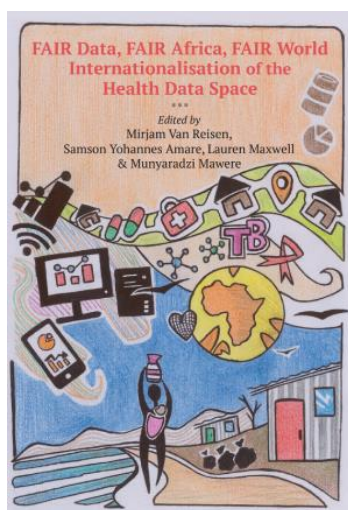# Narratives in Public Agenda-Setting for FAIR Data and Health Data Management in Africa: Enhancing Maternal Health and Infectious Disease Outcomes

Putu Hadi Purnama Jati & Mirjam van Reisen

Chapter in:
Fair Data Fair Africa Fair World:
Internationalisation of the Health Data Space

Contents

Chapter 15

Narratives in Public Agenda-Setting for FAIR Data and Health Data Management in Africa:

Enhancing Maternal Health and Infectious Disease Outcomes

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Abstract

Agenda-setting for the FAIRification of patient health records in low- and middle-income countries is crucial for ensuring that health data contributes to improved patient care, policymaking, and health system strengthening, particularly in maternal health and infectious disease management. Addressing challenges such as data ownership concerns, limited interoperability, and infrastructure constraints, this study established standards and protocols for patient data sharing and the local deployment of FAIR-based systems. The research intervention focused on enhancing patient health data management in Africa by implementing the FAIR data principles, making patient data Findable, Accessible under well-defined conditions, Interoperable, and Reusable (FAIR). Using Kingdon's three-stream model—the problem, policy, and political streams—the study highlights the underutilisation of patient data in improving maternal health and infectious disease outcomes. Through the intervention, stakeholders recognised the availability of alternative solutions. The research aligned with political concerns about patient data control and the interests of data collectors, with participants acting as policy entrepreneurs advocating for change. The convergence of these streams opened a policy window, leading to policy adoption, including in Kenya, where health data was declared national strategic data and the Afya.ke electronic medical record (EMR) system was introduced.

Keywords: Patient records, EMR, FAIR-data, three-stream model

Introduction

A lack of data interoperability presents significant challenges to maternal health and infectious disease outcomes by impeding the seamless exchange of patient information across healthcare facilities and systems (Celuchová Bošanská et al., 2022). In maternal health, for instance, a pregnant woman receiving antenatal care at a rural clinic may later require emergency care at a better-equipped urban hospital. If the health records from the rural clinic are not interoperable with the hospital's electronic medical record system, critical information such as previous pregnancy complications, prenatal test results, and prescribed medications may be inaccessible (Callard, 2024). This lack of continuity in patient history can lead to misdiagnosis, delayed interventions, and even life-threatening complications during labour and delivery (Amare et al., 2025).

Similarly, in the context of infectious diseases, poor data interoperability hinders effective surveillance and response efforts to endemic outbreaks among large populations, causing a high mortality rate among pregnant women (Heemelaar, 2022). For example, during a pandemic, such as the novel coronavirus (COVID-19) pandemic, or an outbreak of, for example, tuberculosis, fragmented health records prevent timely tracking of cases, vaccination history, and treatment adherence, and adverse effects on women and adolescent girls may go unnoticed due to lack of reporting (Abrha & Van Reisen, 2024). Without integrated data systems, public health authorities struggle to identify transmission patterns, assess treatment efficacy, and allocate resources efficiently. As a result, disease outbreaks may spread unchecked and patients may receive suboptimal care due to incomplete medical histories.

The East Africa Health Research Community (EAHRC, 2017) observed that addressing data interoperability is, therefore, essential for improving maternal health outcomes and strengthening the response to infectious diseases. Key challenges in the management and use of health data, particularly in the African context, are the lack of data integration and limited use of data in health facilities (Republic of Namibia, 2024).

Jati et al. (2022) and Mamuye et al. (2022) emphasise the need for structured standards and protocols to facilitate efficient health data exchange across health reporting systems. The absence of interoperability mechanisms limits the quality and accessibility of health data, thereby reducing its utility for decision-making in healthcare facilities. Without standardised approaches, health data remains fragmented, hindering comprehensive analysis and informed policy decisions (Callard, 2024).

Van Reisen et al. (2021) identify incomplete health data as a major obstacle to effective healthcare interventions, particularly in the management of health crises such as COVID-19. The lack of well-curated and comprehensive data restricts the ability of health professionals to respond effectively to emerging health threats (Van Reisen et al., 2022). Proper curation and utilisation of patient data at the point of care are necessary to enhance clinical outcomes and optimise healthcare delivery. Similarly, Van Reisen et al. (2023) underscore the importance of making health data not only accessible, but also actionable in real time, allowing for evidence-based decision-making that improves patient care.

Jati et al. (2022) and Magagna et al. (2023) further highlight the significance of local deployment and responsible data management. The implementation of locally governed data management systems ensures that health data is curated and made available under well-defined conditions, thereby promoting responsible and ethical use. This approach enables healthcare providers to leverage digital tools while maintaining control over data governance and patient privacy. Addressing these challenges requires the development of comprehensive frameworks that integrate interoperability standards, data curation practices, and ethical governance to ensure that health data contributes effectively to improved healthcare outcomes.

Plug et al. (2022) emphasise the necessity of addressing data ownership and privacy concerns, which often pose significant barriers to data sharing within health systems. Establishing trust among stakeholders, including healthcare providers and patients, requires the implementation of clear regulatory frameworks that define data access and control mechanisms. Such frameworks foster a culture of

data sharing and collaboration, ensuring that health data is utilised effectively while maintaining ethical standards.

Basajja, Van Reisen, and Oladipo (2022) highlight the potential for Uganda's eHealth sector to integrate these principles, thereby enhancing data governance and interoperability. Their study demonstrates how structured approaches to data management can contribute to the responsible use of health information while supporting broader healthcare objectives. Similarly, Kawu et al. (2022) examine the alignment of FAIR data guidelines with existing health policies in Nigeria, emphasising the need to balance improved data accessibility with robust data protection measures. Given the sensitivity of health data, ethical considerations must remain central to data governance strategies to safeguard patient privacy while enabling the extraction of valuable health insights (Plug et al., 2022).

The Value-driven Ownership of Data and Accessibility Network (VODAN) Africa researchers have reported some success in the use of FAIR-based solutions, providing a game changer that could contribute to resolving current patient data management issues in Africa. However, it is not enough to demonstrate a potential; the question is whether the outcomes are persuasive enough to contribute to agenda-setting and sufficient to create a conducive environment for these new possibilities.

This article explores if and how the outcomes of the research conducted by the VODAN-Africa have impacted on public agenda-setting. It uses the three-stream model of Kingdon (1984). The model predicts that when the three streams (the problem stream, policy stream, and political stream) converge, a window for agenda-setting can open. The study investigates the extent to which policy entrepreneurs, who invest their time, ideas, and resources to interact with what is regarded as the problem, the alternatives available to solve it, and the political importance of doing so, can push the convergence and help bring new ideas onto the public agenda. The study investigates how the VODAN-Africa research interacted with the public policy agenda and studies whether the research influenced the policy agenda.

Theoretical framework

Kingdon's theory, referred to as the three-stream model or Multiple Streams Framework (MSF), provides a comprehensive framework for explaining a path of action or process in policy making. Developed by John Kingdon in the 1980s, the approach argues that an agenda is formed when three distinct streams—problem, policy, and politics— converge resulting in the opening of a policy window. Each stream functions independently, regulated by its own dynamics and rules (Kingdon, 1984).

The problem stream involves issues that require attention, the policy stream encompasses potential solutions, and the political stream involves the political climate and the saliency of the issue among actors who can influence the decision-making (Rozbicka & Spohr, 2015; Walhart, 2013). To address a problem, it should be recognised as important for the policymakers (problem stream) and understood and explained in a way that resonates with the public and political actors (policy stream) (Ha, Mirzoev, & Mukhopadhyay, 2015). The policy stream is described as the creation of viable solutions (Cairney & Jones, 2015; Kruger et al., 2021). The political stream reflects the broader political context, including public opinion, election cycles, and the influence of interest groups (Hayle, 2015; Robinson & Eller, 2010).

If one of the three elements is missing, the issue remains floating, for instance, if a solution is not available. The "probability of an item rising on the *decision*-agenda is dramatically increased if all three streams—problem, policies, and politics—are joined" (Kingdon, 1984, p. 187). The coupling of the streams is the work of policy entrepreneurs. When the policy window opens, policy entrepreneurs engage to determine the outcome of the policy window. The policy window is time-constrained; it opens and closes.

Kingdon's model has been used in various fields, including health policy, environmental governance, and education reform, as it helps to explain the complexities underpinning how issues are prioritised and addressed within governmental frameworks (Kimmel, Toohey, & Delborne, 2016; Lee, 2022). Ridde (2009) found that Kingdon's model is useful for examining public policy implementation at the

local level as well as valid for analysis in low-income countries, which was confirmed by Mhazo and Maponga (2021). Ogeto et al. (2020) specifically apply the three-stream model to analyse the agenda-setting for public policy formulation in health care (2014–2030) in Kenya, offering further validation of the model for use in health care policy and in Kenya.

Kingdon's three-streams model is particularly helpful for the understanding of how new ideas enter the public policy agenda and can explain how such changes happen, even when issues were not part of a public agenda.

Research approach

This research has a comparative, qualitative, explorative ethnographic research design. The objective is to understand and interpret the cultural practices, behaviours, and experiences of a specific group or community.

