 3. Results

### *3.1. Economic benefits of health data*

The data presentation and discussion from the four health facilities in Kenya, reveal the importance of data for the economic benefits of each country in Africa. While we see the importance of health data for economic development, we need to review what Africa needs to do to take the full value of its health data. Each country can curate the data for its own economic development and job creation especially in ICT technology, especially in digital health innovations [10].

The Council on the Economics of Health for all comprised economists and experts in health under WHO [11] laid a clear vision on how to develop a new understanding and a new narrative about the deep interconnectedness between health and the economy [22, 23]. The vision focus of WHO Economics Health Council was to give direction on intertwined core themes for countries to adopt as follows:

1. There has to be measurement and valuing of Health for All.
2. This calls for capacity strengthening of the public sector in building resilient capacities and creating partnerships to deliver health for all.
3. A key strategic support pillar is finance. This is core to strategic, long term, and transformative finance for all. It calls for
4. Governing innovation towards health for all and very importantly improving the governance of innovation, which has been identified as the critical building block of healthy economies.

5. The governance of health innovation ecosystem lays a good foundation upon which radical changes are needed to ensure it delivers Health for All [12].
6. The long-term vision of WHO Economics Health Council is to offer guidelines on the establishment of new, end-to end health innovation ecosystem that shapes how the public and private sector in health delivery can work together throughout the innovation chain to deliver equitable access to much needed vaccines, therapeutics, diagnostics and other important health supplies
7. The health innovation ecosystem should be governed towards the common good of all by creating purpose driven innovation through a mission-oriented approach. It means reshaping knowledge governance for the common good, reforming corporate governance to better reflect stakeholder value in the long term.
8. This Council also sets goals for building resilience and diverse manufacturing capacity and infrastructure development as now done by VODAN-Africa.
9. Lastly, the call is for introducing conditionality for public investments to build symbiotic public private partnerships, and strengthening the capacity of the public sector in health innovation.

The WHO Economics Health Council gives a global vision on how countries can move towards health data economic benefits by allowing multiple actors and investors in this sector. It also gives guidelines to governance issues so far ignored by private tech start up innovators. Health innovation ecosystem should be governed towards the common good of all within specific countries where health data is generated from Yamey et al [13]. Above all the WHO Economics Health Council agrees with the direction that VODAN-Africa has taken on developing digital architecture to allow Africa governments to be in control over sovereign decision-making relating to the health and allow its citizens access the data that pertains to its health subjects as a resource for information, knowledge and development.

The entry of VODAN-Africa into the space of data infrastructure will develop the much-needed capacity within each country to collect, store and curate much needed data to induce investment into manufacturing of vaccines. The World Health Organization also identifies knowledge barrier as an area which continues to stifle innovation, especially when it comes to the availability and use of vital health technologies and data. Knowledge generation and sharing are critical for medical research and public health is limited. The current system incentivizes innovation through monopolies, in which governments allow the privatization of biomedical knowledge through granting patent protections is not adequate. There is need for availability and use of vital health technologies and data.

WHO called for redesigning health ecosystem for the common good, by shifting from a model where innovation is seen to be driven by market forces, to a model that is collectively governed in public interest. It means each country should embrace innovations that support all aspects of healthcare. To achieve this requires proper tools for health data collection and local storage. This the key contribution by VODAN-Africa. With the entry of VODAN-Africa data research teams, sharing data on medical research and public health. African countries with the support of African Union are challenged to join hands and set aside funds for more data research and data infrastructure development.

### *3.2. Health data as a valuable resource*

VODAN-Africa ventured into understanding the demand for COVID-19 data and its local availability, the major gap was data infrastructure development. The lack of interoperability and reuse of data in parallel health structures was weakening the value of digital data health solutions. The commercial use of that data will create distrust without a sound data collection point in the health facilities. This is why VODAN-Africa understands the purpose of having different regulatory frameworks for data capture and handling with a renewed vision on how to handle data analysis in the continent compared to others.

The opportunity generated by ownership of health data opens a new frontier for the future of Africa. Just as the past centuries the world went through different economic development models that dominated the exchange of merchandise and capital goods using gold and silver, today data production and storage is taking over as the 'new gold' in terms of its importance to being the source for economic development. In our case then, data production and storage in the local country, within health facilities, is starting to influence a new form of economic

value which could benefit not only nations without any minerals but also become a beacon for offering job opportunities in the ICT sector in developing countries of Africa. Taking for example, the recent Covid-19 pandemic data, which is well curated will contribute to vaccine production and stimulate marketing opportunities for nations where Covid-19 pandemic was dominant.

