Data Visiting in Digital Black Holes: FAIR Based Digital Health Innovation during War

S. Y. Amare, Araya Abrha Medhanyie & Mirjam Van Reisen

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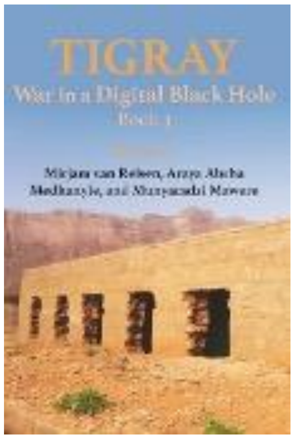

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Chapter 13

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They pour it out in a hurry and sit down and harvest it.

Abstract

The crisis in Tigray hindered data findability and accessibility, creating a 'digital black hole' due to the Internet blockade. A need arose, due to shortages and service interruptions. To address this, a data architecture for patient data was piloted in Tigray's health facilities, focusing on findability, accessibility, interoperability, and reusability (FAIR). The possibility and opportunity arose to deploy a resilient system independent of external sources. The pilot confirmed that data visiting, where algorithms access in-residence data, can overcome accessibility challenges. These junctures shaped the development and deployment of a new approach to developing a digital health system with principles of FAIR-with Ownership Localisation and Regulatory (OLR) compliance. The success shows this system has the potential to drive change to a new global standard for resilient digital health architectures. This approach would help health systems remain effective and operational even in challenging or crisis situations.

Keywords: Tigray war, digital health, resilient health system, critical junctures, FAIR-principles, FAIR-OLR standard, Ethiopia

Introduction

In response to crises, including war, many countries have developed or adopted digital health technologies, which can be a matter of life and death. Digitalisation is a priority for humanitarian organisations such as the International Committee of the Red Cross (ICRC), as it is rapidly transforming how humanitarian operations and assistance activities are conducted, thereby influencing the effectiveness of the humanitarian sector in serving affected populations (Rejali & Heiniger, 2020). During outbreaks of Ebola and severe acute respiratory syndrome (SARS), digital health technologies demonstrated their potential in detecting and combating global epidemics (Alwashmi, 2020). However, these crises also revealed that data often became inaccessible once interventions concluded (Van Reisen *et al.*, 2021). The deployment of eHealth technologies in conflict settings requires further clarification on global norms to ensure their effective use (Bowsher *et al.*, 2021).

The COVID-19 pandemic has further exposed existing weaknesses and gaps in health systems, particularly in developing countries. These nations have faced severe challenges due to under-resourced health facilities, poor data and information coordination, and generally weak health systems, which hindered efforts to mitigate the impact of COVID-19 and other health issues (Van Reisen *et al.*, 2021). The lack of data from marginalised communities significantly impacts the generalizability of data and contributes to data poverty—a situation where machine learning algorithms lack the ability to generalize due to the underrepresentation of marginalised populations (Ibrahim *et al.*, 2021). Addressing these challenges necessitates a holistic approach that recognises health systems as complex and adaptive entities, functioning at multiple interconnected levels with diverse stakeholders (Ajadi, 2020).

On 3 November 2020, the outbreak of a full-scale war in Tigray led to a total siege and communication blackout, inflicting severe damage on the region's health system (ICHREE, 2023; Gesesew *et al.*, 2021; Hagos, 2021). The war caused significant destruction to health infrastructure (Gesesew *et al.*, 2021; Niguse *et al.*, 2024), making access to information nearly impossible and hindering the ability to respond to crises and treat patients. With electronic health information systems out of service and shortages of basic materials such as pen and paper, recording patient data during the two-year siege became nearly impossible. This situation prompted researchers to explore alternative, more resilient data architectures (Gebreslassie *et al.*, 2024). Consequently, a new paradigm for digital health architecture was developed and tested during the war (Gebreslassie *et al.*, 2024).

This study investigates the development and assesses the relevance of a digital innovation designed to address the challenges posed by war in the collection and distribution of health information in Tigray. The design was developed and tested during the COVID-19 pandemic and the Tigray war, which provided the overall context for this innovation. The study aims to evaluate the implementation of a digital health solution that enhances the resilience of the health system during a time of war and siege, focusing on the critical junctures in the design and implementation process.

Multiple crises during an internet black-out

From 2020 onwards, Tigray faced a convergence of multiple crises, including the desert locust infestation, the COVID-19 pandemic, an Internet and communications blackout, a siege, a severe economic downturn, famine, and a widespread humanitarian crisis (Annys *et al.*, 2021). By 2021, Tigray had an estimated 2 million Internally Displaced Persons (IDPs) (Annys *et al.*, 2021). The Tigray war is considered one of the least documented conflicts, as access to information was deliberately obstructed (Hagos, 2021). Effective crisis response necessitates timely access to information, yet paradoxically, data availability was severely limited in this context.

Addressing the information system needs of Tigray's health sector during an ongoing war and pandemic required innovative approaches. The region's Health Management Information System (HMIS) relied on the District Health Information System 2 (DHIS2), which was managed by the federal government. However, the DHIS2 backbone, including the system and data repository, was under the control of the federal government, which was the principal adversary in the Tigray war (Taye *et al.*, 2024). The conflict also involved deliberate and systematic destruction of health facilities and records. The situation in Tigray was unique in that the conflict occurred between the region and the national government hosting it. Consequently, the federal government, upon which the regional health sector was dependent, rendered it nearly impossible for the regional health system to function effectively (Gebreslassie *et al.*, 2024; Taye *et al.*, 2024).