The ethnographic approach aims to gather rich, contextual data through immersive observation and interaction, allowing researchers to develop insights into the participants' perspectives and social dynamics. The ethnographic research approach allows the researcher to understand the context of a particular problem. The engagement, observations, and communications over a long time allow the researcher to gain a detailed understanding of the context in which behaviours and practices occur. The approach allows the researcher to capture the perspectives of the research participants. The constant engagement with participants is a way of gaining insights into how participants experience their lives and how they interpret their world. A qualitative approach gives the researcher an opportunity to document change, by observing and documenting changes over time. A qualitative, explorative ethnographic research design prioritises the depth of the study over the scope.

This study is implemented in real life. Such an approach is helpful when the research aim is to capture the complexities of changes in a natural setting. This helps the discovery of factors that are specific to a particular situation. The contextual factors help us understand the differences in changes between places.

The research design has a comparative element. It is expected that the changes documented in this research are different in the places included in the study. By conducting the research in places that vary significantly, factors that are critical to the changes observed may be identified. This may facilitate the formulation of hypotheses for further research. The explorative design allows the researcher to make discoveries, potentially leading to the generation of new hypotheses. The results may inform future research questions based on hypotheses formulated from the discovered insights.

Timeline of the research

The fieldwork for this research was conducted over a long time, starting in March 2020 and finishing at the end of 2024. The researcher (first author) was an active participant and observer throughout this entire period. The following key moments are relevant to the fieldwork conducted in the study.

- 2020 – Start of the research group and formulation of the research problem
- 2020 - Proof of concept conducted by the research ground, regarding the data-visiting across countries on surveillance of COVID infections
- 2021 – Conducting of studies on FAIR-equivalency with national legislation by the research coordinators
- 2021 – Formulation of Requirements and Specifications for the next phase by the research group
- 2021 – Development of a FAIR template and semantic ontology for outpatient departments (OPD) and antenatal care (ANC) by the research group
- 2021 – Development of mini-services to support and deploy a multifunctional workstream over FAIR patient data by the technical team
- 2021 – Training of data stewards and data-clerks by the technical team
- 2022 – Deployment of a minimal viable product (MVP) in health facilities in Ethiopia, Kenya, Nigeria, and Uganda by the technical team
- 2023 – Assessment and evaluation of the MVP by the researchers

- 2023 – New round of data-collection by researchers
- 2024 – Analysis of the data and engagement in feedback from participants by researchers

Different studies were conducted over this period. For this research, it is relevant to highlight a few key moments.

The researcher was part of the team that formulated the initial needs for the research and overall research objectives. The researcher participated in all the phases of the research, starting in 2020, as a full member of the team and worked with all stakeholders during the research. This allowed the researcher to observe, document, and analyse the different situations in different places, understand the reason for different factors in play in different situations, and have an in-depth understanding of the views and changes of views of all stakeholders. Before the preparation for the series of actions conducted in 2021 and 2022, a study was undertaken on the understanding among project coordinators of the need and relevance of the study. This gave the researcher a good insight into the mindset of the research community.

Research scope

During the research, the researcher made the following observations.

Formulation of the research problem

The researcher was part of the team that initially formulated the research objectives, based on some observations:

- COVID-19 data from Africa was missing and this was hampering surveillance.
- It was also observed that systems in place did not allow for such surveillance to be conducted effectively.
- Control of patient data at a national level was lacking; national administrations had no effective control over the transfer of patient data to other places and data concerning pregnant women and lactating women were particularly absent.

The research was responded to problems observed in the context of patient data recording in Africa.

Substantiation of the research problem

The researcher was part of the team that substantiated the research problem in the following ways:

- The proof of concept demonstrated the availability of a solution that held patient data in a federated format in health facilities, while being simultaneously available for surveillance.
- The studies into the equivalency of the proposed workflow showed that, in terms of its objective, it was similar to the ambitions expressed in policy document studies in a series of countries in Africa.
- An availability of tools emerged that would allow for a practical large-scale test of the proposed solution.

It was found that solutions to the problem of patient data handling were available and that the search for alternatives was in line with policy ambitions in selected countries in Africa.

Wide support for research implementation

The research was actively supported, with little if any financial incentives, demonstrating:

- Support by ministries of health expressed in letters
- Interest by health facilities to participate generated an increase from the originally targeted 30 facilities to 88 facilities, which signed data use agreements and participated in the training
- Introduction of FAIR data formats for COVID data, outpatient department (OPD) and antenatal care (ANC) data
- Availability of volunteer data stewards and data clerks trained in FAIR data curation

The context of the research showed there was wide support (independent from financial incentives) and interest in exploring alternatives to the current practices involved in patient data handling.

Formulation of the hypothesis

During this preliminary period, it was evident that the problem of lack of data and data integration was recognised, that policies were paving the way for a new solution, and there was broad support from different sides. Hence, it was clear that the research engaged with an

identifiable societal problem (formulation of the research problem), the need for a solution was recognised in policy documents (substantiation of the problem), and that there was a lot of interest from within the administration and stakeholders, including in health facilities, which were interested in looking at whether or not a solution was available (support for research implementation). This led the researcher to formulate the hypothesis that the medical personnel themselves were perhaps playing a role in agenda-setting for medical patient data recording. Could the health workers themselves perhaps be policy entrepreneurs?

Even though it was not the objective of the research team to actively set an agenda, would it be a possibility that the research was contributing to agenda-setting? To delve into this question, the scope of the study was formulated to focus on the changes that took place in the agenda-setting during the period of the overall research. It was decided that the study would be based on the dynamic model of Kingdon (1984), with specific attention provided to the constructs: the problem stream, the policy stream (the solutions), the political stream, and the policy entrepreneurs.

Selection of countries and regions
The countries selected for the study were: Ethiopia, Kenya, Liberia, Nigeria, and Uganda. The following regions were involved: Tigray and Addis Ababa (Ethiopia), Niger-state (Nigeria), Uganda several regions (Uganda), Nairobi Metropolitan region (Kenya), and Monrovia (Liberia). The selection of the northern region in Ethiopia is justified by it serving as a test bed for innovation (Tegegne, 2023).

Selection of participants
The coordinators of the research, who engaged with all stakeholders interviewed for this research, included (i) five country coordinators and (ii) four technical development coordinators. Although the final sample is relatively small, their leadership roles and direct involvement in navigating local challenges mean that they are uniquely positioned to provide rich, contextual insights into the implementation process.

Interview format

The interviews followed a semi-structured way in the format of an open conversation. The researcher conducted all the interviews. The researcher used a topic list during the interviews to make sure that all the topics were covered.

The topics prepared for the interviews aligned with the constructs: the perspective the interviewee held on the health data handling problem (problem stream), the perspective the interviewee held on actionable solutions and strategies (policy stream), and the understanding by the interviewee of the saliency of the issue, the available political support, and any resistance (politics stream). The interviewees were also asked to reflect on the role of policy entrepreneurs and the role of the VODAN researchers as policy entrepreneurs.

Data collection

The interviews were conducted in person (August 2024) and via video conferencing (September–December 2024), each lasting 45–60 minutes. A semi-structured format balanced predefined topics on the three streams (problem, policy, and politics) with the flexibility to explore unanticipated, but relevant, topics. The interviews were conducted in English. All interviews were recorded. The recordings were saved with password protection. Informed consent was obtained from all participants, and personal identifiers were removed from transcripts to ensure confidentiality.

Data analysis

For the analysis of the data, all of the interview recordings were fully transcribed, and the transcripts saved with password protection. After transcription, the interviews were read several times for familiarisation, and an in vivo coding was conducted to capture the main impressions. The interviewee identified important elements in each interview.

In the next phase, a thematic coding-labelling was set up using a spreadsheet. The data was coded manually, based on the labels of the four constructs: problem, policy, political, and policy entrepreneur. During this phase segments of text were assigned to labels: problem, policy, political, policy entrepreneur. The coding was subsequently

refined. This entailed reviewing codes for consistency, identifying sub-themes, and consolidating overlapping sub-themes such as 'data ownership' under the problem stream, and 'evidence-based advocacy' under policy entrepreneurship.

Data were summarised in a matrix format, with responses grouped under the themes. This approach allowed for the identification of common themes, such as challenges to implementation or political support. Within each stream, comparisons between respondents were conducted, looking at common and divergent experiences and perceptions.

Results and findings

The findings are organised into three sections corresponding to Kingdon's streams: problem, policy, and political streams, as well as the role of policy entrepreneurs. Each section explores both similarities and differences in participants' perspectives. The analysis of similarities identifies common themes across the three streams and examines how they converge through the actions of policy entrepreneurs and participants' reflections. Conversely, the examination of differences highlights the distinct ways in which the public agenda is reshaped in each country, illustrating the unique dynamics of the policymaking process.

Problem stream

The problem stream examines how participants identify challenges in health data management. Lack of interoperability, the problem of legacy systems, localisation, as well as fragmentation and lack of interoperability to handle variability in health records keeping were identified as the key issues in health data management.