The importance of having up to date machine infrastructure for data production and storage has stood out as an important entry gap for VODAN-Africa. The nine African countries that participated in the maiden research in digital health can attest to the fact that many opportunities have arisen for well-trained data stewards, health records officers and put demand to hospital administration to develop good health infrastructure systems which can keep this important data under lock and key within the country and in health facilities. Instead of relying on data collected and sent abroad with less access by patients and administration, a window of opportunity beacons for African countries to compete and be the custodians of their own data.

### *3.3. The difference between health tech start-ups and innovation by VODAN Africa*

The outbreak of the COVID-19 pandemic made it necessary for countries to look into the whole digital architecture as far as data management was concerned. Until 2020 most health data in Africa was siphoned and funneled to Europe and the US. One good example was when in 2016 Ebola virus was discovered in West Africa and parts of Central Africa, many well intending agencies from the West came into collect data and treat victims of Ebola infection. After six months the data could not be traced in countries where the Ebola virus had struck.

With the emergence of the coronavirus pandemic, most countries of Africa were cautious about keeping data locally for new vaccines development and improving quality of health. The creation of VODAN-Africa in 2020 was to give an answer to the much-awaited clinical data production with concerns for data ownership and improving on what had been until 2020, a limited use of health data for quality treatment at point of care [14].

Most African countries had weak data infrastructure system for storage and curation at point of production, especially in health facilities. Most countries in Africa had foreign owned data infrastructure. The District Health Information System is installed and used by most countries of Africa without the knowledge that this application is foreign owned. It means any patient data collected may not be kept locally but banked abroad. From this data collected it was possible to develop vaccines and sell at exorbitant prices to the very countries they siphoned data from.

It is evident that African countries were not in control over sovereign decision-making process relating to the health data. Their citizens cannot access the data that pertain to resource for information, knowledge and development. VODAN-Africa developed an architecture to record clinical health data and research data collected on the incidence of the COVID-19 pandemic, by producing human and machine-readable data. This architecture supports analytics at point of care through data (re)-visiting, across health facilities, for generic analytics. Algorithm are run across FAIR Data Points to visit the distributed data and produce aggregate findings, based on permissions obtained prior to the analysis. The FAIR data architecture was deployed in Uganda, Ethiopia, Liberia, Nigeria, Kenya, Somalia, Tanzania, Zimbabwe, and Tunisia. It was evident that different contexts should be explored so that the problem at hand could be properly defined and responded to [15].

### *3.4. Data control policy in Kenya*

The Kenya Constitution and Vision 2030 development blueprint requires the country to provide the highest attainable standard of healthcare through adoption and use of ICT and the Ministry of Health developed the Kenya Health Policy fulfil this mandate [24]. This comes at an important time when the health sector is implementing far reaching reforms to achieve universal coverage. This concept is anchored on the achievement of Vision 2030, whose overall goal in health is to have an "equitable and affordable healthcare at the highest achievable standard" to her citizens. It is informed by the strategies and results emanating from the implementation of the Kenya Health Policy Framework, 1994-2010, the health sector strategic plans and the e- Government and Shared Services Strategies implemented through the e-Government Directorate and the ICT Board respectively.

In the past thirty years the Kenya government has come to understand the value of developing policies that would address the importance of data generation with FAIR pertaining to the qualities of findability, accessibility, interoperability and reuse. However, the gap remained how to make sure that data is controlled by the government through respective ministry of health and local health facilities.

The solution of VODAN-Africa was that data is created and held in the facility where the data is produced under the regulatory framework of the county and national state jurisdiction. This delivers a resource in which the data remains as an asset for the health facility, both in terms of providing improved health care as well as contributing to other use of the data. The discussion features the economic aspect where the data is produced in Africa to generate (self-)employment and benefits in Africa.

The Kenya Health Policy, 2014-2030 gives directions to ensure significant improvement in overall status of health in Kenya in line with the Constitution of Kenya 2010, the country's long term development agenda, Vision 2030 and global commitments. It demonstrates the health sector's commitment, under the government's stewardship, to ensuring that the country attains the highest possible standards of health, in a manner responsive to the needs of the population. This policy is designed to be comprehensive and focuses on the two key obligations of health: realization of fundamental human rights including the right to health as enshrined in the Constitution of Kenya 2010 and; contribution to economic development as envisioned in Vision 2030 [24].

