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Health information systems in extreme contexts: Using mobile phones to fight AIDS in Uganda

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Abstract

The HIV/AIDS pandemic is a global issue that has unequally affected several countries. Due to the complexity of this condition and the human drama it represents to those most affected by it, several fields have contributed to solving or at least alleviating this situation, and the information systems (IS) field has not been absent from these efforts. With the importance of antiretroviral therapy (ART) as a starting point, several initiatives in the IS field have focused on ways to improve the adherence and effectiveness of this therapy: mobile phone reminders (for pill intake and appointments), and mobile interfaces between patients and health workers are popular contributions. However, many of these solutions have been difficult to implement or deploy in some countries in the Global South, which are among the most affected by this pandemic. This paper presents one such case. Using a case-study approach with an extreme-case selection technique, the paper studies an m-health system for HIV patients in the Kalangala region of Uganda. Using Heeks' design—reality gap model for data analysis, the paper shows that the rich interaction between social context and technology should be considered a central concern when designing or deploying such systems.

KEYWORDS

AIDS, antiretroviral therapy, design-reality gaps, health information systems, HIV, m-health, Uganda

1 | INTRODUCTION

The HIV/AIDS pandemic remains a critical global problem to date. About 38.4 million people worldwide were living with HIV by the end of 2021, most of them located in low- and middle-income countries. The situation is especially critical in Sub-Saharan Africa, home to two-thirds (67%) of people living with HIV. There were more than 1.5 million new infections in 2021, representing the smallest annual decline in new HIV infections since 2016. A total of 51% of these new infections occurred in sub-Saharan Africa, with women and girls accounting for 63% of all new infections. In addition, sub-Saharan Africa accounted for 59% of the 650,000 AIDS-related deaths in 2021 (UNAIDS, 2022). To make things worse, the crises that have shaken the world over the last two years have had a devastating impact on people living with HIV. As a result, the AIDS response has been strained, and communities already at higher risk of contracting HIV are now even more vulnerable, such as sub-Saharan Africa, which

remains the region most affected by HIV. However, efforts continue to be made in the region to address this pandemic in terms of awareness, prevention, testing, care, and treatment, and many countries in the region are expected to reach the 95-95-95[1] targets soon (UNAIDS, 2022).

The importance of achieving these targets lies in the fact that antiretroviral therapy (ART) has transformed this disease into a long-term condition (Cooper et al., 2017), thus highlighting the value of treatment adherence. The latter is understood as the degree to which patients take the medication as prescribed by their healthcare providers (Armitage et al., 2020; Osterberg & Blaschke, 2005). However, treatment adherence remains a significant challenge due to factors, such as poor patient-provider communication (Haskard Zolnierek & Dimatteo, 2009; Ondenge et al., 2017) and forgetfulness (Dowshen et al., 2012; Kalichman et al., 2016). Different interventions to increase adherence to treatment have been studied (Spaan et al., 2020; Whiteley et al., 2021). Although none can improve adherence by itself, it has been suggested that mobile technologies (e.g., phone calls, short message service (SMS)) have the potential to improve treatment adherence in resource-limited settings such as developing and transitional economies (Chib et al., 2012; Cooper et al., 2017; Hirsch-Moverman et al., 2017; Lester et al., 2010; Orr & King, 2015; Siedner et al., 2012). Those technologies offer several features, such as ubiquity, mobility, and flexibility, which make them a suitable alternative to increase patients' adherence to ART.

The results of research using mobile technologies indicate positive outcomes by increasing adherence among HIV patients when using these types of interventions. However, the need to analyze mobile technology interventions (henceforth to be referred to as m-health interventions) among specific communities has also been identified (Catalani et al., 2013; Cooper et al., 2017; Devi et al., 2015; Tufts et al., 2015). To address this gap, the following research question guides this study: What are the technical, organizational, and cultural challenges of m-health interventions based on mobile reminders on HIV treatment adherence in the Global South? To explore this question, the mobile fishing communities of Kalangala, Uganda, which have unique contextual characteristics, are studied. The study is conducted following a single case study methodology (Yin, 2009) using an "extreme" case selection method (Seawright & Gerring, 2008).

The remainder of this article proceeds as follows. Section 2 briefly describes previous research on mobile technologies in HIV treatment adherence. Section 3 presents the research question of this study, while Section 4 focuses on the methodology by presenting the research setting and the theoretical background. Section 5 presents the main findings of this extreme case study, and section 6 discusses the key implications and limitations of this research to conclude the paper.

2 | M-HEALTH APPROACHES TO ART ADHERENCE

Adherence to treatments can be defined as the extent to which patients take medications as prescribed by their healthcare providers (Armitage et al., 2020; Osterberg & Blaschke, 2005) and can be analyzed using either process-oriented or outcome-oriented views. An outcome-oriented view uses the result of treatment (e.g., cure rate) to measure success, while a process-oriented view employs intermediate variables (e.g., pill count) to measure adherence (De Geest & Sabaté, 2003). This study adopts a process-oriented view of adherence because a digital intervention alone cannot guarantee a particular treatment outcome, hence discarding an outcome-oriented approach.

As mentioned before, ART has transformed AIDS into a long-term condition (Cooper et al., 2017). However, treatment adherence in HIV patients remains challenging due to several contributing factors, such as poor communication between healthcare providers and patients and forgetfulness (Dowshen et al., 2012; Martin et al., 2005). Poor adherence can bring negative consequences, such as drug resistance, less effective viral suppression, increased risk of HIV transmission, and poor quality of life (Schneider et al., 2004; Shah et al., 2019).

Several interventions can be introduced to improve treatment adherence. Face-to-face interventions require investing resources and time, and it might be difficult for patients to access them (Cooper et al., 2017). Thus, e-health strategies, tools, and services offer an accessible alternative. In particular, the development of mobile devices has enabled m-health interventions seeking to treat health conditions such as AIDS (Nhavoto et al., 2017). These interventions can provide consistent services to a broad population at a low cost (Muessig et al., 2015). Different types of m-health interventions for ART adherence have been studied (e.g., phone calls, use of SMS, and apps) and are briefly described next.

