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Reinforcing HIV/AIDS Prevention and Control through a Sustainable Data Management System

Argyo Demartoto[1]*, Bhisma Murti[2], and Sri Hilmi Pujihartati[3]

[1,3]Department of Sociology, Faculty of Social and Political Sciences, Universitas Sebelas Maret, Indonesia
[2]Department of Public Health, Universitas Sebelas Maret, Surakarta, Central Java, Indonesia
Email: [1]argyodemartoto_fisip@staff.uns.ac.id, [2]bhisma.murti@staff.uns.ac.id, [3]srihilmi@staff.uns.ac.id

Abstract

The digitalization of healthcare services has significantly improved access to data and information regarding HIV/AIDS patients, thereby enhancing monitoring and evaluation efforts. However, discrepancies in data across various providers can lead to inefficiencies and hinder the formulation of comprehensive HIV/AIDS prevention and control programs. Therefore, integrating sustainability into healthcare service digitalization practices is essential. This research aims to explore the reinforcement of HIV/AIDS prevention and control through a sustainable data management system, using Giddens' structuration theory as the framework. A qualitative research method with an exploratory approach was employed, including data collection through observation, in-depth interviews, Focus Group Discussions (FGD) with key informants, and document processing. The informants included the person responsible for health promotion at the Health Office of Surakarta City, members of the Regional AIDS Commission (KPAD), staff from hospitals and several public health centers (Puskesmas) in Surakarta, field officers, members of the Peer Support Group (KDS), non-governmental organizations (NGOs) involved in HIV/AIDS prevention and control, as well as HIV/AIDS patients and at-risk individuals. The research findings reveal that both people (as the agency) and institutions responsible for health data collection must collaborate to establish a sustainable data system. This collaboration ensures data accuracy and continuity, which, in turn, strengthens HIV/AIDS prevention and control programs. A sustainable data system also supports medication adherence, timely updates on patient information, and various other aspects of HIV/AIDS prevention and control.

Keyword: HIV/AIDS prevention, sustainable data management, healthcare digitalization, structuration theory, health information systems.

1. INTRODUCTION

The Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) pandemic has become a critical global health issue. According to data from the United Nations Joint Program on HIV/AIDS (UNAIDS), as of 2023, there are approximately 39.9 million people living with HIV (PLHIV) worldwide. In Indonesia, as of early 2025, there are around 570,000 PLHIV. In

Surakarta City, the number of people living with HIV/AIDS (PLWHA) increased by 465 cases by the end of 2024 [1]. Monitoring of HIV/AIDS cases in Indonesia is conducted regularly using various strategies, one of which focuses on qualitatively reducing the number of new cases. Alongside this, a combination of prevention and control measures has been implemented, targeting both promotive-preventive and curative-rehabilitative aspects of HIV/AIDS care [2].

The prevention and control of HIV/AIDS face numerous challenges across international, national, local, and individual contexts. One of the major obstacles is the stigma and discrimination against PLWHA, which limits their access to essential healthcare services. Additionally, there is a significant gap in public knowledge about HIV/AIDS, highlighting the need for more widespread information distribution through communication, education, and outreach initiatives. The difficulty in accessing healthcare services and vital information further complicates efforts to successfully prevent and control HIV/AIDS [3][4].

In today's age of rapid technological advancement, digital tools are significantly influencing HIV/AIDS prevention and control. Efforts previously conducted through conventional methods are now being complemented by digital platforms that facilitate greater access to HIV/AIDS-related information. Digital platforms such as health applications, social media, and official websites allow for the swift and widespread dissemination of information. In Indonesia, the HIV/AIDS Information System (Sistem Informasi HIV/AIDS or SIHA), developed by the Ministry of Health, plays a central role in managing data and promoting awareness. In Surakarta City, websites from hospitals, public health centers (Puskesmas), and non-governmental organizations (NGOs) are critical for data collection and health promotion. These websites provide access to online counseling services, health monitoring, and reminders for ARV consumption, offering more personalized and convenient care. Digitalization also enables public participation in educational campaigns and helps reduce stigma against PLWHA through inclusive and interactive communication [5], [6], [7].