However, to achieve this milestone, the Kenya Government set up an authority to monitor and direct all data information and especially health data. The Kenya ICT Authority was created in 2019 to lay out a platform for better policy implementation and monitoring. Under this authority then, it is understood that the specific mandate is to ensure coherence and a unified approach on the principles that govern the acquisition, deployment, management and operation of data production in ICTs across the public service, state agencies, with the aim of promoting service integration, adaptability, and cost savings through economies of scales in ICT investment. Compliance to this state policy will bring about an efficient and effective service delivery to citizens (GOK ,2016, Kenya Health Enterprise Architecture, ICT Authority Government ICT standards, first edition 2016) [25].

The Kenyan policy lays a good foundation for making sure data is stored in Kenya for better use and support to wellbeing of the country. However, the weak area not address with this ICT Authority mandate is the discussion of FAIR data and curation. It remains vague on how health data can be stored, controlled and shared, for research while allowing any independent agency to access, control and use patient data. The examples in mind are the tech start-ups which are not under an organized government health data infrastructure. VODAN-Africa has a found a way of helping respective governments especially Kenya Government ICT Authority to solve this problem.

### *3.5. Case study of four health facilities*

In 2020 the COVID-19 pandemic affected the whole world. A group of researchers involving nine countries of Africa came together to address data from COVID-19 for future use and storage in local health facilities. The study teams from these countries looked at the existing data infrastructure systems in each country. They commonly used the district health information science. Countries like Kenya later adopted DHIS2 to Kenya Health information system. But the key gap remained the same. Working within the framework of the health ACT (2017, revised in 2019, 2021) the Health Act Section XV, article 104, directs the Ministry of Health to administer health information banks, including an interoperability framework, data interchange and security [26]. The VODAN-Africa Kenya team led by Tangaza University College, Nairobi, supported by the VODAN-Africa technical teams in Mekelle University, Leiden University Medical Centre, and Stanford University, were able to understand why data interoperability is not enough. The whole data infrastructure required a big overhaul. There was need to develop software to allow a new application which would test how data can be collected, stored and curated within local health facilities and remain available and interoperable with data held in other facilities elsewhere. Therefore, the VODAN-Africa built a platform which comprises a network of systems fitted with sets of tools to produce, use and reuse FAIR data. This system builds on the globally known and widely used standards that allow FAIR Data management. By the time the project was finished in 2022, 88 health facilities had been accessed included and 77 were producing data in more than nine countries across Africa.

The Figure 1 demonstrates the process followed by VODAN-Africa to key objectives of the research and data presentation. Figure 1 over the page gives a summary of the policy consideration towards data access, control, storage and curation.