Investigating change in digital architectures

This study looked at the redesign of a digital architecture in the context of a new situation in a fundamentally altered digital ecosystem. This can be referred to as a critical transition, which is the change resulting from new conditions that create a critical threshold into the alternative regime. This new situation is defined by new needs, new opportunities, and new possibilities, in which alternative architectures can emerge. The design of an alternative architecture passes through critical junctures that define the outcome. In the context of this research, the design was influenced by the exposure of the designers to a new paradigm for data architecture. This is discussed below.

Hysteresis and alternative regimes of digital architectures

Architectural design decisions play a crucial role in software architecture; hence they need to be an explicit part of software architecture (Jansen & Bosch, 2005). If the security of the system is compromised and authorised users have no access to the system, it cannot continue. If the system has been designed to work with Internet connectivity and when there is a sudden communication blackout, then the system cannot function beyond this situation unless it is re-designed whenever possible to run with the new scenario. Whenever there is a distraction of necessary software, hardware, and data, the system, no matter how well it was designed, does not function as expected. Hysteresis refers to the delay in response observed in a system when reacting to changes in the conditions that moved it to a new state (Stocker, 2024). Therefore, the software system may become dysfunctional.

The blockade rendering the system dysfunctional, may cause a tipping point to occur, a transition to an alternative regime, that corresponds to the new situation (Hardy, 2008). Bourdieu (1990) explained such a change for social ecosystems, but this may equally apply to technologies that are functioning in a social context and an extension of that social context (Van Stam, 2017). A resilient technical system is a system that can respond to provide the outcome it was designed to release, when the social circumstances change. A transition in software architecture is the point in time when changes in the social system require the software system to respond. If the software is no longer functioning or providing the output it was designed for, it will be amenable to change. Such moments are critical transitions.

Critical junctures in software architecture

If the architecture is amenable to change, some decisions leading to change during a process shape the outcome of it, and these are termed critical junctures. Decisions made in such critical moments, alter outcomes. The criticality of such events can be seen in how these shape divergence from the past through causal logic (Soifer, 2012). The critical junctures are the points of decision-making that have a causal effect on the design as it progresses to respond to the critical transition.

When a critical juncture occurs, it is important to carefully consider the implications of any technology change to the entire software architecture and how it relates to the social environment in which it should function. These changes can have a significant impact on the future of the software system, so it is important to make sure that they are well-thought-out and implemented in a way that minimises risk. Architectural design decisions play a crucial role in software architecture; hence they need to be an explicit part of software architecture (Jansen & Bosch, 2005).

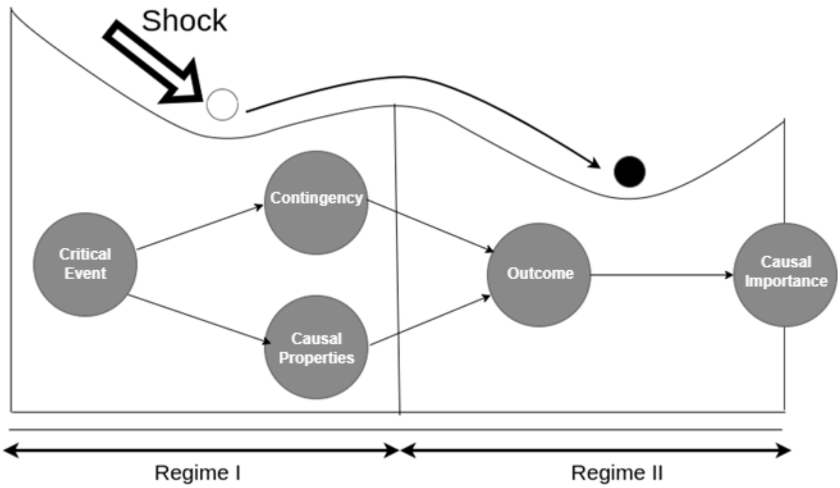

Figure 13.1. Critical junctures in adapted framework

Source: Based on concepts drawn from Hardy (2008)

Critical junctures present two causal conditions: permissive condition and productive condition. The critical junctures are spaces in time where political agency can be exercised, and choices can be made to play a decisive causal role in setting a certain path of development that persists over a long period. The critical junctures are marked by events that are well-bounded episodes in the history of a case. They are marked by a particular occurrence or specific pattern of activity (Soifer, 2012). The permissive condition refers to the easing of constraints leading to an ease of structures that make change a possibility (Soifer, 2012). The productive condition on the other hand presents us with the outcome or range of outcomes that are then reproduced after the permissive conditions disappear and the juncture ends (Soifer, 2012).

The framework was used as a lens to identify the critical events during the design and implementation of the alternative new software system. The contingency refers to what has happened in the context of what could have happened because of the event. The causal property shows the resulting causality leading to a certain outcome that has causal importance allowing an agency or contingency to shape divergence from the past. A regime shift which entails a shift from the current system state to an alternative regime, represented here by the ball, because of a shock from critical events leading to an important outcome. The ability to respond to situations in a stable state is referred to as resilience; a resilient system is a system that can absorb external shocks.