Lack of interoperability

Commenting on what they viewed as one of the main problems that needed to be addressed in digital health data management, interviewees emphasised the difficulty of obtaining data in a consistent and usable format across different research facilities. This challenge is often referred to as the lack of interoperability between healthcare systems. This was identified as a common issue in healthcare informatics, where disparate systems may not

communicate effectively with each other, leading to siloed data and hindered research efforts. The limitations of usability caused by the interoperability problem were explained by a participant in the following way:

So even in the facilities that we work with, for instance, for research, usually, they use different kinds of systems, and getting data, in the right format for you to be able to understand and use it for research, is a challenge. Even, the availability and the usability of the systems in each of the facilities is, also a challenge, because doctors face a lot of challenges trying to use the medical record systems, where they have a lot of usability issues, a lot of difficulty in trying to especially classify and represent the patient data in the right diagnosis. Those things really have questions that would come, from the doctors, for us to be able to solve it for them. (Interviewee #3, October 22, 2024, virtual interview, Ethiopia, interviewed by the researcher)

The interviewee criticised the lack of usability of medical record systems. The quote shows irritation. The interviewee speaks to a situation in which doctors and healthcare professionals often find these systems cumbersome and difficult to use, which can lead to inefficiencies in patient care and data management. The challenges faced by doctors in the data handling of patient medical records suggest a lack of integration with clinical workflows. This points to systems not being designed with the end-user in mind. Such systems can disrupt, rather than enhance, clinical processes. Subsequently, frustration among healthcare providers and potential errors in patient data management may make a situation worse. Poor usability can result in the misclassification of patient data and inaccurate diagnoses, which are critical for both clinical practice and research.

The interviewee also pointed out that the availability and usability of systems varies significantly across facilities. This variability can create inequities in healthcare delivery and research capabilities. Facilities with more advanced and user-friendly systems may have an advantage in terms of data accuracy and research output, while those with outdated or poorly designed systems may struggle.

The interviewee also suggested that the difficulties in data formatting and system usability directly impact on the quality and efficiency of using the data for research. Researchers rely on accurate and accessible data to draw meaningful conclusions. When data is hard to obtain or use, and their quality is disputable, this not only affects the

use of the data at the point of care, but slows down research progress as well.

The problem of legacy systems

A participant explained how the current system was disconnected from the District Health Information System (DHIS) that applies in the country and is often centralised by the government. The perception is that the aggregate patient data were sent to the government, without giving the health facilities any benefit from the data that was provided.

> *The DHIS2, it is really a centralised system that is based at the ministry, and most use the technologies that are there. So, for us, we wanted to see if we can adopt the federated data infrastructure and also contemporary data management, adopting the data management principles and making the data from care to be available for research.* (Interviewee #3, October 22, 2024, virtual interview, Ethiopia, interviewed by the researcher)

The interviewee highlights that DHIS2 systems are centralised and based at the ministry level. Centralised systems have the advantage of providing a single point of control and management, but they can also be inflexible and may not adequately address the diverse needs of different healthcare facilities and regions.

In the quote, the phrase "technologies that are there" suggests that these systems rely on outdated or legacy technologies. This can lead to inefficiencies, compatibility issues, and a lack of advanced features crucial for modern healthcare data management and research.

The interviewee expresses a desire to adopt a federated data infrastructure. Federated systems allow for decentralised data management, while still enabling data sharing and interoperability. This approach can provide more flexibility and scalability, allowing different facilities to manage their data locally, while still contributing to a broader research ecosystem.

The emphasis on adopting contemporary data management principles indicates a recognition of the need to modernise healthcare data systems. Contemporary data management practices often include the use of advanced analytics, machine learning, and real-time data processing, which can significantly enhance the quality and usability of healthcare data.

The interviewee stressed the importance of making data from patient care available for research. This discussion highlights the dual purpose of healthcare data: to support clinical decision-making and for this data to inform research that can improve healthcare outcomes. The interviewee stressed the need to bridge the gap between clinical care and research. By making data from patient care available for research, healthcare systems can foster a more integrated approach to improving patient outcomes. This integration can lead to more evidence-based practices and innovations in healthcare delivery.

The interviewee's quote reflects a critical assessment of the current systems for managing healthcare data, which are centralised and legacy-based. It advocates for a shift toward federated data infrastructures and contemporary data management principles to enhance data availability and usability for research. This transition is deemed necessary for improving the integration of clinical care and research, ultimately leading to better healthcare outcomes.

Localisation

The need for localisation of solutions to enhance data ownership and data control was often mentioned in the interviews. One interviewee explained that data handling methods used by DHIS2 did not provide any concrete results for clinical practice at the point of care:

> *The reporting system, DHIS2, is being used to do what they call one plan, one report, and one budget and try to optimise and see, and do the planning based on, the data from there. But I think there is not much evidence that the different health information systems are bringing health outcomes.* (Interviewee #3, October 22, 2024, virtual interview, Ethiopia, interviewed by the researcher)

This quote provides insights into the use of the DHIS2 reporting system and its role in health planning and budgeting, while also highlighting concerns about the impact of health information systems on health outcomes.

The interviewee mentioned that DHIS2 is used to implement a unified approach to planning, reporting, and budgeting, often referred to as "one plan, one report, one budget". This approach aims to streamline health data management by integrating these processes into a single system. DHIS2 is designed to collect, visualise, and analyse health data, making it a critical tool for health management information systems (HMIS) in many countries. DHIS2 is not

immediately used for insights at the local level produced in local health facilities and does not generate insights in the health facilities themselves. Therefore, the data, produced in the health facility in this way, does not bring value to the care service for patients.

The DHIS2 system is used to optimise planning based on the data it collects. This data-driven approach is essential for informed decision-making and resource allocation. The ability to generate reports and analyses from DHIS2 data allows stakeholders to track key health indicators and make evidence-based plans. However, despite the potential benefits of DHIS2, the interviewee expressed scepticism about the actual impact of health information systems on health outcomes. The phrase "there is not much evidence" indicates the interviewee believes there is insufficient evidence that the DHIS2 leads to improved health outcomes. This conclusion could be due to several factors, including the complexity of health systems, the low quality of the aggregate data collected, the variability in data quality, and the challenges of attributing health improvements directly to information systems.

The quote underscores the need for comprehensive evaluations of health information systems like DHIS2. While these systems offer powerful tools for data management and analysis, their ultimate value lies in their ability to improve health outcomes. The interviewee's comments also imply that there is room for improvement on how DHIS2 and other health information systems are implemented and used.

Another interviewee also speaks to the challenge of DHIS2, referred to as a 'donor-driven system'. This highlights the severe tension between external funding priorities dictating the use of DHIS2, and local needs. The interviewee states:

> *And most of the donors that want to implement any digital health; want aggregated data. So most of the implementations are, some systems that capture those statistical data for national and international consumption, but not helping the clinician in his or her day to day.* (Interviewee #2, August 28, 2024, face-to-face interview, Leiden, interviewed by the researcher)

This quote highlights a significant disconnect between the priorities of donors implementing digital health initiatives and the practical needs of clinicians on the ground. Referring to 'donor priorities', the

phrase 'most of the donors that want to implement any digital health, they want aggregated data' indicates that, according to the interviewee, it is the donors who are primarily interested in collecting and utilising aggregated data. It is the donors who are driving systems that produce aggregate data. This is relevant for high-level insights to guide national and international health strategies, but not for practical insights for health workers at the point of care.

The interviewee suggests that the systems implemented are designed to capture aggregate statistical data for consumption at the national and international levels, and not for the local level. This suggests that the primary beneficiaries of digital data management systems are policymakers, researchers, and global health organisations, who use aggregated data to track progress, allocate resources, and make informed decisions, but not the patients, whose data is collected.

The phrase "not helping the clinician in his or her day-to-day" underscores a critical gap in the current approach to collecting aggregate data for digital health.

The interviewee speaks to a disconnect between the goals of donors and the needs of clinicians. The suggestion highlights a potential misalignment in the priorities of data handling initiatives. Donors are focused on broad, population-level data that can inform policy and programmatic decisions, while clinicians need tools and data that support individual patient care. This misalignment can lead to frustration among healthcare providers and may hinder the adoption and effective use of patient data management systems. This lack of interest may also negatively affect the quality and reliability of the data input in the system.

An observation was made in passing that:

> *The head of the ward passes in all the rooms to collect the day's aggregates at midnight in the DHIS2 template, the end of the day when these need to be reported, and everyone is tired. These are not reliable figures. And no one can check them, so it doesn't matter.* (Interviewee #3, August 28, 2024, face-to-face interview, Leiden, interviewed by the researcher)

The quote highlights significant issues with the current process of collecting and reporting aggregated data in a healthcare setting using the DHIS2 template. The timing of data collection, staff fatigue, and

the lack of verification mechanisms all contribute to the unreliability of the data. As the data is irrelevant to the clinical decision-making by the healthcare workers, there is little if any stake in the quality of the data.

The problem of data not being relevant locally was also expressed by this participant:

> *So the experience of Ebola informed the COVID research. And so we wanted to make sure that health facilities had the equipment to be able to, first of all, keep [digital] records. And also keep data locally.* (Interviewee #5, August 27 2024, face-to-face interview, Leiden, interviewed by the researcher)

The sentence "the experience of Ebola informed the COVID research" indicates that the interviewee makes the connection between lessons that could be learned from how the 2014 Ebola outbreak in Liberia was handled and how the lessons were applied to the response and research efforts for COVID-19 by VODAN.

The lessons to be learned according to the respondent relate to the recognition of the importance of digital records and local data management in health facilities. The Ebola outbreak highlighted the need for robust data collection and management systems to track and respond to infectious diseases effectively. The records are a critical element of what has been missing, this respondent suggests, an emphasis on ensuring that health facilities have the equipment to keep digital records. The digitisation of records is necessary for tracking patient data, monitoring disease trends, and facilitating real-time data sharing and analysis. This is particularly important in the context of infectious disease outbreaks, such as Ebola, where timely and accurate data is essential for effective response strategies.

The respondent emphasises the need to "keep data locally", highlighting the importance of the management of the patient data locally. The emphasis on the 'localisation' of the patient data highlights the problem that data must be readily available and accessible at the point of care to enable healthcare providers to make informed decisions quickly.