Most interventions are delivered via SMS. These interventions might involve one-way messages—predominantly as reminders—or two-way messages, where participants can respond by confirming adherence or accessing further information (Cooper et al., 2017). Messages tend to be covert, without referring directly to either ART or HIV (Moore et al., 2015; Sabin et al., 2015). Previous research has analyzed SMS in resource-constrained settings such as Kenya, South Africa, and Uganda (Crankshaw et al., 2010; Lester et al., 2010; Mitchell et al., 2011; Pop-Eleches et al., 2011; Rana et al., 2015), highlighting its low cost and accessibility in remote areas (Saberi & Johnson, 2011). In terms of outcomes, SMS reminders have been shown to significantly reduce appointment non-attendance rates, increase medication adherence, and improve physiologic measures such as CD4 count[2] or viral load[3] (Mayer & Fontelo, 2017). Interventions delivered by SMS are acceptable to patients (Cele & Archary, 2019; Cooper et al., 2017), with reported benefits such as being reminded about appointments or medication intake, as well as easier

[1]More than 95% of people living with HIV know their HIV status, more than 95% of people who know their HIV status access treatment, and more than 95% of people on treatment have suppressed viral load.

[2]This is a test to measure the amount of CD4 cells (a type of white blood cell) in the blood.

[3]This is a test to measure the amount of HIV copies in the blood. A successful ART should reduce the viral load in the patient.

access to healthcare support (da Costa et al., 2012; Smillie et al., 2014). However, technical barriers, such as lost phones or chargers and temporary service disconnection (Norton et al., 2014) must be considered. In addition, concerns over privacy and security (e.g., unintentional sharing of health information) must be addressed, especially given that sharing mobile devices is common in African countries (Cele & Archary, 2019; Saberi & Johnson, 2011).

M-health interventions also employ mobile apps. These apps allow participants to record or track their medication intake and access information on HIV and ART using different resources, such as text, video, or games (Horvath et al., 2019; Whiteley et al., 2018). Moreover, interventions with such apps might have the same purpose as the formerly described SMS interventions (e.g., sending messages to participants) but employing other popular apps, such as WhatsApp or Facebook (e.g., Stankievich et al., 2018). Such interventions have been shown to reduce viral load and improve self-reported adherence, as well as symptoms, such as anxiety or neuropathy (Schnall et al., 2018). The interactive features of apps also increase the engagement of participants and their awareness of HIV and the need to comply with ART (Cooper et al., 2017). Mobile apps can be accepted by patients, especially if they are easy to use, support participants, and do not have glitches (Horvath et al., 2019).

Finally, a few interventions employ phone calls. Past research indicates that daily calls help to increase self-reported adherence and reduces viral load (Belzer et al., 2015), as opposed to less frequent calls (e.g., two weekly calls) that do not have an impact on such variables (Huang et al., 2013). Interventions delivered through phone calls elicit positive feedback from participants regarding feeling supported by a facilitator and experiencing an increased motivation to comply with ART (Cooper et al., 2017).

This brief review indicates that past research has found positive outcomes of m-health interventions to increase ART adherence among HIV patients. However, reviews on the subject also highlighted the need to analyze m-health interventions in specific communities (Catalani et al., 2013; Cooper et al., 2017; Devi et al., 2015; Tufts et al., 2015). It is critical to consider the specific characteristics of such communities (e.g., the need to tailor language to different ethnic groups or the usage of text in rural areas versus apps in urban settings) when exploring the effectiveness of such interventions (Cele & Archary, 2019). Therefore, this study approaches an extreme case in Uganda to expand the current knowledge on this kind of intervention and the factors that should be considered while designing such systems.

3 | RESEARCH QUESTION

This research focuses on the effectiveness of e-health interventions, especially mobile phone reminders (m-health), to improve treatment adherence in HIV patients in the Global South. Furthermore, the research is interested in the factors (e.g., technological, social, cultural) that mediate (i.e., improve or hinder) that effectiveness. Since e-health in the Global South is a challenging enterprise (Agarwal et al., 2015; Braa & Sahay, 2004), it is essential to explore what factors are at play in this kind of project, where the challenges come from, and how they can be conceptualized and modeled.

The question of the conceptualization of challenges has been discussed at length by authors such as Heeks (2006). However, there are still open questions about where the challenges come from, how they manifest themselves, and how they develop over time (Masiero, 2016). Furthermore, these challenges are contingent, localized, and tightly bound to local contexts and conditions (Heeks, 2002b). Therefore, each case will pose different challenges that could influence the system's effectiveness. Also, each case is a new opportunity to learn something new about the challenges of e-health in the Global South.

Furthermore, the inherent characteristics of the Global South call for more research on the challenges that can arise in these contexts, especially in regions or communities that deviate from average cases. Only then, the academic community can develop concepts, frameworks, and strategies to address these challenges at least partially. With that in mind, the research question of this research is as follows:

RQ: What are the technical, organizational, and cultural challenges of m-health interventions based on mobile reminders on HIV treatment adherence in the Global South?

4 | METHODOLOGY

Following Blaikie (Blaikie, 2000, p. 60) classification of research questions, the one proposed in this research is a mix between a *what* and a *why* question with objectives linked to *description* and *explanation*. Additionally, the fact that e-health in general, not only in the Global South, is a social phenomenon that cannot be controlled (thus discarding experiment-based methodologies) or predicted (thus ruling out methodologies with a strong positivistic epistemology) leads the researchers to select a case study method. This decision should be followed by three other considerations: the type of case study design to follow, the case selection technique, and the research design and protocol.

Following the classification proposed by Yin (2009) and considering the resources available for this project, this research is limited to a holistic single-case design. In line with the motivations of the research question, this single case was chosen using an "extreme" case selection method.[4]

[4]See Seawright and Gerring (2008) for an in-depth discussion about case selection methods and a comparison between them.

According to Seawright and Gerring (2008, p. 301), "the extreme case method selects a case because of its extreme value on the independent (X) or dependent (Y) variable of interest". The rationale for this selection method is to identify highly unusual cases that could either allow for the discovery of previously ignored independent variables or illustrate previously unstudied interactions between known variables (Seawright, 2016). Furthermore, an extreme case could contribute more to the current literature than a case in an average context when discussing challenges particular to the Global South.

Next, the case will be presented (section 4.1), followed by the research protocol (section 4.2). Finally, section 4.3 will introduce the conceptual framework used for data analysis.