New requirements: FAIR Guiding Principles

Digital health enables the management of healthcare by leveraging digital tools and services to transform care delivery, thereby empowering individuals and populations (Alwashmi, 2020). Central to digital health is the production and reliance on digital data. The processes governing how, where, by whom, and for what purposes data is stored and utilised determine the underlying structures of benefit, control, and power.

This design research is framed within a set of data stewardship principles known as FAIR, which emphasise that digital data should be Findable, Accessible under specific conditions, Interoperable, and Reusable by both humans and machines (Wilkinson, 2016). Additionally, FAIR encompasses Federated AI-ready data, positioning itself as a paradigm that enhances or complements the concept of Open Data by integrating considerations of privacy, data ownership, sovereignty, regulatory compliance, data quality, and the explicit articulation of digital data's value (Jati *et al.*, 2022).

The FAIR principles support data federation and ensure data remains in its original location by enabling the accurate tracking of data provenance. This research employs the FAIR principles as the theoretical foundation for evaluating crisis response solutions. Consequently, the FAIR Ownership, Localization, and Regulatory (FAIR-OLR) Framework has been proposed for implementation (Van Reisen *et al.*, 2023).

The implementation of FAIR principles in digital health data has been identified to address the challenges posed by data fragmentation and lack of integration, specifically tailored to different social contexts (Van Reisen *et al.*, 2021). The FAIR principles advocate for the development of new practices that:

- Ensure data serves the public interest and is governed by public policy,

- Expand collective knowledge through data-driven science,
- Promote science that addresses practical solutions and services, and
- Encourage public scrutiny and citizen involvement in knowledge discovery, thereby democratizing science and its application (Van Reisen *et al.*, 2021).

The Go FAIR methodology encompasses a transformative approach to data architecture, integrating three key processes: Go BUILD (the creation of new designs), Go CHANGE (adaptation of designs to fit specific contexts and circumstances), and Go TRAIN (training to establish common standards and advance shared objectives). The combined application of these processes is particularly relevant for design initiatives based on FAIR principles within an African context (Van Reisen *et al.*, 2020).

Methodology

The study followed an autoethnographic participatory case study design; the researchers used participatory observation while participating in the design process. Field notes, documents, design specifications, and design artifacts of the system were used to assess the main drivers. Formal and informal interviews and focus group discussions with health workers, business officials of the health bureau, technical teams, and health information technology professionals were conducted for the researcher to reflect and to uncover the critical junctures and key drivers during the implementation.

Autoethnography

Autoethnography draws on and analyses or interprets the lived experience of the author(s) (Rapp, 2018). This method connects insights of the researcher(s) which has specific relevance to Human Computer Interaction and refers to locating the research with awareness of self-identity, cultural rules and resources, communication practices, traditions, premises, symbols, rules, shared meanings, emotions, values, and larger social, cultural, and political issues. It is an autobiographical genre of academic writing which takes the following six steps: selecting an approach; ensuring ethical responsibility; deciding theoretical underpinnings; assembling and gathering data; reflecting and analysing; and disseminating work with supporting drawings, photography, and other evocative formats (O'Hara, 2018).

Symbiotic autoethnography (Beattie, 2022) is a research approach that blends personal narrative with ethnographic study to explore and critically analyse the interplay between individual experiences and broader social, cultural, and political contexts. The purpose of symbiotic autoethnography, particularly when incorporating the seven features of a political transformative focus, evocative storytelling, temporality, reflectivity, interpretative analysis, researchers' omnipresence (in the situation), and polyvocality, is multifaceted:

1. Political transformative focus: This feature ensures that the research aims not only to understand but also to challenge and transform existing power structures and social inequalities. It emphasises the role of research in advocating for social justice and political change.

2. Evocative storytelling: By using narrative techniques that evoke emotions and resonate with readers, this approach seeks to create a deep connection between the audience and the lived experiences being studied, making the research more impactful and accessible.

3. Temporality: This aspect highlights the importance of time in understanding experiences. It considers how past events, present circumstances, and future possibilities interact to shape the subject's experiences and the research narrative.

4. Reflectivity: Reflectivity involves the researcher's continuous self-examination and critical reflection on their positionality, biases, and the research process itself. It ensures that the research is conducted with awareness and ethical sensitivity.

5. Interpretative analysis: This feature emphasises the interpretation of the data collected, going beyond mere description to uncover deeper meanings, patterns, and implications of the studied experiences within their broader context.

6. Researchers' omnipresence: By being omnipresent in the research situation, the researcher integrates their own experiences, emotions, and reflections into the study, acknowledging the inseparability of the researcher from the research context and subject matter.

7. Polyvocality: Polyvocality involves incorporating multiple voices, perspectives, and interpretations into the research. This inclusivity ensures that the research reflects a diversity of experiences and viewpoints, enhancing the depth and richness of the analysis.

Overall, symbiotic autoethnography, with these seven features, serves as a powerful tool for examining and transforming complex social realities. It aims to produce research that is not only scholarly but also personally and socially meaningful, contributing to both individual understanding and broader societal change (Beatty, 2022).

This research method was selected because the authors were not only researchers but also implementers of the intervention and residents of Tigray during the war and pandemic. Symbiotic autoethnography is particularly suited for this study as it allows for a deep exploration of the researchers' lived experiences, both as participants and observers. By drawing on the reporting of their own lived experiences, the researchers could engage in a reflective and interpretative analysis that acknowledges their omnipresence in the situation. This approach enables the identification of critical junctures caused by the crisis in Tigray and the impact these had on the software architecture. Through the use of evocative storytelling and the inclusion of multiple voices (polyvocality), the study provides a nuanced understanding of how the war and pandemic influenced the intervention, ultimately aiming for a political transformative focus that seeks to address the broader social implications of these events.