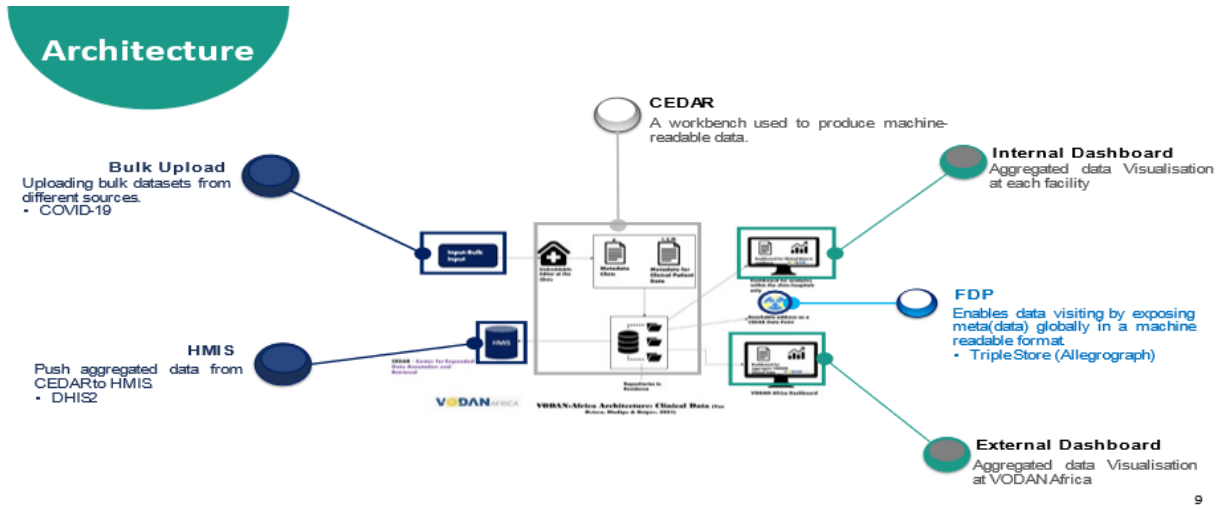


**Figure 1**. A diagram showing a synopsis of an elaborated architecture for data ownership and retention in places where data is produced.

A summary of the policy consideration towards data access, control, storage and curation:

1. Ownership of data in the place where it is produced.
2. Localization of data, to make sure provenance is retained
3. Regulatory compliance based on specific requirements in the location where data is produced and re-posited.

It was concluded from the study that a health data architecture should promote data ownership, localization, and regulation compliance (OLR), which is described as FAIR-OLR [15] within the FAIR-specifications.

A key outcome of the VODAN-Africa was the development of a software infrastructure that enabled data to be curated according to the FAIR-OLR principles. The localized software was developed on the basis of CEDAR Metadata Centre (https://metadatacenter.org/) and the tests of it demonstrated that it allowed algorithms to visit the data held in health facilities in different places across borders in federated format, based on prior permissions obtained [27].

On the basis of the outcomes obtained on the development of data held in location, the team developed the concept of the Africa Health Data Space as a transnational space which connects data curated as FAIR quality ethical Africa health data for pandemic preparedness and quality of care for vulnerable populations. Inspired by the aspiration of the development of a European Health Data Space which aims to regulate the transmission and sharing of health data across the EU for both private individuals and researchers or policy makers, the African Health Data Space will have a similar role for Africa. In order to unleash the full potential of health data for the individuals and society in Africa a Health Data Space should be developed in parallel to the European Health Data Space being developed at this stage. It aims to foster health research, reduce health care costs and produce quality data following FAIR principles.

So far nine countries have joined and the health facilities participating in VODAN-Africa. The African Health Data Space will lay the foundation to ensure that the services are contributing to better informed health care. Health facilities will benefit from the use of data in the health facilities and the data analytics across the facilities. The objective is to create a better representation of patients in remote and vulnerable settings. It stimulates a data space which is set up with inclusiveness (including data from facilities in remote and vulnerable settings).

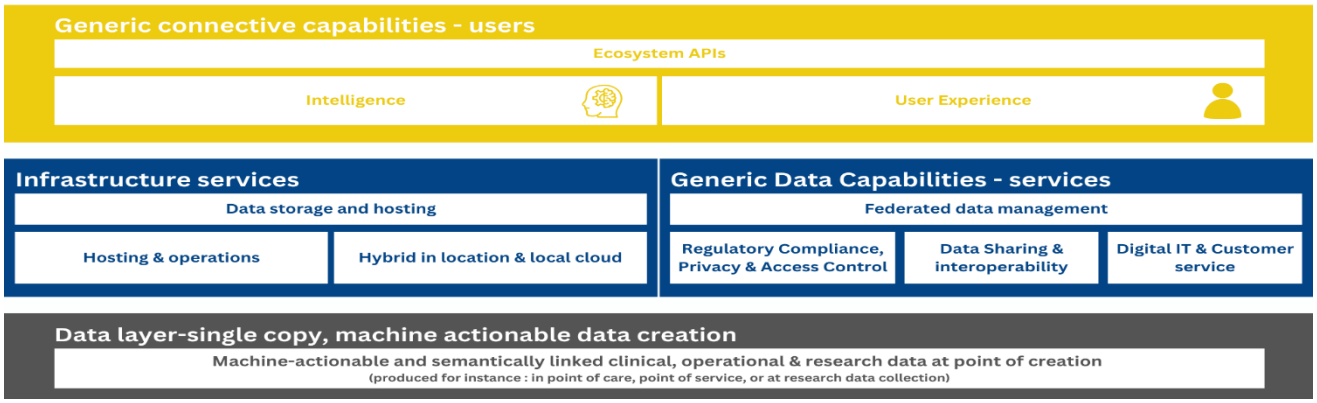


**Figure 2**. Architecture of a Federated Health Data Space as a proposed landscape (Van Reisen, Amare, Gebremeskel, Plug & Stocker, 2023).