The respondent highlights the common problem between the 2014 Ebola experience and the 2020 COVID-19 pandemic outbreak; both crises highlighted the problem of the lack of digital record-keeping

and local data management in health facilities. The quote suggests that the relevance of this problem was realized by the respondent by participating in the VODAN research, which focused on patient record keeping in local health facilities.

<u>Fragmentation and lack of interoperability to handle variability in health records keeping</u>

Patient health data record systems shows a wide variety of variables being considered. The participants recognised the absence of interoperability in managing the diverse range of health information systems for analysis. The problem that was most often addressed by all respondents was the lack of interoperability causing digital health system fragmentation:

> *One is the interoperability issue, data visualisation issue, data quality issue, and silos of data databases, which have no interaction among themselves among the database.* (Interviewee #1, August 26, 2024, face-to-face interview, Leiden, interviewed by the researcher)

The essential point made by the interviewee in this quote is that there are multiple, interrelated challenges in managing and using health data effectively, which all centre around the lack of interoperability of health patient data. Specifically, the respondent highlights four key issues.

Firstly, the respondent highlights that different health data systems often struggle to communicate and exchange data seamlessly. This lack of interoperability hinders the integration of data from various sources, making it difficult to obtain a comprehensive view of patient health or public health trends. This problem is referred to as an interoperability issue.

The interviewee also points out problems with data visualisation, which is crucial for making data accessible and understandable to stakeholders. Effective data visualisation tools are needed to transform raw data into meaningful insights that can inform decision-making. The lack of data visualisation is connected by the participant to the localisation issue; the health patient data is not available for visualised insights within the health facility.

As other respondents do, this interviewee also refers to the problem of the quality of health data as a significant concern. The problem of

poor data quality, including inaccuracies, incompleteness, and inconsistencies, can lead to unreliable analyses and misinformed decisions. Ensuring high-quality data is essential for accurate reporting and effective use of health information. While the respondent stresses the problem of interoperability, the list of problems provided suggests that the respondent realises that the problem of data reliability precedes the problem of data interoperability and data visualisation.

The interviewee further mentions the problem of data silos, where databases operate independently without interaction or integration. These silos prevent data from being shared and used across different systems, leading to fragmented information and inefficient data management practices. The interviewee emphasises that addressing the problem of interoperability is linked to data visualisation, data quality, and data silos. The problems are linked in that these are critical for improving the overall management and utilisation of health data.

Policy stream

The policy stream is the dynamic in which the possible available alternatives (solutions) are floating. The issues identified are collaboration and adaptability, interdisciplinary team building, real-life research, interest in discovering new solutions, and engagement with stakeholders.

<u>Collaboration and adaptability</u>

A participant explained the value of the collaborations as follows:

> *I think the solution is coming out from the experience of using CEDAR, then we tried out with Stanford University, even Leiden University. But now we are arriving at a solution where we say, can VODAN now direct the process of developing its own application because the other application seems not to work to what the research question is about. Because we are trying to see that when you go to a hospital, data should be owned locally.* (Interviewee #5, August 27, 2024, Face-to-face interview, Leiden)

A participant emphasised the importance of demonstrating impact rather than relying on external support:

> *Good ideas must be translated into action. If we showcase our capabilities, funding will follow. Sitting idly and asking for resources without proving our value does not*

generate innovation. (Interviewee #5, August 27, 2024, face-to-face interview, Leiden)

This interviewee emphasises that innovation requires action; ideas must be implemented and tested in the real world. This reflects a mind-set of measuring alternative solutions by execution, rather than theoretical potential.

The statement "sitting idly and asking for resources without proving our value does not generate innovation" can be interpreted as a critique of entitlement and dependency. It suggests that simply requesting funding without showing tangible results is ineffective and does not contribute to innovation. The underlying message is that the creation of alternative solutions depends on a mind-set that accepts it and is realised only through effort, experimentation, and proof of concept. The interviewee's comments align with entrepreneurial and research-driven approaches, reflecting a self-sustaining mode of innovation, where progress, rather than persuasion, secures funding.

The alternative solution considered can be generated by ensuring that these are adapted to the local context in a way that is suitable for practical implementation in the health facilities.

> *But I have only good ideas. So if my good ideas can turn into gold then you have the gold. But you're sitting at the temple begging, does not make you generate good ideas. So, you don't want to sit in the temple of VODAN asking, give me give me give me, but you're not able to showcase what you're able to do. If we showcase what you're able to do, money flows. That's our philosophy". "I think the solution is coming from, the experience of using CEDAR, then we tried out with Stanford University, even Leiden University. But now we are arriving at a solution where we say, can VODAN now direct the process of developing the application because the other applications seem not to work to resolve what the research question is about. Because we are trying to see that, when you go to a hospital, data should be owned locally.* (Interviewee #5, August 27, 2024, direct interview, Leiden, interviewed by the researcher)*

Along with talking about how important collaboration is, participants also say they are becoming more aware of how important data standards are and how important it is for people from different fields to work together when the country coordinators think about how to find problems and use FAIR-based technology. The implementation process enhances the knowledge of data standards both for the country coordinators and the stakeholders.

Participants agreed that the future leader involved in the project needs to learn from past and ongoing projects and adapt to evolving technologies. Although the current process already involves the various stakeholders, it should be continued, as showing tangible benefits is key to proposing a solution.

Interdisciplinary team-building

Beyond stakeholder collaboration, participants highlighted the increasing awareness of data standards and the benefits of multidisciplinary interaction. Country coordinators emphasised how the process of problem identification and FAIR-based technology implementation enhanced both their own understanding and that of stakeholders. Participants underscored the value of working with diverse groups, including academia and information communication technology (ICT) professionals, to refine solutions:

> *Coming from academia, I've always been open to new knowledge. Working with ICT experts has been enlightening, as they bring engineering expertise that enhances our solutions. This multidisciplinary collaboration is invaluable.* (Interviewee #5, August 27, 2024, Face-to-face interview, Leiden)

This quote highlights three key themes to the generation of alternatives to tackle the problem identified and discovered. These themes are (i) openness to knowledge, (ii) the value of multidisciplinary collaboration, and (iii) the role of engineering expertise in problem-solving.

The interviewee emphasised that the academic background as a researcher had instilled a continuous openness to learning. This reflected an understanding of the foundational principle of academia, the engagement with new ideas, theories, and methodologies. It suggests that being adaptable and receptive to new insights is crucial in innovation and problem-solving.

The phrase "working with ICT experts has been enlightening" indicates that collaboration with professionals from different fields has broadened the interviewee's understanding. The use of 'enlightening' suggests that this experience has been a game-changer, that it has provided new perspectives and perhaps new alternative solutions that would not have been possible to create within one single discipline. This aligns with the broader principle that complex

or 'wicked' problems, especially in fields like health data management, require input from multiple domains.

The interviewee's acknowledgment of the specific contributions of ICT experts, stating that "they bring engineering expertise that enhances our solutions", highlights the relevance of including practical application of technical knowledge in refining and implementing effective solutions. The phrase "enhances our solutions" implies that while academic research provides theoretical foundations, the integration of engineering expertise makes these ideas more functional and applicable in real-world scenarios.

The interviewee's statement that "this multidisciplinary collaboration is invaluable" reinforces the idea expressed that cross-sector engagement contributed to the exploration of alternative solutions. By referring to it as 'invaluable', the speaker underscores that such collaboration is not just beneficial, but essential. This suggests that the integration of different areas of expertise (academic knowledge, ICT skills, and engineering solutions) leads to more effective, well-rounded outcomes.

The participant suggests that there is a need for better collaboration between researchers and clinicians to address all these challenges. Doctors and researchers often have questions and issues that require technical solutions. This highlights the importance of interdisciplinary collaboration in improving healthcare systems and research methodologies. The importance of multidisciplinary teams to generate new solutions was strongly suggested in the testimony of this participant:

> *The ICT experts Mhmm. The data stewards, data clerks Mhmm. Health records officers together to discuss how to develop this pipeline of data flow. And I think, where we are now, we should be able to achieve that because we are assembled here, for example, in Leiden University. Mhmm.* (Interviewee #5, August 27 2024, face-to-face interview, Leiden, interviewed by the researcher)

Another participant also suggested that the alternatives considered for solutions should balance technical and academic elements.

> *I'm very lucky. First of all, coming from academia, you're always open to new knowledge. That was able to interact with you guys who are very good in ICT. And you're already developing a concept to find a solution. The engineers have also added value to it. That you can have an ICT expert, professional, work with the ICT*

engineers, then you're actually with the hard engineering. All to working together. (Interviewee #5, August 27, 2024, direct interview, Leiden, interviewed by researcher)

This participant highlighted the necessity of breaking silos—academic researchers, ICT professionals, and engineers must collaborate to create practical, impactful innovations. This reinforces the applied nature of technology development, where real-world problem-solving relies on integrating knowledge from different disciplines.

<u>Real-life research</u>

The theme of combining technical and academic approaches emerged regularly, extending to an appreciation of implementation research implemented in real-life. One participant explained it in the following way:

So we need to think of some kind of a prototype that if we have this concept, put it in our system, we're able to see these results. So the testing out was very important that different stakeholders involved are able to see the flow of the problem, the concept, conceptualisation Mhmm. To actualisation. So there is a flow of knowledge that requires more research and involvement of the stakeholders. (Interviewee #5, August 27, 2024, face-to-face interview, Leiden, interviewed by the researcher)

The participant highlighted the importance of prototyping, iterative testing, stakeholder involvement, and the transition from concept to implementation. The interviewee sees prototyping as a critical step in translating ideas into practical solutions. This methodology allows the testing of alternative solutions within a real-world system, which is essential for validating an idea. An approach that involves stakeholder involvement ensures that the problem is well understood, the concept is refined, and the implementation of solutions is practical and tested.