VODAN Africa

VODAN Africa served as the research initiative that provided the foundational context for this study. VODAN Africa is dedicated to identifying gaps and challenges associated with digital health data management. In early 2020, a technical team comprising software architects, programmers, and domain experts from nine African countries, alongside a team of experts from Leiden University Medical Center (LUMC), was established to contribute to data collection efforts related to the COVID-19 pandemic. The researchers involved in this study were members of the VODAN Africa technical research team.

The VODAN Africa initiative encompassed the implementation of a FAIR-based system across Tigray and eight other countries. Mekelle University established a specialised team of technical experts responsible for the implementation in Tigray as part of the broader VODAN Africa project. The Tigray team actively engaged in developing solutions to ensure that COVID-19 and other clinical data, adhering to the FAIR principles. This effort involved studying and applying the guiding principles of FAIR data management to clinical and research data. The principles were implemented across 88 health facilities, facilitating the management of both clinical and research-related data.

Data collection

Ayder and Mekelle hospitals in Tigray were purposefully selected for the study. Ayder Hospital is the largest referral hospital in the region and Mekelle Hospital is a general hospital which at the time was a sole isolation and treatment centre for COVID-19.

During the research period, the Tigray VODAN project team was actively engaged with health workers in the health facilities. The researchers engaged in the development and deployment of the architecture, being concerned about how this could work during the siege causing a blockade of the Internet.

During the process, the researchers conducted formal interviews and focus group discussions. During the formal interviews and focus group discussions, a topic list was used. The structured interviews were conducted with individuals from the regional health bureau and health information directorate of the regional administration and with health workers, health management information technology professionals in health facilities, doctors, and nurses.

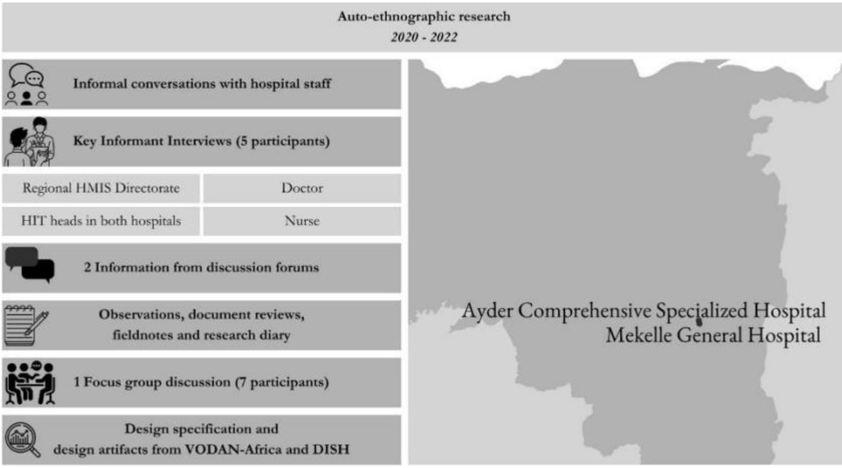

Figure 13.2. The data used and collected for this study

Work-related meetings with implementing health workers and management of health facilities were also recorded in the form of field notes and research diary. The researchers also recorded observations in a research diary.

Design thinking framework

Designing a digital health solution capable of functioning in extreme conditions such as war and siege, as experienced in Tigray, represents a wicked problem. Wicked problems are characterised by the presence of interdependent factors that render them exceptionally challenging to resolve, necessitating extensive deliberation and analysis (Matthews *et al.*, 2022). These problems are fundamentally conceptual, with solutions emerging from rigorous research or the reframing of the issues at hand (Matthews *et al.*, 2022). The design research framework must incorporate two intersecting dimensions, defined by the approach and mindset: one emerging from a research-led perspective and the other from a design-led perspective (Sanders, 2008). Design thinking offers a methodological framework for understanding the problem and provides insights into the approach taken to address it. According to design thinking principles, solutions are identified at the intersection of Need, Possibility, and Opportunity. The research aimed to incorporate the users of the system into the design process, adhering to a human-centred design approach for developing computational solutions.

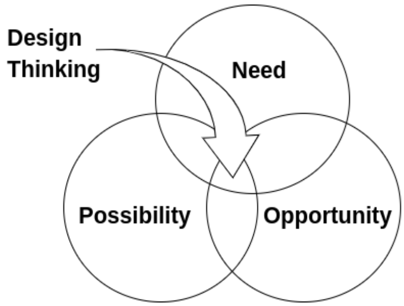

Figure 13.3. Design thinking: solutions are found at the intersection of need, possibility, and opportunity

Source: Carlgren *et al.* (2016)

A synthesis of multiple data sources, coupled with active engagement by the project team with health workers in the health facilities, provided a reflective mirror for the researcher, who had been personally involved in the development and deployment of the VODAN architecture. A topic list was employed to guide both group discussions and individual interviews. Additionally, work-related meetings with health workers and the management of health facilities were documented through field notes and a research diary. The data collected from these various sources were systematically analysed, considering the context, timing, and the composition of the research team, both individually and collectively. Supplementary materials that reflected the engineering process were also reviewed. The researcher thoroughly examined all these data to identify critical junctures that influenced the overall design.