The innovation of digital health solutions is expected to better serve to improve health outcomes. Hence, it should help provide solutions for the following problems:

1. Lack of data-ownership on the African continent and migration of data away from care providers and data subjects;
2. Lack of data-use and reuse, including for quality of care at the level of health facility;
3. Inadequacy, lack of representation and poverty-based bias of data from Africa in global health analytics, impeding pandemic preparedness;
4. Poverty-based bias in health data from African which lead to further exclusion of people living in poverty, which are poorly represented in the development of digital AI based health tooling innovation;
5. Lack of interoperability of data for the use of health care providers, due to vertical digital upstream solutions that do not integrate at the level of point of care and preventative medicine;

An African Health Data Space is based on health data curated as Findable, Accessible (under well-defined VODAN-Africa conditions), Interoperable and Re-usable (FAIR) that is machine-actionable, and creates a space for strong high quality and ethical data for analytics, with the following characteristics that are better adapted to patients in these settings. This will ensure that:

1. Data can reside in the health facility where the data is produced (just as the patient records do), or held under control of the facility;
2. Data is useable for analytics within the health facility and can contribute to quality health services at point of care;
3. Data can be visited for de-identified computational analytics across health facilities and across borders through algorithmic data visiting;
4. The creation of an inclusive data pipeline across larger and smaller areas and facilities in connected and remote areas will increase representativeness of the data, and remove poverty-based bias and assist in pandemic preparedness;
5. The creation of interoperable health data will increase the relevance of digital health innovations and assist in horizontal integration of these innovations.

There are various ways proposed to realize this space through digital innovations that are coming up and this will be a source for new generation of economic opportunity. VODAN-Africa concluded that it should support this as a conduit for the channeling of research grants to local universities in Africa and help build the expertise necessary to create and build relevant ethical and locally owned data infrastructures.

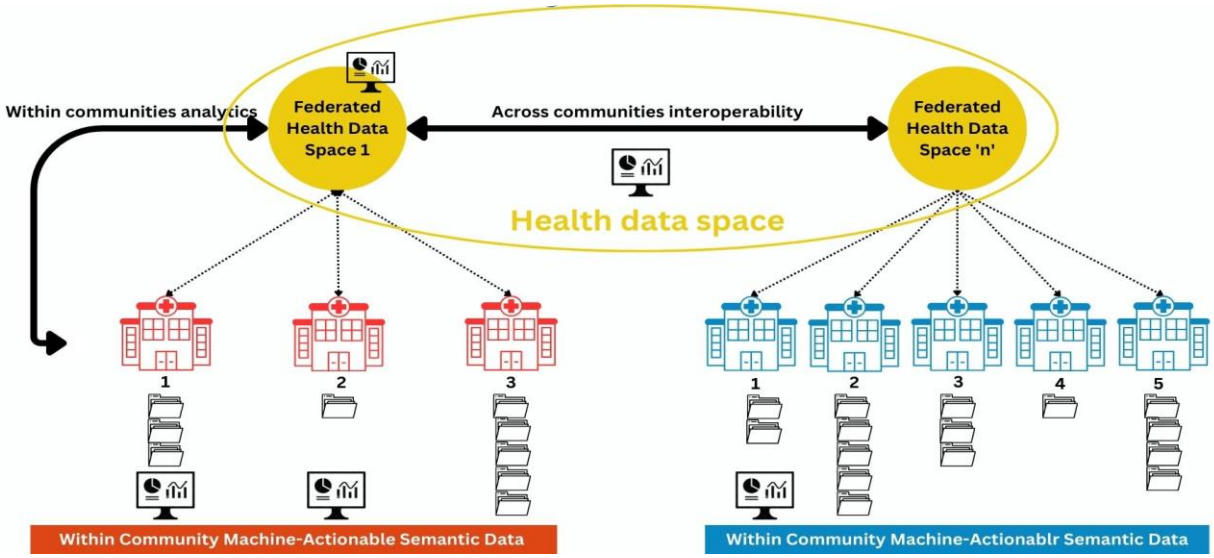


**Figure 3**. FAIR-OLR Federated analysis and learning.

The mission of VODAN-Africa is to create open-source innovation by African engineers and health workers to enhance health data interoperability problems in Africa. The VODAN-Africa works closely with researchers from Europe, Asia and the Americas and is linked in to the research carried out at Leiden University on the use of FAIR-Data for improved health outcomes. The outcomes from the VODAN-Africa community of practices are leading to the wider perspective in creating Africa Health Data space.