The statement that "different stakeholders involved are able to see that flow of the problem, the concept, conceptualisation… to actualisation" suggests a structured progression in development involving the identification of the problem, the conceptualisation of a solution, the translation into a prototype for testing and validation, concluded with actual implementation. This aligns with design thinking and iterative innovation, where feedback loops drive improvement.

The statement "there is a flow of knowledge that requires more research and involvement of the stakeholders" reinforces the idea that knowledge development is an ongoing process. It suggests that stakeholder input is essential for refining solutions, ensuring that innovations are contextually relevant and effective.

The emphasis on collaborative development suggests that innovation is not a solitary process, but requires the engagement of multiple actors, including those involved in real-life processes. Another participant echoed this sentiment:

> *So they expect me to support my argument or my, you know, my, dialogue, supported by evidence. And evidence caps, comes from actual implementation. Like, yes, I can talk about what's available in the literature, the concepts in the literatures, but that's not enough to convince. So showing from real experience, from real implementation is what is needed.* (Interviewee #4, September 27, 2024, virtual interview, Ethiopia, interviewed by the researcher)

This participant underlined the importance of evidence-based argumentation, the gap between theory and practice, and the necessity of real-world implementation for credibility. This approach demands substantiation, where claims must be backed by tangible proof rather than theoretical assumptions. This aligns with a pragmatic, results-driven mind-set, where decision-makers prioritise demonstrable outcomes over abstract models. The interviewee highlights the importance of practical application, pilot testing, and case studies as stronger forms of evidence than theoretical discussions. The statement implies that action and experimentation play a crucial role in validating ideas and influencing stakeholders.

The strategy to point to experiences resulting from research in real life is used by the country coordinators to demonstrate tangible benefits of the proposed solution.

Interest in discovering new solutions

While the problem with current patient data handling systems lacking localisation of patient records was clearly expressed by the interviewees, the interest in exploring alternatives to solve the problem also emerged. A respondent explained the participants in the VODAN research felt eagerness when they were introduced to the possibility of collaborating towards an alternative system:

But now when they understood VODAN, they were so curious. Oh, Oh, I think this is unique. We need to be involved. To start understanding the problem, the concept, the application, where the gaps are. Then together, we think of a new way of making sure that it's localised, produced, and owned by the local customer. (Interviewee #5, August 27 2024, face-to-face interview, Leiden, interviewed by the researcher)

This interviewee provides insights into the positive reception and potential impact of the VODAN research initiative, highlighting the shift in understanding and enthusiasm among stakeholders. The use of phrases like "they were so curious" and "Oh, oh, I think this is unique" indicates a strong initial interest and excitement about VODAN. This enthusiasm suggests that stakeholders recognise the novelty and potential value of the initiative, which aimed to create a network for sharing and analysing data related to infectious diseases and pandemic outbreaks.

The stakeholders' reaction underscores the perceived importance of VODAN. The phrase "We need to be involved" indicates a sense of urgency and commitment. This recognition seems to demonstrate an understanding that effective data sharing and analysis are crucial for managing disease outbreaks and improving public health responses at the point of care.

The interviewee emphasised the importance of understanding the problem, concept, and application of solutions proposed by the VODAN research group. This involves grasping the specific challenges related to data sharing, interoperability, and analysis in the context of viral outbreaks. The stakeholders' curiosity suggests a willingness to understand these complex issues, find solutions for them and learn how these potential solutions can be advanced.

The mention of identifying "where the gaps are" highlights a proactive approach to addressing the limitations and challenges in the current data ecosystem. This could include technical gaps, such as the lack of interoperability between different data systems, as well as organisational gaps, such as the need for better coordination and collaboration among stakeholders.

The phrase "together, together, we think of a new way" emphasises the importance of co-creation and collaboration in addressing these gaps. This collaborative approach is perceived as essential for

developing innovative solutions that are both effective and sustainable. The emphasis on ensuring that the solution is "localised, produced, and owned by the local customer" again highlights the importance of local relevance and ownership. This approach ensures that the solutions developed are tailored to the specific needs and contexts of the local communities, making them more effective and sustainable. Local ownership also promotes a sense of responsibility and commitment among stakeholders, which is crucial for the long-term sustainability of the initiatives emerging from the VODAN research.

The interviewee implied that a focus on local production and ownership has implications for control over the data and creates interest in the value of the data. By involving local stakeholders in the development and implementation, the initiative can empower them to take ownership of the data and the solutions developed. This empowerment is good for building local capacity, which can ensure the initiatives can be successfully rooted in the local context.

The phrase "a new way of making sure" suggests a willingness and dedication to innovate and explore new approaches. This openness to innovation is crucial for addressing the complex and evolving challenges related to viral outbreaks. It also reflects that the VODAN research group is seen as being dynamic.

The interviewee expressed enthusiasm, curiosity, and commitment towards the VODAN research initiative. The interviewee identified specifically the importance of understanding the problem. The solution is also addressed in a collaboration to develop localised and innovative solutions. The emphasis on local ownership and empowerment is perceived as crucial for the sustainability and effectiveness of the initiative in managing diseases and improving clinical health responses.

Nigeria's participants highlighted the problem of a lack of data storage facilities and the absence of backup procedures among the data stewards. This caused the interviewee to be concerned about the solidity of the implementation process of the available solutions:

> Could just get corrupted because of the incident, and that will lead to loss of data. Or at least the man-hour that was used to enter those data or records. And, hence,

I've also been an advocate that while we seek to adopt the technology, we have to do it in phases. A phase where we do it together with manual processing, meaning they calculate and slant data on their paper and sheet while they enter this data on the system later in case there are issues like that. (Interviewee #7, November 15, 2024, virtual interview, Dublin, interviewed by the researcher)

The potential solutions required a phased approach, according to this participant, making sure that the implementation was accompanied by a robust data validation process, and ensuring that integration with other health systems was available. The interviewee also emphasised the need to ensure that the data collected is both accurate and actionable.

The interviewees agree on the need for digital patient data management solutions that bridge the gap between aggregated data and clinical utility. They are excited that this could evolve into systems that not only collect and analyse aggregated data, but also provide clinicians with access to detailed, granular patient-specific information. Such integrated solutions would support both macro-level decision-making and day-to-day clinical practice.

It is also clear from the interviewees that digital patient data currently lacks impact on patient care due to the lack of clinical utility in current digital health implementations. The problem is identified in the importance of designing digital health systems that are clinician-centric and patient-focused.

Engagement with stakeholders

Most of the participants explained that involving health facilities in identifying and co-creating a suitable solution offered stakeholders a clear perception of what it was that needed to be changed. In this process, two elements were highlighted, the need for education of stakeholders on the potential benefits of quality data for improved health outcomes at point of care; and the need to change the priorities among policymakers to ensure data utility. This engagement was a response to the problem of aggregated reporting, such as in DHIS2, which the interviewees highlighted is not suitable for health workers. This is also a response to visualisation of the data not being available in most of the health facilities.

The interviewees stressed the point that patient data needs to have actionable insight that helps their decision-making to improve the

health services to the patients. This engagement represents the initiation of a systemic transformation. The interviewees explicitly articulated that a significantly enhanced approach to patient data management would enable healthcare facilities to harness better health outcomes as a result of producing the digital patient data.

Political stream

National events and trends play a role in shaping what is high on the policy agenda for policymakers. The COVID-19 pandemic revealed the importance of digital tools for tracking and managing health crises.

> *The policies remain sometimes in draft form. They have the willingness. They have the spirit, but the politics, especially financial politics, you know, in terms of you have given us this policy, so we have to have an implementation framework. Therefore, there has to be a budget that supports it. Yet governments are struggling with mobilising resources. So they prioritise security. They prioritise, you know, even health, but maybe primary health care, maybe mother and child health care, without the entire burden of health care. But the good thing is that, somehow, they bring on board non-governmental agencies that can support, the process itself, and also stakeholder engagement.* (Interviewee #9, December 7, 2024, virtual interview, Kampala, interviewed by the researcher)

This participant highlights the gap between policy drafting and implementation, financial constraints, government prioritisation, and the role of external stakeholders in bridging these gaps. The interviewee notes that governments prioritise security and primary health care, such as maternal and child health, over comprehensive healthcare reforms. This reflects a strategic, but constrained approach, where pressing and politically visible issues receive funding, while long-term, systemic reforms remain underfunded.

Thus, the policymakers in all countries involved recognise the value of data in governance and decision-making. When discussing the motivation of the policymakers, participants feel policymakers are motivated by accessible, actionable data that informs decisions and addresses urgent challenges.

Another common theme that emerged was the desire to modernise operations and reduce costs. Therefore, the network of the policymakers, such as the local authority and the national authority, is

considered important. The common approach of this phase is to get the support from the leader and then follow it to broader groups.

> *So the motivation comes from top to down because the Ministry of health has prioritised digitisation and data use. Because of this, the policymakers are now aware and motivated to be part of any initiative that could happen in, at the lower level, like, for example, in our hospitality and so on. So they motivate, the motivation has to have to be initiated from the top, from the minister of health.* (Interviewee #1, August 26, 2024, face-to-face interview, Leiden, interviewed by the researcher)

In addition, all the country coordinators suggest extending connections to the other non-governmental organisations (NGOs) or organisations that have a similar initiative is crucial.

Similar to the statement from the problem stream, evidence-based advocacy is seen as the best way to engage with the policymakers and health facilities leadership's expectations.