4.1 | Case context

The Kalangala District is located on Lake Victoria in southwestern Uganda. It has an area of 9066.8 km^2, but only 432.1 km^2 (4.8%) is land, while the rest is water. It borders Mpigi district to the north, Mukono to the east, Tanzania to the south, and Masaka and Rakai districts to the west. Kalangala district consists of 84 islands scattered in Lake Victoria, but only 64 have human settlements. The largest island is Bugala, which has an area of 296 km^2. It comprises Bujumba and Kyamuswa counties and seven sub-counties of Mugoye, Bujumba, Kalangala Town Council, Kyamuswa, Mazinga, Bufumira, and Bubeke. To access Kalangala from the mainland, with no bridges linking the islands to the mainland, only two modes of transportation can be used: by water (boat/ferry) and by air. Only Bugala Island is connected to the mainland via ferry to Masaka and Entebbe via ship. In addition, transportation among the islands is complicated and expensive. For example, it takes 4.5 h on average to travel from Bugala Island to Nkose/Lujaabwa Island (if the lake is free of disastrous winds). The remaining islands can only be reached by local private or public boats, so the Kalangala Islands are primarily remote and inaccessible (Bwette, 2014; The New Humanitarian, 2012).

Most of the population is involved in clustered fishing along Lake Victoria's shores. The fishing industry makes an important contribution to the national economic development, estimated at 2.3% of the National Gross Domestic Product (Uganda Bureau of Statistics – UBOS, 2022). It also contributes to food security and household income. Fishing is complemented by farming, with palm oil mainly grown in the sub-counties of Bujumba and Mugoye and Kalangala Town Council (Lubulwa & Chekwech, 2021).

The latest population projection for Uganda indicates that Kalangala has a total population of 69,500, with a female-to-male ratio of 1:3 (Uganda Bureau of Statistics – UBOS, 2022). This ratio could explain why authorities have attributed the spread of HIV/AIDS to men sharing sexual partners (Athman, 2019). Moreover, most reside in rural or isolated fishing areas, making transportation and access to clinical ART services difficult. In addition, several languages are spoken in the region because of the many tribes in Uganda (Uganda Bureau of Statistics – UBOS, 2022), and Kalangala is a composition of almost all ethnicities together with migrant workers/fishermen from the neighboring countries of Congo, Tanzania, Kenya, and Rwanda. The fishermen in these communities are highly mobile, always looking for better fishing grounds. Similarly, sex workers are often highly mobile in search of new markets. Literacy levels vary across the islands, but the fishing population of Kalangala is mostly semi-literate (Bwette, 2014; The New Humanitarian, 2012).

Regarding communication capabilities, the GSM mobile phone network is quite good in Kalangala Town Council. However, the telephone network is usually poor outside this municipality, especially on the other small and remote islands. Some telecom operators[5] have very limited and unreliable network connectivity, while others[6] have none. This issue is related to the higher costs of installing telecommunications network infrastructure towers by telecommunications operators, which are hindered by the geographic terrain and thick vegetation blocking connectivity. In addition, although the possession and usage of mobile phones in Kalangala have been growing over the years, many patients do not have valid contact numbers. Some patients lose their phones and do not replace the old SIM cards; they buy new ones instead since it is cheaper than replacing the lost SIM card.

Furthermore, shared ownership of mobile phones is common (e.g., husband and wife), as not everyone can afford a personal mobile phone (Burrell, 2010). Moreover, out of the 64 islands with settlements, only two (Buggala and Kitobo) have an adequate electric supply, further hindering the use of mobile phones. People rely on solar power on the rest of the islands to charge their phones, while the few that can afford it use generators. Thus, mobile phone users often miss phone calls while the phone is charging.

The advances in the fight against HIV and AIDS between 2010 and 2020 in Uganda are commendable, as it became one of eight countries worldwide to achieve the 90-90-90 target by 2020 (Uganda Aids Commission, 2021), ensuring that 90% of People Living with HIV/AIDS are aware of their HIV-positive status, 90% of those who test HIV positive are on treatment, and 90% of these are virally suppressed. Despite these achievements, the epidemic is still widespread, and Kalangala district remains the most affected, with the highest prevalence rate of 18%, compared to the national rate of 5.4% (Uganda Aids Commission, 2021). Despite the higher HIV prevalence rates, the Kalangala islands are served by only 15 health centers, with only one level-IV health center (KHCIV) serving as a regional health center (Kwiringira et al., 2021). In addition, only

[5]Airtel Uganda, Uganda Telecom, and K2 Telecom.
[6]Africell Uganda, Vodafone Uganda, Smile Telecom, and Smart Telecom.

nine ART clinics are organized at these health centers, usually on Tuesdays and Thursdays. Since the existing health centers are in only seven[7] of the 65 inhabited islands, patients must traverse from one island to another to seek ART clinic service, which is very costly (Monitor, 2016).

In the ART clinics, medical records for HIV patients are first captured on paper and then entered in the Open Medical Records "OpenMRS"[8] and DHIS2[9] systems. Treatment adherence is measured by consistent visits to the ART clinic to pick up subsequent doses, keeping appointments, and correctly taking the required number of pills at specified intervals (pill count at the time of the next visit). In the KHCIV ART clinic alone, when the OpenMRS was introduced, there was a large room full of paper files of HIV patients missing from care, with only 23% of patients active in the program, meaning that the remaining 77% have been lost in care, died, or migrated. These figures are concerning and a high indicator of sub-optimal adherence.

In summary, Kalangala district is characterized by its high HIV prevalence rate, poor means of transportation to health facilities and the mainland, uneven and unreliable GSM network coverage, limited electricity coverage, constant immigration and emigration of people, and low levels of literacy. These factors make this a rich and complex context to study the use of m-health interventions to fight AIDS.

4.2 | Research protocol

This research followed a qualitative approach and used semi-structured interviews (by phone and in person) involving a wide range of stakeholders in the case. In-person interviews were preferred, but the remoteness and logistical challenges of the region forced the researchers to perform phone interviews in some cases, especially with counselors and village health teams (VHTs) from distant islands such as Nkose and Kachungwa in Mazinga sub-county and Nkese and Jaana in Bubeke sub-county. Phone interviews, although sub-optimal, allowed the researchers to verify and experience the challenges with network coverage and reliability in the area. Additionally, extensive observation and document analysis were included in the data collection.