Despite the positive impact of digitalization, there are several challenges related to the implementation of technology in HIV/AIDS prevention and control. Technology often collects large volumes of data based on community activities, which is then processed according to the available features. However, digital humanism provides a critical perspective on the development of technology, especially concerning the risks faced by individuals as data producers. Implementing digital tools in HIV/AIDS prevention and control requires careful consideration of privacy, accessibility, and data usage implications. More than just the data from PLWHA, the public, healthcare providers, and other stakeholders must be considered when integrating digital solutions into health practices [8][9].

The digital community faces various challenges, including privacy concerns, inconsistent data, and issues with data processing. One of the primary challenges for the Indonesian government in the digitalization of healthcare is ensuring the consistency and sustainability of data from multiple sources, which can lead to inefficiencies in healthcare delivery [10][11]. To address these challenges, data generated through digital technologies must be processed within a sustainable framework. Building a sustainable data ecosystem requires collaboration among all stakeholders involved in HIV/AIDS prevention and control. If each actor ensures the responsible management of HIV/AIDS data, the overall prevention and control efforts will be strengthened. The concept of structuration, as proposed by Giddens, emphasizes the dynamic interaction between structure and agency, which is relevant to this practice. This research aims to explore how sustainable data management practices can enhance HIV/AIDS prevention and control. In Surakarta City, the Health Office, hospitals, public health centers, the Regional AIDS Commission (KPAD), NGOs, and the Solo Plus Peer Support Group (KDS) use Information and Communication Technology (ICT) to improve HIV/AIDS care in promotive, preventive, curative, and rehabilitative domains [12].

2. METHODS

This research utilized a qualitative research methodology with an exploratory approach [13]. The qualitative approach was chosen for its ability to provide an in-depth understanding of the multifaceted nature of HIV/AIDS prevention and control in Surakarta City. An exploratory approach was ideal for uncovering new insights and gaining a deeper understanding of the challenges, successes, and dynamics of HIV/AIDS care that are not yet fully understood or documented. This approach allows the researcher to explore complex phenomena in a more flexible and open-ended manner, which is crucial for studying a sensitive and evolving issue like HIV/AIDS. Figure 1 is flow of this research.

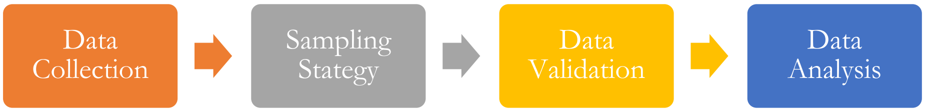

Figure 1. Research Flow

2.1. Data Collection

The data were collected through multiple techniques to ensure a well-rounded and comprehensive analysis of the topic. Observation was used to gather real-time insights into the actual practices and interactions within healthcare settings, particularly hospitals and public health centers (Puskesmas) in Surakarta. This method allowed the researcher to observe how healthcare professionals interact with HIV/AIDS patients, how health education is communicated, and the practical challenges involved in executing HIV/AIDS prevention and control programs. Observing these practices firsthand provided valuable context that complemented the other data collection methods. In addition to observation, in-depth interviews were conducted with key informants, including healthcare professionals, community leaders, members of NGOs, and individuals directly affected by HIV/AIDS. These interviews allowed for the collection of rich, detailed narratives about the experiences, perceptions, and challenges of those involved in or affected by HIV/AIDS prevention and care. The semi-structured format of the interviews provided flexibility for informants to share their perspectives while ensuring that the necessary topics were covered.

The study also used Focus Group Discussions (FGD) to engage various stakeholders in open discussions about HIV/AIDS prevention and control. FGDs brought together different groups, including healthcare workers, local community members, and individuals at risk of HIV/AIDS, creating a collaborative environment where participants could share their thoughts, opinions, and experiences. This method was particularly effective in highlighting group dynamics and identifying areas of agreement or disagreement on key issues related to HIV/AIDS prevention and control. Finally, document processing was used to collect secondary data from existing sources, such as government reports, health records, academic literature, and relevant policy documents. This step helped to contextualize the primary data and provided additional background information on the HIV/AIDS situation in Surakarta. The document review also served to verify the findings from the interviews and FGDs and to understand the broader policy and organizational landscape in which HIV/AIDS prevention efforts take place.