The VODAN-Africa approach showed curation of comprehensive data which were supportive of Kenya government policy on interpretation of SDG3 within the wider health sector. A case in point is the need to identify a proper health infrastructure tool which would store data within all hospitals to strengthen the Kenyan capacity for research, vaccine and medicine development and patient treatment.

## 4. Discussion

The establishment of the Virus Outbreak Data Network (VODAN)-Africa, was triggered by past experiences on data loss, following the Ebola crisis in West Africa in 2014. The international Community resolved to assist with a great investment in diverse digital data. The moment the crisis was solved, the digital capacities migrated, leaving behind a weakened health infrastructure. The diverse health digital data quickly moved with the experts to Europe and USA. The accessibility of data was not there. When the global fraternity started experiencing the Covid-19 pandemic, there was immediate concern not to repeat the mistake of 2014. There was immediate demand for global health data when the Covid-19 pandemic broke out. The realization was that data from Africa was not reflective of many remote or accessible areas nor included people who did not access health testing centers.

Another challenge emerged, as observed by the VODAN-Africa research teams. The work undertaken in health facilities in Africa on digitization of patient data, where this data is highly structured, rich and digitized, is normally exported for analysis by Ministries of Health and then sent to Europe and USA for further use. Once the data leaves heath facilities it could not be traced nor accessed. The data remained mostly aggregated, with no allowance for more complex interoperability and reuse.

The Kenya Health Data Act defines "health data" as data related to the state of physical or mental health of the data subject and includes records regarding the past, present or future state of the health, data collected in the course of registration for, or provision of health services, or data which associates the data subject to the provision of specific health services, as earlier discussed [24]. We shall use this definition of health data for this discussion.

The Constitution of Kenya states the right to health is a fundamental human right and provides that every person has the right to the highest attainable standard of health, including the right to health care services [24]. This is also reflective of the Sustainable Development Goal 3 which aims to ensure healthy lives and well-being for across all stages of life [24]. Kenya is one of the countries that has a policy around preparing national Health

data standards and interoperability guides. The Kenya Government created a Kenya ICT Authority in 2016, which covers health data too. The Government of Kenya has identified ICT as a catalyst to attaining efficiency in healthcare service delivery and picks out ICT as a major catalyst for achieving efficiency in the multiple facets of better health service delivery.

Most health facilities in Kenya used District Health Information System (DHIS) 2. This system had many limitations. Other than the DHIS2 serving as a platform for Health Management Information System Software for routine aggregated health data from the lower health facility up to the Ministry of Health, DHIS2 could not capture all business processes starting from registration up to medication dispensation. The limitation experienced was in collecting patient level data.

### *4.1. A new path opening for policy on health data in Kenya*

While most countries are preparing for national health data standards and interoperability guide lines like Kenya's ICT Authority, there is limited practices on the ground. At the completion of the VODAN-Africa study and implementation, over 88 health facilities used as part of the study and with 77 able to produce data in residence. The Integration of the health data life cycle called for enhancing quality of care in health facilities by enabling reuse and interoperability of data by health workers while also assisting with analysis of health data across health facilities for various purposes and use cases based on different algorithmic-pathways.

Therefore, to realize this there was the development of a technical infrastructure to enhance Findability, Accessibility, interoperability and Reusability, usually referred to as data FAIR of digital resources such as patient data, for both human and machines, called FAIRification, which allows learning from data without data leaving the residence or placed of provenance based on Ownership, Localization and Regulatory compliance. The VODAN-Africa research technical teams were able to create an architecture which could be used for scientifically obtained data and make sure data sets are interoperable, by using the same VODAN-A-Portal (same bio portal resource). By implication, VODAN-Africa has made a strong case that with proper investment and support to research centers in Africa, it is possible to collect, store and access health data curated by respective health ministries and scientific data.