A total of 30 semi-structured interviews were conducted. The respondents were purposively sampled to have broad coverage of the types of stakeholders involved in the case and its geographical area. When explicitly consented by the respondent, the interviews were audio-recorded. The chosen key informants in this research were ART clinicians, adherence officers, ART clinic counselors, HIV/AIDS support NGOs' representatives, VHTs, and treatment supporters. The patients were never interviewed for ethical and vulnerability reasons. However, the interviewed stakeholders have ample experience and possess information that virtually no one else has, and they are authorities in their areas. Also, due to their close association and constant interaction with patients, they are the closest representation of patients' views that can be included in this research without ethical breaches.

The languages used for the interviews were mainly English and Luganda, depending on the interviewee's choice. When the interviewees were not fluent in these languages, the help of an interpreter was sought. All interviews not conducted in English were translated into English during the transcription process.

4.3 | Data analysis and conceptual framework

As mentioned in section 4.1, this case study followed an extreme-case selection technique. As such, the conceptual framework used to analyze these data should provide adequate tools to understand the circumstances of extreme or non-mainstream cases. Based on these requirements, the researchers select the design—reality gap model proposed by Heeks (2002a, 2002b) as the main conceptual framework for this research. This model seeks to understand the gaps between the design and reality of a particular ICT or ICT-based initiative (Heeks, 2002a): the aspects that are assumed or given for granted by the ICT designers but do not correspond to the local reality in which the ICT will be used. These gaps can arise in many ways or dimensions, as represented in Figure 1 by the ITPOSMO[10] model.

Gaps result from the physical or contextual distance between dominant stakeholders in the design process of a particular ICT and the context in which the said ICT will be deployed and used. A classic example of this is IT professionals in the Global North, who base the design of ICTs on the widespread availability of broadband internet connection, literacy (specifically in English), or electric power coverage that might not be the standard in the Global South. Local actors, however, can also be a source of design—reality gaps. This could happen, for example, when local stakeholders are educated in foreign institutions (located mainly in the Global North) and act as Trojan horses (Heeks, 2002a, p. 108) for designs or design heuristics that are inconsistent or incompatible with local realities.

[7]Buggala, Bufumira, Lulamba, Bukasa, Bubeke, Mazinga and Lujjaabwa.

[8]OpenMRS is an open-source software for managing medical records. It started from a partnership between the School of Medicine of Indiana University (USA) and Moi University (Kenya). OpenMRS Inc., a United States-based non-profit organization, runs it. It is supported by organizations such as the United States Centers for Disease Control and Prevention (CDC), Canada's International Development Research Center (IDRC), the National Institutes of Health, Fogarty International Center, the Millennium Villages Project of the Earth Institute (Columbia University), the Rockefeller Foundation, and the World Health Organization. See https://openmrs.org/.

[9]An open source, web-based health management information system. See https://dhis2.org/about/.

[10]This is an acronym for **I**nformation, **T**echnology, **P**rocesses, **O**bjectives and values, **S**taffing and skills, **M**anagement systems and structures, and **O**ther resources.

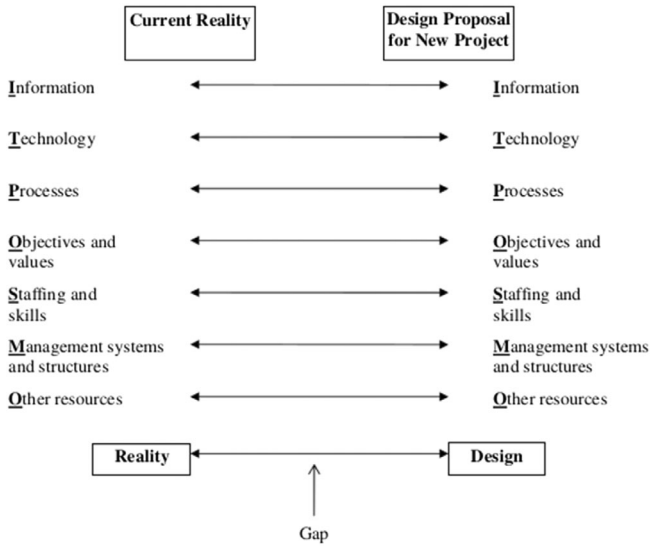

FIGURE 1 Design–reality gaps. *Source*: (Heeks, 2002b).

The importance of understanding these design—reality gaps lies in the fact that gaps could bring about the failure[11] of the ICT or the ICT-based initiative (Heeks, 2002a). In other words, the likelihood of success or failure of an ICT-based initiative (especially in the Global South) can be understood as a function of the gaps' size. This is especially important as some gaps can create irreconcilable differences between an ICT and its context. For example, an ICT designed under the assumption of widespread electric power coverage will fail if this coverage is not present. Similarly, an initiative designed under the assumption of government data that is trustable, up-to-date, and easily accessed will fail if even one of these assumptions is not present in the local context. Hence, design—reality gaps should be understood and managed across the initiative's life-cycle to reduce the chances of failure.

Finally, this model is chosen because it has a good trajectory in research on ICT in developing countries (Bati & Workneh, 2021; Gwamba et al., 2018; Hawari & Heeks, 2010; Kubuga et al., 2021; Masiero, 2016).

5 | FINDINGS

The OpenMRS was introduced in 2016 in all health centers with ART clinics in Kalangala district as part of the national rollout plan. OpenMRS is a client–server system, which means that it is designed to operate in an environment where many client computers access the same information on a server. The objectives of introducing this system were to improve the storage, processing, and management of HIV/AIDS patient records, which until then had been kept only in data files for reporting purposes. It was also envisaged that the system would improve treatment adherence by automatically sending daily SMS messages to patients with reminders about medication intake, and to generate appointment logs/lists that could be used to call patients to remind them about their ART clinic appointments.

The following is the analysis of the design—reality gaps and the degree of the gaps between the requirements and assumptions of the mobile reminder system design and the reality in the context of the Kalangala fishing community after the implementation of mobile reminders, according to the ITPOSMO dimensions. Each dimension gap is rated by the authors, from 0 to 10, based on the evidence found on the field and using the criteria summarized in Table 1.