2.2. Sampling Strategy

The selection of informants was carried out using purposive sampling, where individuals were specifically chosen based on their relevance to the research topic. The targeted informants included those directly involved in HIV/AIDS prevention and care, as well as those who could provide critical insights into the challenges and strategies related to HIV/AIDS control. Key informants included the Health Promotion Officer at the Health Office of Surakarta City, who oversees HIV/AIDS programs at the city level; members of the Regional AIDS Commission (KPAD), which is responsible for coordinating HIV/AIDS efforts within the region; and representatives from hospitals and Puskesmas in Surakarta, who are directly involved in patient care and prevention programs. Additionally, field officers, members of the Peer Support Group (KDS), and staff from NGOs working on HIV/AIDS prevention and education were selected for their on-the-ground experience and engagement with communities. The research also sought input from HIV/AIDS patients and individuals at risk, as they could provide firsthand accounts of their experiences and the challenges, they face in accessing care and support.

2.3. Data Validation

To ensure the credibility and reliability of the findings, triangulation was applied to validate the data. Source triangulation involved comparing information from different sources, such as interviews, FGDs, and documents, to check for consistency and accuracy. This process helped to identify common themes and patterns across various data sources. Additionally, method triangulation was used, where different data collection methods (e.g., observation, interviews, FGDs, and document analysis) were employed to cross-check findings and ensure the robustness of the research results. This approach helped mitigate the risk of bias or inaccuracies that might arise from relying on a single method or source of data.

2.4. Data Analysis

Data analysis followed an interactive model, which is an iterative process involving continuous data reduction, data display, and conclusion drawing throughout the study [14]. Data reduction involved organizing the raw data and selecting the most relevant information that addressed the research questions. During this process, unnecessary or redundant data were removed, and key themes or patterns were identified. Data display then involved structuring the reduced data in a manner that facilitated easier interpretation, such as through tables, charts, or narrative summaries. This helped to provide a clear view of the trends and relationships within the data. Finally, conclusion drawing and verification was an ongoing process, where initial interpretations of the data were made and continuously refined through feedback loops, ensuring that the conclusions were grounded in the evidence and aligned with the research objectives. The iterative nature of this analysis allowed for flexibility and the integration of new insights as the study progressed.

3. RESULT AND DISCUSSION

One of the key challenges in the digitalization of healthcare services in Indonesia is the sustainability of information and data provided by online-based websites and platforms. The data needed to inform policy formulation or to devise sustainable strategies for controlling HIV/AIDS often struggles to reach the right target audience in a timely manner. Non-sustainable data can cause significant issues, including inefficiency, by either expanding the scope of the target inappropriately or narrowing it too much, thereby limiting the effectiveness of the program. This lack of consistency in data management can prevent the comprehensive implementation of HIV/AIDS prevention and control programs, reducing their overall impact [15].

The integration of digital systems into HIV/AIDS prevention and control has allowed the use of quantitative data to represent the program's achievements. Commonly tracked metrics include the number of HIV cases, AIDS cases, people living with HIV (PLWH), individuals accessing Antiretroviral (ARV) treatment, HIV/AIDS-related deaths, and more. These data points are essential for determining effective strategies for further HIV/AIDS prevention and control. Furthermore, policymakers and stakeholders rely on this data to develop efficient, appropriate, and comprehensive policies to address the epidemic [16].

However, despite the adoption of digital tools, Indonesia still faces significant issues in the integration of digital information systems, particularly concerning data sustainability across various data-providing institutions. For instance, the data published by the Ministry of Health of the Republic of Indonesia often does not align with the data provided by the Central Bureau of Statistics (BPS). This lack of synchronization makes it difficult to design effective and comprehensive programs. These discrepancies underscore the need for harmonization and standardization of reporting systems across institutions to ensure that the data provided is accurate, reliable, and accountable. Moreover, inter-sector collaboration is critical in ensuring that policies are based on the most up-to-date and valid data available [17].