> *So, by creating awareness and letting them understand what you are doing and align it with the prioritisation of the Ministry of Health. And then these committees or these stakeholders, because they have direct communication with the ministry of health and they influence the ministry of health, they will bring this awareness to the ministry of health so that the Ministry of Health is the one who say go or not to go* (Interviewee #1, August 26 2024, direct interview, Leiden, interviewed by the researcher)

This quote highlights the role of awareness, stakeholder influence, and government decision-making in policy implementation, particularly in the health sector. It suggests that successful policy implementation or technological adoption requires stakeholder engagement and alignment with their priorities. The emphasis on committees and stakeholders highlights the indirect, but crucial role they play in shaping governmental decisions. The approach adopted reflects a bottom-up strategy, where external actors influence policy by ensuring alignment with national goals.

The quote suggests that, ultimately, the Ministry of Health holds the authority to approve or reject proposals ("the Ministry of Health is the one who says go or not to go").

Despite only highlighting the immediate benefit, the participant suggests focusing on long-term goals. The grassroots-driven approach is necessary to gain local insight that will reshape the policy. The specific role of grassroots is in the engagement in informing and

implementing policies. In the process of introducing the proposed solution to the stakeholders, the participants face various challenges such as logistical issues (e.g., connectivity), and managing health workers' expectations regarding new initiatives. The need to bridge to political interests is also expressed by this participant:

> *So, everybody wants to be a part. It's just getting policymakers to buy into it and to put resources into it.* (Interviewee #8, August 28, 2024, face-to-face interview, Leiden, interviewed by the researcher)

When the various problems of lack of data interoperability were raised in Ethiopia by the country coordinator, the policymakers' response focused on addressing data fragmentation and ownership. In addition, all the participants from Ethiopia explained that policymakers themselves have also noted gaps between policy and practice. In Nigeria, the policymakers' response to the problem highlighted the technical and capacity limitations in making health data accessible.

Despite sharing a similar perspective on the motivation of policymakers in supporting digital health data innovation, influencing policymakers to support digital health and inclusive solutions requires a focus on what is relevant to politicians. In Ethiopia, country coordinators focus on centralised initiatives, and workforce development highlighting the importance of systemic and resource-based solutions. In Liberia the emphasis was on gender equity and science, technology, engineering, and mathematics (STEM) education, showcasing the value of leveraging policymaker's based on their political interests.

Policy entrepreneurs

Policy entrepreneurs are individuals or groups that invest their resources to advocate for specific policy solutions. They play a crucial role in bringing together the three streams (problems, policies, and politics) to push a new issue onto the policy agenda, as a result of which the public agenda can change.

The interviews showed three critical ways in which the leadership in the VODAN research engaged with the policy agenda: (i) by engaging with officials in the administration; (ii) by collaborating with ministries of health and (iii) by training.

Engaging with officials in the administration

Demonstrating tangible benefits remains key to gaining broader acceptance and support for FAIR-based solutions. This includes finding a way of explaining the political relevance of the issue. A participant explained the way he approached the conversation with an official:

> *Different applications Mhmm. That are handling digital health data in Kenya. Two hundred and sixty-three. Without interoperability, that's a loss to the Kenyan government.* (Interviewee #5, August 27 2024, face-to-face interview, Leiden, interviewed by the researcher)

In the interaction with the government, the interviewee emphasised the scale of the problem: the mention of "263 different applications handling digital health data in Kenya" underscores the magnitude of the interoperability challenge. The respondent stresses the need for the government to address the fragmentation, which keeps data siloed across numerous systems, undermining preparedness for infectious diseases and leading to inefficiencies and potential data loss. By emphasising the sheer number of applications, the interviewee made a compelling case for the need for a unified approach to data management for the government.

The interviewee identified that "without interoperability, that's a loss to the Kenyan government". This links the problem directly to the issue of economic and operational inefficiencies, which the interviewee presumes to be of interest to the administration. The interviewee expressed the view that officials in the government can be convinced—highlighting the lack of interoperability results in duplicated efforts, increased administrative burdens, and potential errors in data management, which are in the interest of the government to address. Particularly when it is pointed out that these are inefficiencies that translate to financial losses and reduced effectiveness in healthcare delivery, as implied in the sentence. Emphasising the need for collaboration among stakeholders, including healthcare providers, technology vendors, and policymakers, may show the government that addressing interoperability requires a collective effort. This collaborative approach can lead to more sustainable and effective solutions.

The participant from Kenya consistently stated that data ownership should be prioritised to improve facility-level transparency and control and that the solution should be usable in the long term. The interviewee's citation shows an awareness of leverage to convince the government of the relevance and urgency of tackling data interoperability by highlighting the scale of the problem, the economic and operational losses, and the impact on healthcare quality and access.

The reverse strategy was adopted in Ethiopia, where the buy-in at the level of the administration was an important step for adoption by health workers in health facilities:

> *And the addition of the ownership, the localisation, and the regulatory compliance, I think give people the sense that better data management could be done through those principles. And once we have a buy-in at the managerial level, then we try to move to the health workers and those facilities to adopt those.* (Interviewee #3, October 22, 2024, virtual interview, Ethiopia, interviewed by the researcher)

This interviewee's quote shows the interplay between top-down and bottom-up engagement, to align institutional leadership and health workers in digital health transformation efforts.

Advocacy by demonstration

A common theme that returned in the interviews was the role of the participants in advocacy, sometimes referred to by participants as "evidence-based advocacy", or "advocacy through demonstration":

> *Yeah. I think there is a need for a regular, well-planned approach to bring this issue to the attention of the policymakers. But so far, the opportunities we have is, we are implementation researchers. So when we implement any innovation, including the data system, we work with health bureaus or ministries. So through, doing or through demonstrating or through implementing, we got a chance to demonstrate or to show the importance of this.* (Interviewee #4, September 27, 2024, virtual interview, Ethiopia, interviewed by the researcher)

This participant identified three points: (i) the importance of strategic policy engagement, (ii) the role of implementation research as a means of engaging on new ideas with policymakers, and (iii) the power of demonstration in influencing decision-makers. The relevance of ongoing policy engagement aligns with Kingdon (1984), who argues that sustained advocacy ensures that an issue remains

visible until a policy window opens to push it on the public policy agenda.

In the conversations held with government officials, they sometimes offered ideas on how best to approach the situation. This included the idea of convincing the administration through the results of implementation by demonstrating how the VODAN research showed that a difference could be made. A participant reported that he had received the following advice from an official:

> *Why don't you start at the grass roots? Go to two, three health facilities, demonstrate, show us where the problem is, then present to our board. And I tell you, that was an eye opener up to now. That is what we're trying to develop.* (Interviewee #5, August 27, 2024, face-to-face interview, Leiden, interviewed by the researcher)

The advice given was to "start at the grass roots", suggesting a bottom-up approach—to start with healthcare facilities, to understand and address problems from the bottom-up. After gathering first-hand data and insights, the next step advised was to "present [the information gathered from the grass roots] to our board". This implies that the government is receptive to using the findings to inform decision-making at a higher level. The approach implies that ensuring buy-in from all stakeholders, including frontline workers and board members, is crucial for the success of this approach and assumes that this will result in some better definition of the problem, the solution, and the importance of it.

The final sentence "that is what we're trying to develop", indicates that the insights and methods gained from this approach are being integrated into ongoing efforts to improve the healthcare system. The quote emphasises the value of direct observation and engagement with frontline healthcare settings to understand and address issues effectively. It also highlights the importance of a bottom-up approach in identifying and solving problems, rather than relying on top-down directives. The involvement of the board in the process indicates a collaborative approach to decision-making, where bottom-up insights inform higher-level strategies.

The interviewees speak to the relevance of grassroots, hands-on approaches to identifying and addressing problems in healthcare facilities. This highlights the value of first-hand experience and

collaboration in driving meaningful improvements in the healthcare system. All country coordinators emphasised the role of trained professionals (e.g., data stewards, researchers, health professionals) and institutions (e.g., ministries of health, universities) in advocating for digital health.

<u>Training</u>

The participants found that the implementation approach involved informing and training data stewards, who then try the solution and act as ambassadors to promote its adoption.

> *One is this, and the other is we also are involved in training, course materials for the people who are involved in, data collection in the facilities. So in both we try to be involved in both, to elevate the both challenges, along with the stakeholders and Minister of Health.* (Interviewee #1, August 26, 2024, face-to-face interview, Leiden, interviewed by the researcher)

This interviewee discussed the importance of training and capacity building within healthcare facilities. The first focus is on providing training and developing course materials for individuals involved in data collection within healthcare facilities. This suggests a commitment to building the skills and knowledge of health workers and engaging with them in practical ways. The second focus is on engaging with stakeholders, including in the Ministry of Health, to demonstrate challenges in the healthcare system and how these can be addressed. The mention of working "along with the stakeholders and Minister of Health" highlights the importance of collaboration and partnership that involves officials in the administration during the research implementation. It suggests that the efforts of training are not isolated but are part of a broader, coordinated strategy involving key decision-makers and influencers. In some countries, the training involved officials from the ministry as participants so that they also gained an understanding of the power of the innovation created. This also helped build a network of contacts across the Ministry of Health and the trainees from the health facilities. In some cases, the Ministry of Health was most actively involved through the local Bureau of Health, which would report to the Ministry of Health.

Balancing the resources and efforts between training and stakeholder engagement can be challenging. Ensuring that both areas receive adequate attention is crucial. The interviews show that effective

coordination between frontline workers, trainers, stakeholders, and policymakers is essential for the success of this approach. Misalignment or communication gaps can hinder progress.