5.1 | Information – Rating: 7.0/10

The gaps in this dimension show the difference between the information requirements and assumptions of the mobile reminder system design and the reality in the Kalangala ART clinics after implementation. The design assumed the availability of accurate, complete, and up-to-date medical records for all patients—including their mobile phone contacts—and the telephone contacts of their respective treatment supporters. In reality,

[11]In this discussion, we adopt the definition of success, partial failure, and failure proposed by Heeks, 2002a. In this definition, a successful initiative is one in which most of the stakeholders achieve their main objectives and do not see any significant adverse outcomes. A partial failure is an initiative unable to meet major goals, or one in which these goals were met but came with significant adverse outcomes. Finally, a failed initiative is one that is never implemented, or one that is implemented but immediately abandoned Heeks (2002b).

TABLE 1 Criteria for gap rating. Based on Heeks (2008).

Range	Likelihood of dimension being a contributor to failure
8.1–10	Very likely
6.1–8.0	Likely
4.1–6.0	Possible
2.1–4.0	Unlikely
0.0–2.0	Very unlikely

many patients' medical records were inaccurate, incomplete, and did not contain patient phone contacts. For example, at the KHCIV, only 20% the medical records initially captured in the system had phone contacts.

When HIV-positive patients come to the ART clinic for the first time, in addition to providing personal information, they are asked for the mobile phone number of the people they prefer to receive support from during their treatment and who can even pick up the medications if required. However, as one counselor interviewed at KHCIV said, *"In some cases, patients do not give correct and complete information about themselves; for example, a patient may give us wrong names and telephone contacts. It may also happen that some patients do not actually have a cell phone, but others deliberately refuse to provide telephone contacts [claiming] that they do not have a mobile phone. This happens especially with female patients who share mobile phones with their partners and who have not disclosed to them that they are on HIV treatment. It is also frequent with those patients who are still stigmatized and do not want to be known"*. The counselor added that *"when we have the contact numbers of the treatment supporters, we end up discovering these cases when talking to them (…) they share with us the correct patient information; otherwise, it is very difficult to get in contact with this type of patients"*.

In addition, patients sometimes give inconsistent information about themselves on different visits to the ART clinic and end up with multiple (and conflicting) records on the OpenMRS. One ART clinician reported that this occurs when the patient fears judgment about missed ART clinic appointments. There are also cases of patients irregularly changing phone numbers, especially when phones are lost or damaged while fishing. Considering that the cost of replacing the SIM card is higher and must be done from Kampala, most patients prefer to buy a new SIM card.

5.2 | Technology – Rating: 7.5/10

The gaps in this dimension show the difference between the technological requirements and assumptions of the mobile reminder system design and the reality in the ART clinics and the Kalangala fishing community after implementing mobile reminders. The design assumed the availability of personal computers suitable for running the OpenMRS system in all ART clinics, with reliable power supply and mobile network signal to send daily SMS messages to patients. In addition, the design assumed that all adult patients had cell phones with good GSM coverage where they live, the ability to charge their phones, and enough airtime to receive the SMS.

The KHCIV ART clinic has three computers running the OpenMRS system, while the rest have one computer each. However, an EMR officer[12] pointed out that "*these computers often fail as a result of normal wear and tear or misuse by users, and when computers on the farther islands, such as Mazinga, break down, it can take even a month before they are repaired because they have to be taken to the main island, Bugala, for repair*.It is costly to hire a private boat for a computer technician to go to an island such as this to repair a single computer. Regarding internet connectivity, ART clinics use mobile internet dongles to connect and subscribe to internet data every quarter. However, some sites have unreliable and slow internet connectivity due to poor telecommunications network coverage, and others run out of data before the end of the quarter, leaving the system without internet. This issue was evident at the Health Center III (HCIII) in Bukasa, where data rarely last longer than one month. In terms of electricity, of the 84 islands, only the largest (Bugala) has electricity. The rest of the islands use solar energy, inverters, or generators to run the computer systems of the health centers and ART clinics. As for charging phones, most patients on the isolated islands usually charge them in public places. During a focus group, some of the treatment supporters on Bubeke Island emphasized that "*we usually charge phones in public video libraries or movie theaters because they have solar power or generators, but the phones usually take a long time to fully charge, and the generators and solar power damage the batteries in our phones*."A VHT member from the same island also raised the concern that "*while the phones are being charged in those public places it is possible that the SMS reminder may arrive, and others may read the SMS on the patients' phone, which goes against confidentiality*."

Mobile phone ownership is increasing. However, many patients still do not have personal mobile phones. The head of the KHCIV ART clinic estimates that 40% of patients do not have personal mobile phones, and of the remaining 60%, only 20% have smartphones. In other words, shared ownership of mobile phones among islanders is common. As a counselor at the KHCIV ART clinic stated, "*The percentage of patients who*

[12]EMR officers manage patients' information (i.e., capture, update, report generation) on OpenMRS and DHIS2.

share phones with their partners is about 30%, and one realizes that a good number of them have not disclosed their HIV status to their partners, so one can call a patient and if their partner answers the call, it can be complicated". A VHT in the Mwena fishing area reported that one of the reasons for sharing mobile phones between couples is that some men deliberately refuse to let their wives have mobile phones for fear of infidelity. In addition, patients are often unreachable when their phones are not charged or without a signal. As for airtime, on most remote islands, the cost of an airtime voucher is increased by 100 or 200 UGX compared to the cost on the mainland. Finally, telephone network coverage is poor on the islands. A health educator from the Kalangala Comprehensive Public Health Services Project (KCPHSP), who works in collaboration with the ART clinics and periodically visits the islands of Kalangala to educate HIV patients and provide them with household materials, stated "*most of the islands have very poor network coverage for most telecommunication operators. On some islands, such as Lwabaswa, Bubembe, and Kisujju, patients must go to specific points on the islands to be able to make calls with the operator Airtel, which is very common because its call rates are low*." A treatment supporter of the Bubembe Island raised a similar concern, adding that "*if we receive a call and we are not on those particular network points, we are not available, thus, to make and receive calls, we make sure we move to those network points*." One of the researchers also noted that even the telecom operator with the best network coverage in Uganda (MTN) does not cover the whole of Bugala Island and has some dark spots from where calls cannot be made or received.