Another major challenge in managing digital data for HIV/AIDS prevention and control is the sustainability of the data itself. Both health-related and non-health-related institutions are involved in collecting data on HIV/AIDS patients, which is then used to generate quantitative metrics or graphical representations of program achievements. At a macro level, data sustainability is necessary to maintain continuous monitoring and evaluation of programs, allowing for adjustments and improvements until specific targets are met. This is particularly important for long-term program implementation. On a micro scale, individuals accessing ARV treatment also need continuous monitoring to assess the effectiveness of their medication. Information such as phone numbers or active contact details for individuals on ARV regimens is crucial for ensuring they adhere to their medication schedules. In these cases, the technical aspects of digitalization must be harmonized with humanistic considerations, recognizing that the ultimate goal is to achieve better health outcomes for individuals living with HIV/AIDS [18].

Sustainable HIV/AIDS data management involves the coordinated efforts of various stakeholders. The Ministry of Health of the Republic of Indonesia, the Central Bureau of Statistics, the Health Office in each region, and NGOs all play vital roles in collecting and managing patient data. In Surakarta City, key institutions responsible for data collection include the Health Promotion Office, the Regional AIDS Commission (KPAD), hospitals, public health centers (Puskesmas), field officers, the Solo Plus Peer Support Group (KDS), and various local NGOs involved in HIV/AIDS prevention and care. The community members, patients, and ARV users themselves form the agency of this system, as they provide essential data through their participation. However, problems arise when there is a lack of consistency and collaboration between the structures (institutions) and the agencies (individuals). For example, patients and community members, who serve as the producers of data, are often left out of the process of ensuring the sustainability of data. Without the involvement of these agencies, the sustainability of health data collection is jeopardized. Therefore, collaboration between these two elements—structure and agency—is crucial to ensure continuous, accurate, and sustainable health data collection. From the perspective of digital humanism, data collection should not infringe upon the rights of individuals but should instead be seen as a collaborative effort that benefits all parties. Individuals must have authority over their own data, and the process of collecting health data should be respectful of their rights and privacy [19].

For a sustainable data management system to be effective, those involved in data collection, management, and dissemination must possess both technical skills and an understanding of the humanistic aspects of data management. This includes the ethics of data collection, the importance of safeguarding personal information, and the responsible management of data to avoid harm to individuals and communities. To achieve this, institutions responsible for data collection should offer technical training to their staff on best practices for humanistic and sustainable data management. Moreover, collaboration between various stakeholders—government agencies, private sector entities, and community organizations—is essential to ensure the sustainability and accuracy of collected data. Previous research has primarily focused on Mobile Health (mHealth) as a technology that facilitates healthcare services [20, 21, 22, 23, 24]. However, the novelty of this research lies in its emphasis on information and data management in the context of HIV/AIDS prevention and control. By focusing on the humanistic aspects of mHealth practices, this study seeks to critically examine the intersection between technology and human rights. Furthermore, this research supports the idea of collaborative health data usage, which is becoming a model in European countries such as Germany. Countries like Germany have been pioneers in leveraging digital innovation and artificial intelligence (AI) for collaborative health data management at the continental level [25].

This research, using a case study of HIV/AIDS prevention and control in Surakarta, Indonesia, underscores the critical need for a Sustainable Data Management System that seamlessly integrates technical, ethical, and humanistic considerations. By doing so, it aims to enhance the effectiveness, accuracy, and long-term impact of HIV/AIDS programs, ultimately ensuring more equitable and efficient healthcare delivery.

4. CONCLUSION

A sustainable data management system is crucial for strengthening HIV/AIDS prevention and control efforts. Its implementation requires a collaborative approach, bringing together the structural elements represented by institutions such as the Ministry of Health, the Central Bureau of Statistics, the Health Office, NGOs, and other relevant organizations, as well as the agency, which includes community members and patients. These two components are interdependent, working together to ensure continuous, reliable data collection while also addressing the humanistic aspects of healthcare. The practice of healthcare digitalization, particularly in the context of epidemic prevention and control like HIV/AIDS, relies on sustainable data to create effective, comprehensive strategies. Patient data directly influences the accessibility and efficiency of healthcare services, ensuring consistent treatment, timely updates on patient conditions, and, on a larger scale, contributing to the success of HIV/AIDS prevention and control programs. Providing technical training for all stakeholders involved in sustainable data collection will further strengthen these efforts, enhancing the overall impact of HIV/AIDS prevention and control initiatives.

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