The interviewees highlight the importance of a comprehensive and collaborative approach to improving healthcare systems. By focusing on both capacity building through training and engagement with stakeholders, the VODAN research group aimed to address the problem from multiple angles. From the experience of the country coordinator in promoting the FAIR-based project as the solution for the problem identified in the health facilities as the VODAN-Africa participant, there are three main points highlighted: collaboration with institutions, adaptability to the local context, and the need for sustainable funding models and government support.

Discussion

Discussion of results

The VODAN research group developed a clear strategy to investigate the issue of data ownership and management in health systems. They engaged multiple stakeholders from various sectors to better understand the problem's core. Central to their findings was the lack of clarity regarding data ownership involving patients, health facilities, and government authorities tasked with protecting sensitive information.

Their research identified key principles for handling data, encapsulated in the framework of Findable, Accessible under well-defined conditions, Interoperable, and Reusable, along with Ownership, Localisation, and Regulatory compliance (FAIR-OLR) (Van Reisen et al., 2023). The emphasis on these principles served to highlight that data should remain with patients and health facilities to enhance care quality. Additionally, they noted that existing solutions, such as the District Health Information Software (DHIS), often fail to address these needs. The study pointed out that centralised analytical and storage systems, especially those located outside the African continent, do not respect data sovereignty and may compromise the integrity and ownership of patient data.

The group adopted a strategy to showcase alternative solutions to the issue of data ownership and management. This approach sparked enthusiasm and curiosity, particularly regarding the transformative potential of retaining patient data within local facilities and countries while still enabling comprehensive investigations across this data. Although it is acknowledged that the MVP implemented by the VODAN Research group served only as a first prototype, its deployment within health facilities demonstrated the capability to generate insights both within individual facilities and across multiple facilities, even those in different countries, while ensuring that the data remained in its original location. This highlighted a crucial new idea: viable alternatives for data handling exist.

The third stream regarding the political climate aligns closely with the observation of digital data as a valuable resource. It emphasises the importance of harnessing this resource to create benefits in the regions and countries where the data is generated. Additionally, there is a strong need to integrate with emerging global policies that focus on personal data protection, and to recognise digital data as a strategic asset. Careful handling of public data, in accordance with FAIR principles, provides the opportunity to ensure that autonomy over data is respected and upheld.

The VODAN Africa research group actively positioned itself as a policy entrepreneur in the agenda-setting process. The interviews reveal a clear understanding of the need to strategically engage ministries and bureaus of health to influence policy discussions. Across all streams, the focus remained on how to effectively interact with officials, reinforcing the group's role in shaping the policy agenda. As policy entrepreneurs, the VODAN Africa research group recognised its relevance in driving change through continuous engagement, targeted advocacy with policymakers, and training initiatives. By demonstrating the potential of alternative approaches to health data management, they not only raised awareness but also showcased how improved practices could lead to better outcomes. Their efforts exemplify the crucial role of policy entrepreneurs in translating technical solutions into actionable policy shifts.

New elements on the public agenda

New ideas enter on the policy agenda, says Kingdon (1984) when three independent streams converge, the problem stream, the recognition of an issue as a policy problem; the policy stream; the availability of feasible alternative solutions; and the politics stream, the political willingness to act. Policy entrepreneurs act as 'couplers', linking these streams (such as a crisis or political shift) opens, increasing the likelihood of policy change. The opening of a policy window, which is time-bound, is the moment when new ideas can emerge and find their way to the public agenda.

Ogeto et al. (2020) found that Kenya was leading the policy in the African region, setting an agenda for a regional framework focused on inequalities in health access and requiring action for the inclusion of vulnerable people, paving the way for implementation by the WHO Regional Office for Africa (AFRO) in 2013 on considering how the policy in Kenya could be implemented broadly in African countries. Meanwhile, how such policies translate to implementation remains challenging and this may explain the strong advice given to the VODAN Africa group that Implementation Research was an important starting point for convincing stakeholders in the health facilities as well as in the administration. The research confirms the role of Kenya in health policy in advancing new ideas onto the policy agenda, not only in Kenya but with impact on priorities in multiple African countries. The positive uptake of the Health in All Policies (HiAP) as an approach towards public policies in health relating across sectors to understand health system implications of decisions, on population health and health equity may have provided a good foundation for new issues brought to the agenda, as the VODAN Research group did. The Kenya Digital Health Act No 15 (2023) identified that "health data is a strategic national asset" (art. 4a) and "establish a system of shareable and portable personal health records, based on best practices and standards" (art. 6d) in line with the key concerns brought by the VODAN Research group.

In Uganda equally, the implementation framework was changed recently in 2025 with an instruction by the Ministry of Health that health facilities should incorporate Electronic Medical Records systems. This policy is consistent with the trend to ensure that digital

data records of patients should first help health workers in health facilities make better decisions for their patients. In 2025, Open EMR Uganda was being installed in 1400 facilities (Uganda EMR, u.d.) https://emrportal.mets.or.ug/about-emr/), supported by among others WHO and the German government as per decision in 2024 (WHO, 2024).

In Ethiopia the interoperability of health data also moved up onto the policy agenda; the National Data Management Center for Health (NDMC) at the Ethiopian Public Health Institute (EPHI) is the centre responsible for ensuring evidence utilisation for decision making Federal Ministry of Health (FMoH), utilising visualisation to ensure data is available for decision-making in the country and responding to the political moment created by the COVID crisis that data-led surveillance must be enhanced:

> *Infectious disease real-time analytics and modelling for rapid characterisation, identification, estimation, and projection of disease parameters. Estimating and presenting the magnitude of the disease, disease severity and mortality differential across demographic groups of infectious diseases have significant input for prevention and control plans, and response actions. For instance, in the case of COVID-19 this platform forecasts the possible number of cases, hospitalisation and ICU requirements, and deaths, by considering the implemented set of intervention policies, social interaction characteristics, and socio-economic and biological demography of our country.* (National Data Management Center for Health, u.d.)

Nigeria is equally engaged in a new architecture where the emphasis on digital health is on "Efficient Data Exchange". Enhancing healthcare access and efficiency by enabling electronic medical records (EMR) focusing data exchange systems for medical facilities, with emphasis on the useability of findings for better healthcare decisions in the health facilities for patients' outcomes (Ministry of Health and Social Welfare Nigeria, 2024).

The relevance of narratives: Extending the three-stream model

This chapter examined how the three streams, problem, policy, and political, intersect from the perspective of the country coordinator and the dynamics involved in opening the policy window. It explored the process through which these streams converge and the role of the country coordinator as a policy entrepreneur in facilitating this convergence. Specifically, it highlights how the coordinator reshapes

digital health system solutions through the implementation of FAIR-based principles within the VODAN-Africa research projects, with the result of driving policy change.

The outcome of this research is particularly relevant in policy advocacy, technology adoption, and FAIR data implementation, where proof of concept and real-world use cases drive acceptance. It reflects a growing shift toward empirical validation, ensuring that solutions are not just theoretically sound but practically effective, in line with what was needed according to Stocker et al (2022). In digital health and data governance, this thinking aligns with the necessity of pilot programmes, prototype testing, and stakeholder engagement before full-scale implementation.
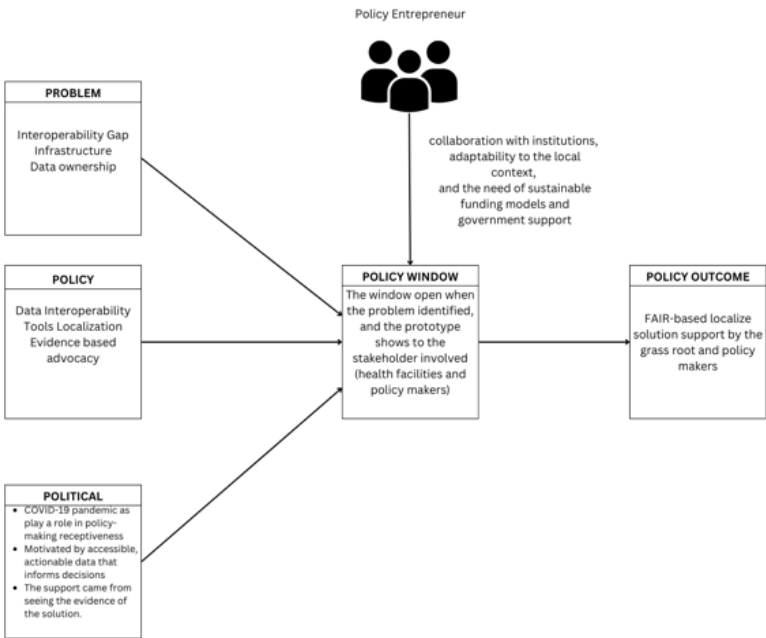

Figure 1. The dynamics of the policy window process

The findings confirm a trend in research and technological development: interdisciplinary collaboration as a driver of innovation. In sectors like health data management, combining academic research, engineering, and ICT expertise leads to scalable, practical solutions. It also highlights the importance of bridging gaps between

theoretical knowledge and practical application, reinforcing that innovation thrives when disciplines work together rather than in silos.

The country coordinators played a pivotal role in identifying the strategy forward. At the grassroots level, country coordinators systematically identified pressing issues such as interoperability challenges, infrastructural gaps, and the lack of data ownership. These problems were validated through local evidence and direct observations from health facilities. The emerging issues were effectively communicated at every stage of implementation, ensuring that both local and national stakeholders fully comprehended the severity and impact of these challenges.