5.3 | Process – Rating: 8.5/10

The gaps in this dimension show the difference between the organizational practices and processes expected when designing the mobile reminder system and the reality in ART clinics after its implementation. The design assumed that, upon first coming to the ART clinic after testing positive, the patient receives appropriate counseling and is advised to start the treatment. Patients' medical history and personal information are recorded in a paper file when they agree to the treatment. These are then entered into OpenMRS by the EMR officer. On subsequent visits, patient records are checked to see if any information is missing and is updated accordingly. The OpenMRS then processes patient information and generates SMS reminders that are automatically sent to patients based on the dates for upcoming appointments and medication intake schedules. In addition, the system generates a list of patients whose next appointment is scheduled in the next 48 h for the adherence officer or responsible clinician to call patients and remind them of appointments. It was also assumed in the design that patient records are captured in real-time or immediately after the ART clinic visit so that patients start receiving mobile reminders as soon as possible and are proactively called and reminded of upcoming ART clinic appointments before the due date.

In reality, phone call reminders are usually made after patients miss an ART clinic appointment rather than proactively, as the design assumes. The adherence officer reported that patients who miss three consecutive ART clinic appointments are classified as lost-to-follow-up or lost-to-care and as dropped-out if they miss a fourth appointment. On the other hand, a counselor said, "*Sometimes we give all the information to the adherence officer when patients are due for upcoming ART clinic appointments, but he sometimes forgets to call patients and ends up carrying the files in his car, where they even get misplaced*." In addition, the medical records are not captured in real-time. For example, until recently, the KHCIV was still capturing backlogged patient data stored in file folders since 2004, when HIV treatment began in Kalangala. "*During the first year of the OpenMRS implementation, we had only records for over 8,000 patients, so the process of capturing information has taken longer than expected*", said the KHCIV ART manager. He added, "A*t the moment, it takes some time for new patients to receive mobile reminders*."

In addition, patient records at ART clinics are rarely updated on an ongoing basis. The EMR officer noted that "*some ART clinic counselors are reluctant to update patient records when patients return for subsequent visits; for example, many of the files of patients who did not have phone numbers at the initial visit at the KHCIV and Mugoye ART clinics have remained without those contact numbers because most counselors tend to ignore the normal process of updating missing patient information on subsequent visits*."

5.4 | Objectives and values – Rating: 8.5/10

The gaps in this dimension show the differences between the objectives and values (i.e., through which culture and politics manifest) of the mobile reminder system design and the reality after its implementation. The system design assumed a cost reduction objective would be achieved when compared to physically visiting the patients at their homes. In addition, other objectives were set, such as tracking lost-to-care patients, increased adherence, and better management decisions. However, some stakeholders did not share some of those objectives and values. They were concerned about the confidentiality and privacy of patients, which could be violated with the mobile reminders. Other stakeholders, such as the adherence officer and clinicians at different ART clinics, felt that learning the new system was stressful. It also felt burdensome for them to use OpenMRS, which generates the patients' appointments and the contact list for mobile reminders. This resistance was mainly due to moderate computer literacy, fears of job loss, and increased workload, as reported by the Uganda EMR contact person at Kalangala District. Furthermore, while a favorable scenario could have indeed resulted in cost reductions for the health system, it would have also resulted in rising costs for patients who will now have higher costs associated with the operation of their mobile phones, such as more airtime, SIM replacement fees,

quickly replacing lost or damaged phones and keeping the phone charged. Given the socio-economic vulnerability of the general population in Kalangala, this seems to be an unacceptable transfer of costs from the national health system to patients.

The design also assumed no cultural restrictions regarding the ownership and usage of personal mobile phones among adults. The cultural values of the local Kalangala fishing community do not prevent any adult from owning mobile phones. However, some men in Kalangala fishing communities deter their wives from owning personal mobile phones. In such situations, they associate mobile phone usage with family breakups.

Regarding mobile reminders, the system design assumed they would be convenient for the patients and privacy would not be an issue; thus, patients were contacted or sent reminders over the phone. Mobile reminders are indeed convenient to a small portion of patients who came out publicly and declared to be living with HIV/AIDS. For most patients who have not made this known to others, privacy is a serious concern, worsened by the shared ownership of mobile devices. They were afraid of community-directed stigma. The adherence officer noted that *"the patients that declared publicly don't mind about privacy when receiving these mobile reminders and they comfortably talk about HIV/AIDS freely; however, those that haven't, don't even want me to go to their homes because generally, the public thinks that every time I go to a certain home, there's an HIV patient that isn't adhering well to the medicine"*. On the same note, the ART clinician in charge at the KHCIV advised that confidentiality depended on how the patient dealt with stigma. Patients who have publicly disclosed their HIV-positive living status and are adhering well, albeit a small number, are termed "expert patients/clients." Those expert patients play a fundamental role in helping others to deal with the stigma and disclose to improve their adherence. With continuous disclosure, the issue of privacy and stigma shall become less critical.

5.5 | Staffing and skills – Rating: 6.0/10

The gaps in this dimension show the difference between the qualitative and quantitative competencies expected when designing the mobile reminder system and the reality of ART clinics and patients after implementation. The design assumed a wide range of skills and knowledge required from ART clinic staff (to use the OpenMRS) and patients (to use mobile phones). For instance, it assumed that all ART clinic staff would be knowledgeable about the OpenMRS or similar systems. It also considered that all patients can use mobile phones (e.g., making phone calls, sending, and reading text messages).

Regarding ART clinic staff, several counselors and ART clinicians took specialized training to use the OpenMRS system. After the training, they trained others. However, the adherence officer was unfamiliar with the system, so he relied on data from the counselors and EMR officers to make calls. The ART clinician in charge noted that *"while many ART counselors/clinicians and some expert clients who are computer literate have been trained in using the OpenMRS system, the data entry speeds are still low since users are not much experienced and for similar reasons, the system is not optimally utilized"*. The staffing levels are deemed good enough since there are four counselors, one adherence officer, one expert client, and ART clinicians who help with the data entry into the OpenMRS.

Regarding patients, the knowledge to use the mobile device around the fisherfolk community was not as expected. Due to high illiteracy levels, many patients cannot send and read text messages on their phones. In such cases, they just ignore the SMS. In worst-case scenarios, patients take their mobile phones to a third party to read the messages for them, which is a clear privacy issue.

5.6 | Management systems and structures – Rating: 4.0/10

This dimension represents the gaps between the required management systems and structures for the successful implementation and operation of the OpenMRS mobile reminder system and the actual management and structures at the health centers after implementation. The design required decentralized management and decision-making, allowing the decisions to be made at the ART clinic departmental level. Additionally, considerable top management support was needed for the system to succeed.