Findings

The findings are organised to describe the new situation that was observed, and the needs, opportunities, and possibilities that emerged from this new alternative situation for the re-design of a health information system to serve a population under siege.

Changed needs: Impact of the war on health data registration

The health system in Tigray faced a critical need for a mechanism to record patient data. The registers traditionally used for this purpose were printed by the federal government. However, due to the siege and the accompanying digital blockade, once the available registers were exhausted, they could not be replenished. Additionally, health facilities in the region began to run out of paper, making it impossible to produce the registers locally. Interviewees reported that, even with the support of international non-governmental organisations (INGOs), printing alternative registers took more than a year and incurred significant costs. Ironically, this situation highlighted the necessity of implementing digital health solutions, as the cost of printing registers became infeasible, particularly given the closure of banks and the difficulties in obtaining paper and toners for printing due to the siege.

This pressing need catalysed the development and implementation of a digital health solution by the research team. However, the creation of digital solutions was not straightforward, as the blockade included restricted Internet access. Furthermore, electricity posed a substantial challenge, mitigated only through the use of solar power and backup generators, which were difficult to sustain due to fuel shortages and high costs resulting from the siege.

The sudden communication blackout exacerbated the situation, leaving some health facilities without any backup systems, causing them to lose access to their own data. Moreover, the existing digital system ceased to function, as it was no longer supported by Internet connectivity, and the government's Health Information Technology staff were discontinued. This situation was explicitly noted in an interview with the head of the Health Management Information System (HMIS) at the Tigray Regional Health Bureau (TRHB):

> *Implementation of electronic medical record (EMR) and HMIS software such as DHIS2 were in a better position before the war when compared with other regions of the country. However, the HMIS data collection and management were centrally managed by the health ministry and almost all facilities in Tigray were working on the online version to ensure quality criteria such as timeliness and completeness.* (Interviewee 001, interview with TRHB HMIS head, face-to-face, June 2022)

The administrator was frustrated, in that Tigray had an advanced system but was not able to use this for the much-needed insights to manage the health crisis as the health system needed to respond to the war, COVID-19, and other crises, all occurring simultaneously:

> *Our officials are being starved of data. We will follow with the data production as clinicians, academics, and researchers to make sure we benefit from the data system put in place. Data on patient charts were not being fully recorded previously and making the data production using digital health tools will enforce mandatory data to be collected properly hence we can get even quality data this time.* (Interviewee 002, interview with Medical Doctor, face-to-face, May 2022)

The problem was specifically identified as a dependency problem on the centralised setup of system, with the backbone controlled in Addis Ababa, from where the siege was initiated:

> *While data is more relevant to lower-level workers, it is ironically least accessible to them in the current centralised arrangement.* (Interviewee 003, interview with Health Information Technology Professional in Mekelle Hospital, face-to-face, May 2022)

Before the communication blackout, data quality was being checked using phone calls. Outpatient Department (OPD) waiting time was also being measured but without communication services operating it was hard to keep-up. The idea of what constituted quality data also changed during the war. It was observed that having access to individual patient data was more powerful than having aggregate reports to the central government.

Systems have breaking points when a change is inevitable. Crisis response requires creative thinking that can create resilient systems. The need for owned and localised data and systems and the need for local mechanisms in the region to ensure the quality of the data were observed in the health facilities:

> *The regional government is more physically close to the data source but it is practically more remote when it comes to having access to the data.* (Interviewee 004, interview with DHI member at Ayder, face-to-face, May 2022)

In addition to the Internet blockade and the software no longer working, other challenges were the lack of incentives as no salaries were paid during the war. The destruction of resources such as PCs, and the destruction of the Woreda-net (wide area network of health facilities in the region) that stopped working has posed challenges.

As a result, alternative digital health systems were demanded to create a HMIS report that would function and be resilient to the changed situation.

New opportunity: Localisation

Following the FAIR framework, the research team has been working on the localisation of a system to low resource settings. The possibility to localise the FAIR based solution is subsequently discussed.

Design decisions

The solutions the research team tested was to deploy a virtual image to be hosted in each of the health facilities. The virtual image has all the tools for FAIRification and was hosted in local machines in clinics. The architecture broadly specifies the input data sources, meta/data stores, and the provision for its access in machine readable FAIR data formats and analytics of the data in the form of a dashboard for the health workers in the health facilities. The architecture ensures data production and data use in a federated modality without data losing its provenance and the data being held in residence. It also enables remote data-visiting and queries.

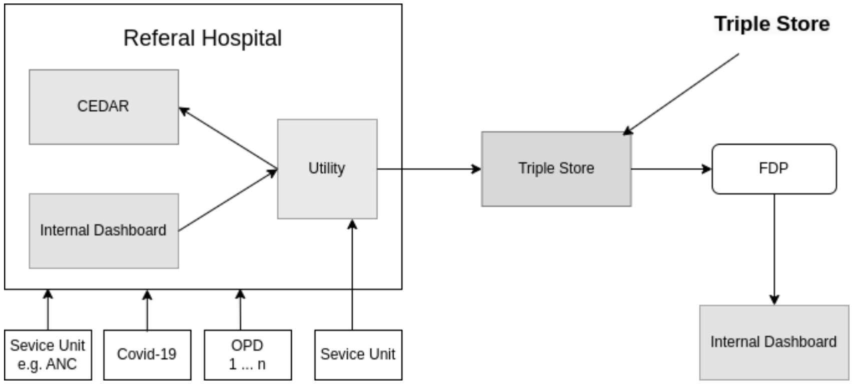

Figure 13.4. Adapted VODAN Africa architecture, created for the Tigray context from the original VODAN Africa architecture

Source: Van Reisen *et al.* (2020)

The picture is an adapted framework to implement the VODAN platform in the health facilities in Tigray. It shows the components of the architecture that have been developed.