## 5. Conclusions

In summary, the discussion of the findings by the VODAN-Africa research team has given a rich argument why data needs to remain in residence of its production. The VODAN-Africa research team concluded that the establishment of an African Health Data Space is the next step that should be realized to improve the health infrastructure in Africa. The expansion of expertise will bring in data stewards, unemployed youth and support the government concern for teaching in vocational education training in data infrastructure development and knowledge transfer.

The paper has made the analysis that the continent of Africa will no longer be a spectator excluded from representation and will be strongly represented at the global health level. Without data being curated at its point of production most developing countries, would continue in their poverty perpetuity. Africa is now ready to lead in the emerging tech community. It means that growth in data intelligence should open opportunities for new innovations that can help developing countries dig into this untapped healthcare economic empowerment of its unemployed youth.

The paper has made fundamental points by challenging existing paradigms on value creation for the health sector. The findings by VODAN-Africa show that developing countries have the potential to have a competitive advantage in digital health data production and sharing with the international community. By controlling their own digital health data, the shift in the paradigm of economic development in countries of Africa and Asia has just started, where now, the value of health data can be invested in health services and exchanged for money as a resource owned by the health facilities who produce and curate the data.

**Author Contributions:**

Dr Reginald Nalugala works at Tangaza University in Nairobi, where he specializes in social transformation across Africa. The key interests touch on digital health data for efficient accessibility by the patients as co-owners of the data and safe storage of that data within place of production. He also addresses data coming from the continent around refugees, migrants, conflicts,

underdevelopment, role of Faith based organizations and the development of Africa. The extractive industry and exploitation of the continent make it important to collect sound data for social transformation.

Professor Dr. Mirjam van Reisen hold the chair FAIR Data Science at the Leiden University Medical Centre. She previously held the chair Computing for Society at the Leiden Institute for Advanced Computer Science. Mirjam van Reisen is also Prof International Relations, Innovation and Care at Tilburg University Faculty of Humanities and Digital Sciences, Department of Culture Studies.

**Funding:** The research was partially supported by Universal Peace Federation Kenya, South Korea

**Data Availability Statement:** Sources can be found at Vodan Africa website at https://www.vodan-totafrica.info/

**Acknowledgments:** I want to Thank Dr Fredrick Wakhisi and Universal Peace Federation for the support in getting this research going. I would like to take this opportunity to thank the Vodan Africa team led by Samson Yohannes, Getu Tadele, Ruduan Plug, Tesfit Gebremeskel, Aliya Aktau, Putu Hadi Purnala Jati and Abdulahi Kawu who participated in the study and the Universities of Leiden, Tilburg, Phillips Foundation, GO-FAIR Leiden, and professors who commented on the VODAN-Africa presentations captured in this paper. We thank Fr Innocent Maganya of the Inter religious Dialogue and Islamic studies for hosting the research team.

**Conflicts of Interest:** I declare no conflict of interest. This is an original study as part of the wider ongoing research on data control, ownership and interoperability in Africa.