Indeed, there was considerable decentralization, and decisions were made at the departmental level. The ART clinician at KHCIV noted, "*We can organize community adherence outreaches and send mobile reminders to patients on our own and just give notice to top management. Top management is very supportive as far as mobile reminders are concerned, and they give the adherence officer, ART clinician in charge, and PMTCT*[13] *officer monthly airtime for calling patients in a bid to improve adherence*". Although top management was very supportive, sometimes it was overwhelmed by requests for facilitation.

5.7 | Other resources: Time and money – Rating: 5.0/10

This dimension represents the gaps between the required resources (e.g., money and time) for the successful implementation and operation of the OpenMRS and mobile reminders design and the reality of the available resources at the ART clinics and Kalangala fisherfolk community. The

[13]Prevention of Mother to Child Transmission.

design assumed that the ART clinic staff would always have the airtime to call patients to remind them about ART clinic appointments and medication as scheduled. Money to make phone calls and send SMS was provided by KCPHSP quarterly.

On the side of patients, charging mobile phones and buying airtime on some islands was costly. For instance, a treatment supporter from Lwabaswa Island noted that *"we usually pay between UGX 500 to 1000 to charge a mobile phone, and because of faulty batteries, one may have to charge thrice in a week. The airtime on our island has been increased, and different prices are charged; an airtime voucher of UGX 500 on the mainland costs UGX 600 here, and that of UGX 1000 costs UGX 1200, and we may take even three days without any single airtime voucher in all shops here before it is brought from Kalangala town"*.

The situation was escalated by the 'Stop Illegal Fishing campaign' administered by the Ugandan Army on Lake Victoria, which left many patients in Kalangala jobless and poorer after forcefully burning their fishing gear and arresting some. Many fishermen could not even afford a regular meal to enable them to take the drugs. As such, it affected the patients' ability to buy airtime and charge their phones; they were just struggling to earn a living. Many patients in Kaagoonya island had been classified as lost-to-follow-up because of this. When visited by the ART clinicians, they reported that they had sold off their mobile phones for survival, and they had even failed to raise transport money to go to the ART clinics to pick up medications. It can be said that even if the system could send the mobile reminder in optimal conditions, it would have been pointless since some patients could not even pick up the medication. And even if that were the case, some of them could not even afford the meal needed to take the medication.

5.8 | Overall assessment of the system based on gap rating

Table 2 presents a summary of the gap ratings for each of the ITPSMO dimensions and the aggregated gap rating of this initiative:

Following the scale proposed by Heeks (2003), this initiative has a high rating and it will likely fail unless concrete action is taken to close some gaps. Particular attention should be paid to the dimensions of technology, processes, and objectives and values. The information dimension is also at a critical rating, but most of the issues in that dimension result from inadequate data collection in the processes associated with the initiative or specific values in the region that impede sufficient data collection.

6 | DISCUSSION AND CONCLUSIONS

This section begins by summarizing the main challenges found in the case. Later, it goes back to the research question presented in section 3 to explain how it was answered. It then discusses the findings presented so far in the paper from two perspectives: the implications to the general literature on information systems in the Global South and practitioners in this field and the contributions to ART adherence and m-health literature. Finally, a discussion about the limitations of the paper is presented.

6.1 | Case study summary

Table 3 shows a summary of the challenges found in the case study. It also classifies the challenges by category (technical, organizational, cultural) and ITPOSMO dimensions (information, technology, processes, objectives and values, staffing and skills, management systems and structures, other resources).

TABLE 2 Summary of gap ratings for the ITPSMO dimensions.

Dimension	Rating
Information	7.0
Technology	7.5
Processes	8.5
Objectives and values	8.5
Staffing and skills	6.0
Management systems and structures	4.0
Other resources	5.0
Overall rating	46.5/70

6.2 | Technical, organizational, and cultural challenges of m-health interventions in the Global South

The main research question of this paper is: *What are the technical, organizational, and cultural challenges of m-health interventions based on mobile reminders on HIV treatment adherence in the Global South?* This question, however, cannot be answered in a generalizable way (see section 6.4); doing so would contradict the importance of a contextualized design discussed earlier in the paper. In turn, this paper answers this question by using an extreme-case method to identify and discuss unusual technical, organizational, and cultural challenges that affect m-health intervention in the Global South (see section 5). While these challenges do arise from a particular and extreme case and are far from average cases, it is precisely this unique character that makes them a significant contribution; these are challenges rarely discussed in the literature regarding m-health interventions.

6.3 | Implications to general literature on information systems in the Global South

This paper uses the design—reality gap model proposed by Heeks (2002b). In doing so, it contributes a new case study validating the explanatory capabilities of the model. The model was indeed able to capture a wide range of design elements and heuristics embedded in traditional ICT

TABLE 3 Summary of the challenges found in the case study.

Category of challenge	Dimension	Challenge
Technical	Information	Mobile device loss leads to changing patients' phone numbers. Multiple records with different mobile phones.
	Technology	Computer failures High repair costs Unreliable and slow internet connectivity Generators and solar charges damaging patients' phone batteries. High cost of airtime on remote islands Network coverage in remote areas
	Processes	
	Objectives and values	Higher costs for patients (e.g., airtime, SIM replacement fees)
	Staffing and skills	
	Management systems and structures	
	Other resources	High cost associated to patients' charging of mobile phones
Organizational	Information	Inaccurate and incomplete patients' medical records.
	Technology	
	Processes	Phone call reminders only made after a missed appointment. Patients' physical medical records carried outside clinics and potentially misplaced. Delayed data capture Patients' records not updated on subsequent visits.
	Objectives and values	Learning to use OpenMRS system deemed as stressful and using it as burdensome.
	Staffing and skills	Not all staff trained and familiar with the system
	Management systems and structures	Top management sometimes overwhelmed with facilitation requests.
	Other resources	
Cultural	Information	Patients give contact misinformation or refuse to provide information
	Technology	Charging patients' phones in public places leads to potential privacy violations, since others can read SMS. Sharing mobile devices with partners Reduced female ownership of devices, which are controlled by their husbands.
	Processes	
	Objectives and values	Female ownership of mobile phones associated with family breakups. Privacy concerns, due to not disclosing HIV status to others. Negative perception of visits by adherence officers.
	Staffing and skills	Illiteracy levels among patients prevents them from reading or sending text messages.
	Management systems and structures	
	Other resources	Patients' economic restrictions to afford medicines.

solutions from the Global North that clash with local contexts in the Global South. As shown in the literature, this clash could jeopardize the effectiveness or sustainability of information systems in the Global South. Practitioners could use this knowledge to be more critical about the assumptions made while transferring technology, designs, or design heuristics from one region to another. For this, the design—reality gap model could be helpful as a pre-hoc evaluation tool to contrast the designs against local contexts and improve them before the implementation efforts, thus raising the design to the local context (Heeks, 2006). Similarly, this analysis can reveal how the context needs to be raised to the design. In those cases, including these needs as an integral part of the project or initiative is essential.