Localisation of CEDAR

The CEDAR Workbench allows the creation of templates that can collect FAIR data and metadata. Based on the FAIR principles, the research team wanted to have full control over the deployment of the system in the hospitals but this was not possible due to the communication blackout. The Tigray team laid out two options: to install the system in the host machine or to make it ready in the form of a virtual image. The global team moved on with preparing the second option. It allowed ease of installation as the image would run similarly on all the sites. However, the team in Tigray could not implement this option as downloading an image the size of 30GB was not feasible due to the siege allowing it extremely limited connectivity.

The Tigray team decide to investigate an alternative solution. This was to repackage the Ubuntu operating system with the miniservices from CEDAR in a localised instance. This way, the installation of the system became easy as the users would seamlessly install the system. This required less skill and above all avoided the need for connectivity to install the system. Moreover, it allowed the use of all the resources in the host machine, unlike the image which only used the portion of the system allocated to the image. This had implications on the performance and ease of use and made the Tigray team's way of deployment comparably superior to other installations.

Another challenge was fulfilling the hardware requirements of the system. The computers that were available in the health facilities did not have the required amount of RAM. The other sites had bought the required hardware, but it was not possible in Tigray as there was no access to the funds and the required hardware was not available in the local markets due to the siege. Hence, the deployment architecture was changed to a client-server architecture as the hospital management allowed sharing their server. This enabled the use of any computer, tablet, or phone that could be connected to the local network and access the system through a web browser. This did not depend on connectivity to the Internet and could function within the 'digital black hole'.

During data production, the system was reaching out to the controlled vocabularies that were hosted on the BioPortal, residing in Stanford in the United States. There was no connectivity for this available in the hospitals. The team then decided to download and host vocabularies with a script developed for it in such a way that they could be accessed without the need for Internet connectivity.

Data stewards were trained on how to create new templates, collect data through the template, and see reports using the internal dashboard which were all hosted locally and available offline. Through the limited connectivity, syncing aggregate and agreed-upon indicators happened to the external dashboard periodically.

To address the challenges the team was facing, and to enhance the features of the system, the team created a set of tools locally. Some of the tools included the bulk input tool that allows FAIRification of existing data (making data FAIR, i.e., convert them to a FAIR format). Analytics on the data provided in dashboards for local facilities was possible and it was also possible to send the analytics through despite the limited connectivity. This allowed aggregate statistics to the external dashboard to be available.

Beyond solving its own issues, the Tigray team started supporting other sites in other countries where low connectivity was an issue, using the model, that had been tested in Tigray. This model also worked in these low resource settings. In this instance, the team added remote query service provision to realising the initial architecture making data visiting through remote SPARQL query possible.

To enhance capacity building, the team participated in a data stewardship programme using the support of the international academic capacity building organisation Nuffic. A blended learning programme named Digital Innovation Skills Hub (DISH) was set up. The programme provides training to youth for three months on a range of topics including data science and FAIR data stewardship. A studio was built from locally available materials. Video in the local language was created based on the English version initially done in collaboration with Kampala International University and other partnering institutions. All the above activities allowed the team to harness opportunities and localise systems through data held in residence. The result was the ability to demonstrate that the dependency on the central backbones could be overcome.

The strength of the architecture to be resilient despite the siege, gained the support from management of the Regional Health Bureau and from the Ayder Chief Executive Director (CED).

The possibility: Interest of health workers in the new system

Doctors and nurses who gave little attention to health data recording regretted the fact that they could not conduct proper research due to the quality and format of the data that was being kept. The health workers amid the harsh conditions would talk about data quality and enhancing the system so that they could serve their patients better.

> *This is not extra work; rather this is an extra commitment that we have to make to serve our patients.* (Interviewee 005, interview with Health Information Technology member at Mekelle Hospital, face-to-face, June 2022)

The health workforce worked under extreme conditions without getting paid for almost two years. The health workers were also receptive to the system VODAN Africa introduced. The implementation team worked with the health workers in the hardest of times without having access to the funds available to implement the programme, as banks were closed due to the siege. This created a strong capacity, an element that contributes in and of itself to the resilience of this home-grown solution that responded to local circumstances.

Critical junctures

Looking at the chronology of events, critical junctures shaped the design decision and technology choices made along the way of implementing the FAIR-based digital health solutions amid the ongoing war, siege, communication blackout, and pandemic. This situation was extreme. Table 13.1 summarises the critical junctures.