## References

1. World Health Organization, Global Spending: weathering the storm. https://www.who.int/publications/i/item/9789240017788
2. Royal Bank of Canada, Covid19 Pandemic research. https://www. rbcroyalbank.com (accessed on 30 January 2023).
3. Africa Private Equity and Venture Association (AVCA 2021). https://www.avca.africa (accessed on 28 January 2023).
4. Torreele, E., Kazatchkine, M. and Mazzucato, M. Preparing for the next pandemic requires public health focused industrial policy. https://blogs.bmj. com/bmj/2021/04/01/preparing-for-the-next-pandemic-requires-public-health-focused-industrial-policy/Torreele (accessed on 24 November 2022).
5. Oxfam, COVID vaccines create 9 new billionaires with combined wealth greater than cost of vaccinating world's poorest countries. https:// www.oxfam.org/en/press-releases/covid-vaccines-create-9-new-billionaires-combined-wealth-greater-cost-vaccinating (accessed on 22 October 2022).
6. World Health Organization, Global Vaccine Market Report. https://www.who.int/ immunization/programmes_systems/procurement/mi4a/platform/ (accessed on 27 May 2021).
7. Allen, A. For Billion-Dollar COVID Vaccines, Basic Government-Funded Science Laid the Groundwork. https://www.scientificamerican.com/article/ for-billion-dollar-covid-vaccines-basic-government-funded-science-laid the-groundwork/ (accessed on 21 December 2022).
8. Robertson, H. and Travaglia, J. The Necro politics of COVID-19: Will the COVID-19 pandemic reshape national healthcare systems? https://blogs.lse.ac.uk/impactofsocialsciences/2020/05/18/ the-necropolitics-of-covid-19-will-the-covid-19-pandemic-reshape-national-healthcare-systems/ (accessed on 20 December 20 2022).
9. Cross, S. et al. Who funded the research behind the Oxford-AstraZeneca COVID-19 vaccine? Approximating the funding to the University of Oxford for the research and development of the ChAdOx vaccine technology. *medRxiv* (2021). https://doi:10.1101/2021.04.08.21255103
10. Reuters, BioNTech wins $445 million German grant for COVID-19 vaccine. https://www.reuters.com/article/health-coronavirus-germany-vaccine-idUSKBN2661KP (accessed on 20 December 2022).
11. World Health Organization Governing health innovation for the common good. In *COUNCIL BRIEF NO.1* (WHO, 2021).
12. Torreele, E., Kazatchkine, M. and Mazzucato, M. Preparing for the next pandemic requires public health focused industrial policy. https://blogs.bmj. com/bmj/2021/04/01/preparing-for-the-next-pandemic-requires-public-health-focused-industrial-policy/Torreele (accessed on 24 November 2022).
13. Yamey, G., Jamison, D., Hanssen, O. and Soucat, A. Financing Global Common Goods for Health: When the World is a Country. *Health System Reform 5*(4), 334-349 (2019). https://doi:10.1080/23288604.2019.1663118
14. Oxfam International, COVID vaccines create 9 new billionaires with combined wealth greater than cost of vaccinating world's poorest countries. https:// www.oxfam.org/en/press-releases/covid-vaccines-create-9-new-billionaires-combined-wealth-greater-cost-vaccinating (accessed on 22 October 2022).
15. Van Reisen, M. et al. Design of a FAIR digital data health infrastructure in Africa for COVID-19 reporting and research. *Adv Genet*. *2*, e10050 (2021). https://doi.org/10.1002/ggn2.10050
16. Mazzucato, M. et al. Waiving covid patents. https://www.economist.com/ by-invitation/2021/04/20/mariana-mazzucato-jayati-ghosh-and-els-torreele-on-waiving-covid-patents.Mazzucato (accessed on 20 December 2022).
17. Foto, Thabiso. Can Africa's start-up sector keep up its record funding run? https://www.ventureburn.com (accessed on 21 December 2022)

18. East African Health Research Commission, Digital REACH Initiative Roadmap, Digital Regional East African Community Health Initiative. https://www.eahealth.org/sites/www. eahealth.org/files/content/attachments/2019-02-06/Digital-REACHInitiative-Roadmap_20171205_custom_size_0.pdf. (accessed on 23 December 2022).
19. Wilkinson, M. D. et al. The FAIR Guiding Principles for scientific data management and stewardship. *Sci. Data* 3, 160018 (2016). https://doi: 10.1038/sdata.2016.18.
20. United Nations, Secretary-General, Addressing Security Council, Pledges Full Support for Creating Emergency Task Force to Prepare Global COVID-19 Vaccine Plan. https://press.un.org/en/2021/sgsm20583.doc.htm (accessed on 1 July 2024).
21. Inau, E. et al. FAIR Equivalency, Regulatory Framework and Adoption Potential of FAIR Guidelines in Health in Kenya. *Data Intelligence* 4(4), 852–866 (2022). https://doi.org/10.1162/dint_a_00175
22. World Health Organization, Coronavirus (COVID-19) Dashboard. https:// covid19.who.int/info/World Health Organization. Establishment of a COVID-19 mRNA vaccine technology (accessed on 22, December 2022).
23. UCL Institute for Innovation and Public Purpose, Inequality, Unemployment and Precarity. https://www.ucl.ac.uk/bartlett/public-purpose/ publications/2020/may/inequality-unemployment-and-precarety.UCL (accessed on 10 December 2022).
24. Republic of Kenya *Kenya Health Policy 2014 – 2030* (Ministry of Health, 2014).
25. Policy Ministry of Information *Communications and Technology, Kenya* (Government Printers, 2016).
26. Ministry of Health *Kenya Health Act 2016-2030* (Government of Kenya, 2016).
27. Mawere, M. and Van Stam, G. In Proceedings of International Conference on Social Implications of Computers in Developing Countries, Dar es Salaam, Tanzania (1–3 May 2019).