A second implication is the need to use a socio-technical perspective (Avgerou & Cornford, 1998) to understand information systems as social systems that make intensive use of information. This is important in any setting, but particularly in the Global South: as shown by the Kalangala case, social systems in the Global South can be extremely different from those in the Global North. These differences cannot be simply ignored or wished away and should be a focal concern of the design efforts. As a result, the logic used to approach these systems in the Global South should be different and tailored to local contexts. The use of what Heeks (2002b, p. 110) calls "hybrids" (people who understand context, organization, processes, and how those elements relate to information systems) or project champions (Renken & Richard, 2019) is common advice.

Assuming cost savings or increased efficiency as central values in information system projects is a good example of the abovementioned issue. Since most of the costs saved come from replacing human labor with automated technology, other values, such as job security, are impacted. Since losing a job could be (much) harder to recover from in the Global South, the ethical and practical implications of this decision are much more complex in this setting; this vulnerability should have a higher priority than corporate or business values. Furthermore, the idea that automated technology is cheaper than human labor, while usually true in the Global North, does not necessarily apply to the Global South (Heeks, 2002a).

Finally, this case shows the importance of widening the conception of the information system project itself. A pre-hoc evaluation of any information system in the Global South using the design—reality gap model will unveil challenges such as those discussed in section 5. Some of these challenges could be addressed technologically by adapting the designs to the local realities. However, other non-technical elements within the information system need different responses that should be included in the project or initiative. For example, in a context such as the Kalangala region, in which electric power coverage is scarce and unreliable, the project could use a low-energy principle to design apps or service interfaces that consume as little energy as possible (a response at the technical level), or the project could include the provision of handheld solar chargers for the end-users of the information system (a response at the socio-technical level).

6.4 | Contributions to ART adherence and m-health literature

This paper extends the literature that analyzes improvements in adherence to treatment in HIV patients using m-health in resource-constrained settings. Previous studies in such environments have examined the feasibility of those interventions, their usefulness as prevention programs, improvements in treatment adherence, and patients' suggestions to make those interventions more effective (e.g., Kenya, South Africa, Uganda; Crankshaw et al., 2010; Lester et al., 2010; Mitchell et al., 2011; Pop-Eleches et al., 2011; Rana et al., 2015). Although those studies employed different research methodologies (e.g., randomized controlled trials, surveys, focus groups), they always focused on the patients and paid less attention to the health (and social) system surrounding them. To the best of the authors' knowledge, this research is the first study that analyzes the gaps in the design and implementation of m-health interventions for ART adherence in an extreme case considering the different actors' perspectives in providing health services for HIV patients. Furthermore, the analysis includes a wide range of social, technical, and economic factors.

Perhaps the most important implication of this research for m-health researchers and practitioners is that m-health initiatives should be designed from a broad socio-technical perspective to provide holistic solutions to issues, such as insufficient income, connectivity, electric power availability, poor or inadequate staffing, lack of trustable data, or many others that can surface in different contexts. To achieve this, a socio-technical view of information systems is advised so that the technical artifacts within the information systems (e.g., the software application) do not overshadow other crucial elements that can create design—reality gaps large enough to jeopardize the initiative.

Following this idea, it is essential to highlight that the factors hindering the effectiveness of m-health interventions are not limited to the patient (e.g., shared mobile phone, illiteracy) but can also come from healthcare providers (e.g., lack of complete information, difficulties in using EMR systems, insufficient staff), or the broader context (e.g., lack of mobile network coverage, unreliable power network, widespread economic vulnerability). This highlights the usefulness of the design—reality gap model in holistically approaching the design of SMS-based m-health interventions.

6.5 | Limitations

As with any other research project, this one is subject to limitations that affect both the results and their generalizability.

While the design-reality gap model was indeed helpful in answering the research question posed in this research, the understanding of how these gaps were formed and, crucially, how to solve them is out of the model's scope; there is no explicit theoretical or methodological tool to address these issues in the model.[14] This limitation of the design-reality gap model has been noted by other researchers like Masiero (2016), who made important contributions to expanding the model. This, however, has little impact on this research because its research question is aligned with the strengths of the design-reality gap model (i.e., identification and classification of factors and challenges affecting the effectiveness of digital interventions in the Global South).

One of the main methodological limitations of this research was not including actual patients in the research process. This decision was made on ethical grounds to protect the privacy of vulnerable people. While researchers in other regions could include HIV patients in their research without putting them at risk, the conditions of the Kalangala region and the social stigma placed on HIV there was the main factor for this exclusion. Nonetheless, patients' perspective was indirectly included through the different health actors that interact with them daily. The researchers are confident that this exclusion, while sub-optimal, had no significant impact on the research results.

Finally, there is the issue of the generalizability of the results. In coherence with the socio-technical view of information systems discussed earlier in section 6.1, this research is not intended to be generalizable in a traditional way (linking independent variables with dependent variables regardless of the context). This is because, from this perspective, information systems are social systems with intensive use of information, and social systems are, by nature, particular and context-bound. Finally, selecting an extreme case makes it harder to find a case similar enough to make this even feasible. This, however, does not reduce the value of this research as it provides practical knowledge and lessons that can be generalizable in the form of design principles or theoretical elements that are just as important as traditional generalization (Flyvbjerg, 2006; Walsham, 1995).

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DATA AVAILABILITY STATEMENT

Research data is not shared to protect the privacy of participants.

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[14]It is worth noting that Heeks (2003) has discussed generic strategies for gap reduction in the context of eGovernment projects, but these are not a core component of the design-reality gap model.

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