Table 13.1. Critical junctures

Critical event	Category	Contingency	Causal properties	Outcome	Causal importance
1. Moving from ViB to CEDAR	Technology	VODAN was meant to work on COVID-19 using WHO eCRF. A decision was made to move beyond COVID and led to challenges in new template creation	New technological and implementation choices were made to address the challenges, and this led to adoption of new architecture	Localisation of CEDAR and hence availability of an architecture that was not dependent on backbones	A FAIR based digital solution for digital patient data was developed and run locally: a key element for sustainability
2. Bulk upload tool developed	Requirement	Existing data that was collected in the meantime needed to be uploaded	This need led the team to create a new tool to address the challenge	Bulk Upload Software Developed	Made FAIR data production by increment a possibility
3. Request for interoperability with DHIS2	Policy	The architecture was designed to address patient recording and reporting needs. A	The need to make automatic reporting to reduce duplication of effort and making one time data entry	Interoperability between the VODAN-architecture and DHIS2 was imple-	Working with the existing system without breaking the workflow is helpful for proper implementa-

Critical event	Cate-gory	Contin-gency	Causal properties	Outcome	Causal importance
		request for interoperability with DHIS2 was demanded by many health facilities	and re-use of data possible, led to interoperability	mented	tion
4. War and destruction of health facilities and health records	Political	The war was unexpected and happened during the critical stage of project implementation and it not only affected Tigray but other sites too	New development teams, new design, creation of virtual images, and many more new implementation choices to fill the gap that was created.	Farther modification of the architecture and implementation mods	Implementation across many African countries has since been changed
5. Commun-ication blackout	Tech-nology	This was not expected and accounted for in the design and implementation process	Difficulty sharing, systems stop functioning, technical and financial support provisioning stopped	Light weight system for offline use developed	It has enabled creative solution provisioning but has also gravely affect the project
6. Siege and lack of materials	Eco-nomic	The siege in Tigray was unexpected	Created permissive conditions to	Permissive Conditions created	The resistance was unexpectedly

Critical event	Category	Contingency	Causal properties	Outcome	Causal importance
		and has resulted in lack of even pen and papers to record patients data	try out the architecture as the situation was complex	for implementing the VODAN-architecture	reduced in an effort to tackle shortage of pen and paper
7. Connected back-up using V-SAT: efforts of solidarity	Operational feasibility	Unexpectedly connected back through collaborative and creative effort and generous support of partners.	Connected back with VODAN global team and contributing again in design and implement what has been developed by both teams	Revised architecture and inclusion of triple store and remote query	The architecture was further enhanced taking lessons from Tigray and the global team and Ayder solidarity efforts showcased on the global podium.
8. Capacity building on data stewardship	Operational Feasibility	Participation in the DISH project and VODAN team	Created capacity in FAIR data stewardship and beyond	Demonstrated resilience	Showcased at the European Development Days – create interest in the Health Data Space

The following phases can be identified:

Phase 1. In the pre-war period, the critical junctures were mostly technical associated with technical requirements for:

- Flexibility
- Bulk upload
- Interoperability needs with DHIS2

Phase 2. The war, the effects of the situation were:

- Failure of the digital systems which depended in central backbones controlled by the adversary in the war
- Destruction of health facilities,
- Digital blockade and Internet blackout
- Siege

The challenges that emerged during the war, prompted a fundamental change in design and operation.

In this study related to the two phases, the following critical junctures emerged:

Critical juncture 1: Moving from provider to self-engineering

The need to have an easy way of template creation was the contingency that led to the adoption of a system that allowed engineers to create and adapt the templates and supporting elements.

Critical juncture 2: Bulk Upload Tool Developed

The newly adopted system did not have this feature which was being requested by end users and the complaint was that data upload was time intensive. This contingency led to an in-house development of a new software system that made this possible and created new possibilities.

Critical juncture 3: Interoperability with DHIS2

The system has been widely adopted and required by ministries to do HMIS reporting and was seen as a critical factor for any digital system, this created a contingency that led to the development of a script that allows the automatic creation of the report and making VODAN and DHIS2 interoperable. This showed that the data, which was entered only once in the system, and stored as semantic machine-actionable instances, could be used in parallel use-cases.

Critical juncture 4: War and destruction of health facilities and health records

This happened abruptly; it affected local and global implementation leading to the establishment of new teams and working modalities and approaches, providing confidence that the architecture is useable in remote and hard to reach areas.

Critical juncture 5: Communication blackout

The software system and the vocabularies it uses needed the Internet to work, and the whole implementation process was also disrupted. This led to the development of a new lightweight software system to be used in low resource and crisis settings. This gave confidence to the idea that the continental architecture could run on locally available services, without dependency on central backbones.

Critical juncture 6: Siege and lack of materials

The daily activities of routine recording and reporting were disrupted. A new and alternative approach was needed and an opportunity for innovation was created which otherwise would potentially have faced resistance to changing systems.

Critical juncture 7: V-Sat connection

A light-weight V-Sat connection was offered that allowed for the integration of what was done locally with what was done globally, without dependency on the connectivity backbone that was blocked by the federal government. It also created an opportunity to provide technical support globally.

Critical juncture 8: Capacity building on data stewardship

Capacity-building efforts by DISH resulted in a data stewardship programme that created data science skills for the youth during an ongoing war and siege. This created a sense of purpose and resilience.

Overall, the critical junctures have shaped the adoption of a new modus operandi on how to develop an architecture, based on FAIR principles. The need for ownership of systems and localisation of them was evident. Moreover, the need to comply with the regulatory framework was also key in implementation.