Investigating how community health workers in India are driving policy changes, Santosh and Kane (2023) propose an extension of the Kingdon model by adding a 'narrative stream'. Investigating the policy change associated with the COVID-19 situation, the researchers conclude:

> *Despite being the bottom - most in the health hierarchy are managing to achieve significant policy changes by collaborating with and mobilising various policy actors, producing and maintaining consistent narratives, and by relentlessly pursuing small and large policy windows.* (p. 256)

The findings of the investigation of this study confirm the relevance of consistent narratives and the pursuit of small and large policy windows resulting in changes. In addition to these findings, the current results also suggest that the period before the opening of a policy window engages with the adoption of understanding of what is the problem, whether alternatives are available, and whether this is relevant, at a personal level. The implementation research approach, which the VODAN research group adopted, and the bottom-up approach it undertook on the advice of officials, suggest that the interventions by the research group themselves were part of the change-making. The bottom-up approach allowed the group to form a consistent narrative that has persuasive power in the current political mood in which digital autonomy is valued. This study found that implementation research, in which individuals are given the chance to assess the relevance of an innovation, is a relevant way to impact agenda-setting.

In bottom-up implementation research, the intervention does not directly influence policymakers but rather affects the study participants. However, these participants can act as policy entrepreneurs. With a deliberate strategy, as demonstrated by the VODAN research group, policy entrepreneurs can effectively engage with the public agenda.

This model provides a valuable approach for examining contextual differences in how interventions shape policy outcomes. In parallel to the official policy-agenda, the policy entrepreneurs developed practical, context-specific solutions based on FAIR principles. These solutions were iteratively refined through implementation interventions responding to local situations and shaped by feedback loops, ensuring they addressed the unique realities of each health facility in each context.
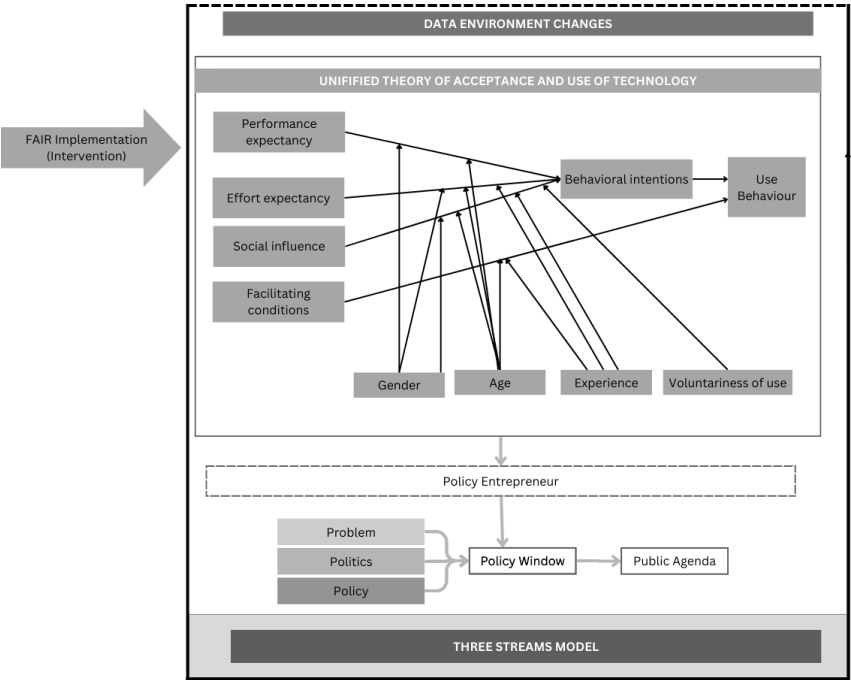

Figure 2. Theoretical framework extending the three-stream model with an intervention in implementation research

Source: Globalization, Accessibility, Innovation and Care (GAIC), 2023

The country coordinators had in common a narrative that the solution should be promoting data ownership of data subjects,

promoting greater control over the data handling to the data controller in greater awareness of the relevance of data sovereignty. This narrative was consistently reinforced in the collaboration with the health facilities. The result was a much better understanding of how the implementation of innovation based on these 'principles' could benefit from the health data processing by making the solution interoperable and adapting to the local context. The policy stream emphasises an exact, evidence-based approach where prototypes and pilot outcomes serve as tangible demonstrations of the solution's potential, thereby building credibility and momentum to propose the solution.

The political context, characterised by factors such as crisis moments such as the COVID-19 pandemic, public opinion, and evolving policy priorities, created an opportune environment for change. Policy entrepreneurs represented by country coordinators were actively engaged with policymakers to align the technical solution with political realities. They forced the timing of external events and internal political shifts to advocate for reforms that enhance digital health management.

When engaging with policymakers, country coordinators, acting as policy entrepreneurs, emphasised evidence-based advocacy to identify suitable solutions. They underscored the importance of fostering understanding at every level of stakeholder engagement. Health facilities needed to comprehend both the problem and the rationale behind the proposed solution. Capacity building within these facilities played a crucial role in raising awareness at the grassroots level. Additionally, showcasing alternative solutions proved to be an effective strategy for enhancing policymakers' understanding and securing their support for new approaches.

The policy window opens when the independent yet interrelated processes in these three streams converge:

- Problem recognition: bottom-up evidence pushes the issue onto the policy agenda, with a clear overarching narrative;
- Viable alternative solutions emerge: tailored, evidence-backed solutions are ready to be deployed and alternatives show viability and responsiveness to contextual differences;

- Political opportunity: the dominant political climate is receptive, often triggered by external events or shifts in public priorities, such as the COVID-19 situation, the adoption of General Data Protection Regulation (GDPR), the African Union Malabo Convention, and FAIR policies affecting the policy environment, and the cycle of policy formulation at national levels.

The policy entrepreneurs play a critical role by acting as a facilitator who can synchronise these streams. They emphasise the dominant narrative, framing the problem stream, they gather and validate local evidence but also support the viability of alternative solutions through strategic, evidence-based advocacy. Their ongoing engagement with stakeholders at all levels ensures that the policy window, once opened, can be used to drive reforms. This dynamic, iterative process highlights that effective policy change is not linear but rather a continuous negotiation among technical, local, and political dimensions, ensuring that the solution remains adaptable, relevant, and sustainable over time.

The agenda-setting narrative for FAIR patient records in maternal health highlights the critical role of structured and interoperable data in improving healthcare outcomes. Maternal health is often compromised by fragmented records, where patient histories are inaccessible across different healthcare facilities, leading to delays in care and misdiagnoses. By implementing FAIR principles, healthcare providers can track maternal health trends, predict complications, and coordinate timely interventions. This data-driven approach has the potential to strengthen health system responsiveness by facilitating evidence-based decision-making and enabling cross-institutional collaboration. Consequently, FAIR patient records not only improve individual maternal health outcomes but also inform broader policy decisions, ensuring that maternal healthcare systems become more resilient and equitable.

Considerations regarding the theoretical framework

Other theoretical frameworks are needed to establish a link between critical events and the adoption of this new framework, such as Soifer's theory of Critical Junctures, to establish historical causations

(2012). Understanding the perception of the linkages between the success or failure of implementation of the VODAN Research could also be better researched with the Critical Incidence technique (Kawu et al., 2025). To understand the adoption of innovations, we could turn to Rogers' Diffusion of Innovations Theory (1962) which explains how new ideas, technologies, or practices spread within a society. Venkatesh theory of Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh et al., 2003), which is based on Ajzen's Theory of Planned Behaviour, accounts better to analyse the individual uptake of innovation (1991).

This research, where we employ the theory of Kingdon (1984) on the three-stream model, allows us to understand the convergence between the understanding of the problem, the availability of alternatives, and how these tie in with the public mood. The theory also allows us to shed light on the role of policy entrepreneurs, which in this research focuses on the participants in the VODAN research group.

Conclusion

This study investigated how the VODAN-Africa research interacted with the public policy agenda and whether the research influenced the policy agenda. Based on in-depth interviews of the team and technical leads, the interaction of the research intervention with the political agenda was analysed, using Kingdon's Three-Stream Model as a theoretical framework.

The findings indicate a deliberate engagement by the study's country coordinators with the problem stream, employing a bottom-up intervention model that maintained a consistent narrative on the importance of data use for improved health outcomes while emphasising ethical considerations of data sovereignty. This narrative proved robust enough to remain relevant across different contextual settings. The bottom-up implementation approach facilitated the emergence of various alternative solutions, reinforcing the notion that viable options existed for addressing data challenges. The political stream was particularly conducive due to the Covid-19 pandemic, which underscored the significance of data for prevention and

surveillance, particularly for the vulnerable group of pregnant women.

The leaders of the VODAN research group actively engaged with officials, incorporating their insights, advocating for data-driven policies, and fostering collaboration through training initiatives. The findings suggest that the leadership of the research initiative functioned as policy entrepreneurs, strategically navigating the three streams to create policy convergence and contributing to the emergence of both incremental and substantial policy windows for agenda-setting.

While the scope of the research does not allow for registering the causal effects of the VODAN research group on the policy agenda, the study contributes to a larger understanding of how intervention studies can lead to an impact on the policy agenda. Intervention studies help to create a persuasive narrative. This research proposes an extension of the Kingdon three-stream model to account for the relation between implementation research and the inclusion of new ideas on the public agenda.

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Authors' Contributions

Putu Hadi Purnama Jati: Conceptualization, methodology, validation, formal analysis; writing including the original draft, visualization. **Mirjam van Reisen**: Supervision and comments on the drafts.

Ethical Considerations

Tilburg University, Research Ethics and Data Management Committee of Tilburg School of Humanities and Digital Sciences REDC#2020/013, June 1, 2020-May 31, 2024, on Social Dynamics of Digital Innovation in remote non-western communities; Uganda National Council for Science and Technology, Reference IS18ES, July 23, 2019-July 23, 2023.

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