The critical junctures led to the establishment of principles for a FAIR-data architecture with Ownership of data in Locale under Regulatory compliance, or FAIR-OLR. This can be seen as a new paradigm for data architectures that are resilient to external shocks.

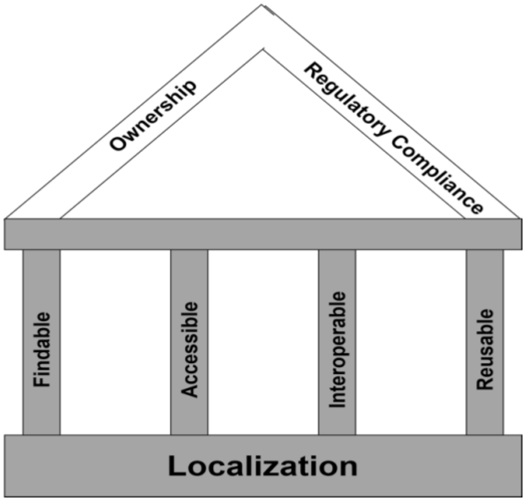

Figure 13.5. The FAIR-house completed with the foundation of localisation (federated data) and delivering a rooftop for data ownership and regulatory compliance of data handling

Source: Van Reisen *et al.* (2023)

Data needs to be owned and managed where it is produced in a federated manner keeping its provenance. The owners of the data can make all the arrangements to make it FAIR.

Systems used to produce FAIR data need to be installed in residence and localised and contextualised to the hosting environment. Being cognisant of the sensitivity of health data was important and all data access and system deployment needed to comply with the regulation, laws, and political landscape so that the intervention is acceptable.

Discussion

Crisis situations necessitate immediate access to reliable data to facilitate an appropriate response; however, the crisis in Tigray severely compromised data findability and accessibility. The region's Internet blockade exacerbated its dependency on a centralised digital infrastructure, controlled from Addis Ababa, where the siege originated. This dependency effectively turned Tigray into a 'digital black hole', a zone from which the transmission and reception of information were significantly hindered, if not entirely obstructed. Overcoming such a digital black hole is intrinsically linked to improving the findability and accessibility of digital data – two essential components of the FAIR (Findability, Accessibility, Interoperability, and Reusability) architecture.

The research demonstrates that findability and accessibility challenges can be mitigated through the concept of data visiting. This process involves maintaining data in its original location (in residence) while sending algorithms to perform scientific computations on the data. Given the siege in Tigray, enabling data accessibility to the global community was critically important. The development of a localised system, which could be directly accessed externally with granted permission, and did not rely on a centralised backbone, emerged as a significant achievement.

This design illustrates a method by which information can bypass traditional gatekeeping mechanisms and escape the confines of the 'digital black hole'. Consequently, Tigray was able to provide real-time information on the health status of patients, facilitating external assistance during the crisis. Since its implementation, Ayder Hospital has become a vital source of information on the direct impacts of the Tigray war.

Analysing the critical junctures and the resultant design adaptations, it is evident that these events not only influenced implementation within Tigray but also shaped broader acceptance of the FAIR-data principles with OLR (Ownership, Localization, and Regulatory compliance). This shift has led to the emergence of a new digital state, wherein dependence on centralised backbone systems is replaced by localised distributed systems. Consistent with the concept of hysteresis, it can be hypothesised that a return to the pre-war digital health architecture may be unlikely and, perhaps, undesirable. Future-oriented digital health architectures that are independent of central backbones may offer enhanced resilience, making them a more favo**u**rable option moving forward.

Conclusion

The Tigray war presented significant challenges to the health system, particularly in relation to patient data recording, as traditional paper registers supplied by the federal government could not be replenished due to the siege and digital blockade. Local health facilities faced severe shortages, with even local printing of registers becoming impossible. Despite efforts by international NGOs, the printing of abstract registers was both time-consuming and costly, taking over a year to implement. The sudden communication blackout exacerbated these challenges, causing some health facilities to lose access to their data due to the absence of backup systems. The digital health infrastructure, reliant on Internet connectivity and centrally controlled by the adversary, was critically compromised, leading to a systemic crisis.

However, these challenges provided an opportunity to innovate and localise digital systems using data held in residence. The study identified critical junctures that defined the direction of the architecture, notably the reliance on central backbones and the disruption of Internet connectivity. In response, a lightweight system was developed for low-resource settings, demonstrating that local systems could function independently of central backbones while enabling local-global integration and technical support without dependency on connectivity. The capacity-building efforts on data stewardship fostered resilience among youth during the siege, inspiring them to explore alternative digital systems.

Overall, these junctures informed the development of a new approach to digital health systems, emphasising the principles of FAIR (Findability, Accessibility, Interoperability, and Reusability) with Ownership, Localization, and Regulatory (OLR) compliance. This approach has the potential to establish a new global standard for resilient digital health architectures, setting a benchmark for creating robust and adaptable digital health systems that can function effectively in challenging or crisis conditions.

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Authors' contributions

The first author is a PhD student at Leiden University Medical Center. He conceived the research and carried it out. The second author reviewed the different versions. The third author reviewed and restructured all of the versions and provided suggestions for the theoretical framework of the study.

Ethical considerations

This study obtained ethical clearance from the Institution Review Board (IRB) of the College of Health Science at Mekelle University, MU-IRB 1982/2022.

This chapter should be read in conjunction with the 'Note on Content and Editorial Decisions'.

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