Leveraging Software Platform Capabilities to Support HIV (ART) Treatment Adherence Management: A Case from Sierra Leone

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Abstract. Research on antiretroviral therapy (ART) programs reveal that HIV positive patients who adhere to treatment substantially improve their life expectancy and lower the risk of progression to full-blown AIDS. While there is a significant body of research in the medical and social science fields on ART adherence, Information Systems (IS) research has paid little attention to this subject. Especially lacking is research on how Information and Communication Technology (ICT) based solutions can be developed to better support ART adherence programs. We argue in this paper that software platforms offer capabilities that can be leveraged to address more effectively the information management challenges associated with ART adherence programs. The motivation for this paper is taken from a broader action research project planned to be carried out to support an ART adherence program in Sierra Leone.

Keywords: HIV • Software platforms • ART adherence • Health Information Systems • Ecosystems • Integration • DHIS2

1 Introduction

Studies reveal that higher ART adherence levels in HIV-positive patients lead to improved patient survival outcomes [1- 6]. Still, research also shows that many intervention programs only manage to achieve very modest improvements in patient adherence [6]. Factors identified to contribute to this are broadly categorized as socio-cultural, technological, attitudinal, and economic in nature [7-12]. But also a major concern in the literature is that the "*inability to monitor adherence may ultimately undermine efforts to treat HIV/AIDS in high-burden areas" (*[13], *p.78)*. Addressed in this paper then is how we can tackle this problem from an Information Systems (IS) research point of view by exploring solutions which can effectively support ART adherence programs particularly in developing countries.

According to clinicians the effectiveness of antiretroviral (ARV) drugs for treating HIV[1] disease depends on strict adherence to stipulated usage guidelines. The World Health Organization's (WHO) guideline documentation[2] for example outlines a three-level program for administering ARV drugs to HIV positive patients, described briefly as follows: a new patient starts on first-level treatment regimen, is monitored for at least 6 to 12 months, and then switched to second and third-level regimen respectively when treatment failure is detected. Differences in patient demographics including age groupings, pregnancy status in women, and the prevalence of other co-morbidities such as tuberculosis (TB) also introduce variations into the ARV drug administration protocols. These guidelines and other information requirements (e.g. for managing HIV opportunistic infections) increase the complexities of patient monitoring hence the need for appropriate information systems. Therefore, this paper proposes information systems solutions that can support effectively the management of HIV treatment and related activities. The aim is towards enhancing health worker ability to monitor patient adherence to HIV (ART) treatment. The expectation is that the appropriate information system is able to support individual patient management activities. For instance including the ability to schedule patient hospital appointments, send automatic reminders to patient on upcoming events like drug refill, notify caregivers when necessary and enhance their capacity to carry out patient follow-up activities. Developing such solutions requires the integration of software systems, technological devices, data from health programs, and alignment of local information management practices around HIV treatment. The system once developed will give a more holistic view of patient treatment data as well as improve caregivers' visibility of the treatment process. In pursuit of the proposed system we argue that software platforms provide capabilities which can be leveraged. The advantages offered include their ability to support the development of relatively cheaper, quicker and highly customizable solutions to meet adherence management needs especially in resource-constrained settings.

This paper introduces a broader research project motivated by an urgent need to restore and improve survival outcomes in HIV positive patients. These are patients enrolled into ART treatment programs within a challenged health context of Sierra Leone, still recovering from the Ebola disease outbreak. It was reported that the pandemic nature of the Ebola outbreak diverted attention and resources from HIV treatment activities resulting in increased deaths among HIV-positive patients. With attention shifted back to HIV as the Ebola subsides, areas identified as requiring immediate attention include; expanding patient access to antiretroviral (ARV) drugs, providing adequate clinical care, and improving ART adherence monitoring. In this paper we attempt to contribute to the efforts aimed at improving ART adherence monitoring. We approach this by investigating the development of appropriate information systems solutions to support adherence monitoring. The study draws extensively from HIS integration work within an international action research program known as Health Information Systems Program (HISP) [20]. Field

[1] HIV/AIDS: Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome. Retrieved October 22, 2016 from http://www.who.int/mediacentre/factsheets/fs360/en/

[2] WHO | Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection, 2016. Retrieved October 22, 2016, from http://www.who.int/hiv/pub/arv/arv-2016/en/

intervention work is currently at an advanced stage of planning waiting for commencement in Sierra Leone. This paper contributes to HIS integration research by highlighting the capabilities of emerging software platforms, and how they can enable the development of ICT-based solutions to help improve the management of ART adherence in resource-constrained settings. The emergence of District Health Information Systems 2 (DHIS2) as a software platform within the HIS field is discussed as an example of the opportunity presented to pursue the development of such solutions. The remainder of the paper is organized as follows: First, background literature review of concepts informing the study is presented. After this the research approach is described with a brief description of the problem diagnosis and the proposed solution. This is then followed with discussion and conclusion.

2 Background Literature

2.1 ART Adherence Monitoring

According to Amico et al. [6] ART adherence has gained wider recognition as a critical health promotion behavior for HIV- positive patients undergoing treatment. However there are still uncertainties about how higher levels of treatment adherence may be initiated and sustained especially in larger populations over longer periods [13, 39]. Because many of these studies are conducted on short-term basis with few patients, the long-term viability of adherence monitoring strategies are still unclear. Reported average study duration is about 20 weeks with an average sample size of about 56.7 participants [13, 40]. The ability to monitor large scale ART adherence programs especially within public health sectors of developing countries still require further exploration. This need is clearly articulated by Amico et al: *the demanding nature of ART regimens underscores the need for more strategic and multifaceted interventions that extend beyond the typical patient-provider interaction or ad hoc clinic discussions (*[6] *p.285).* Furthermore, research indicates that the scaling up of ART adherence programs to cover larger populations increases the complexities of monitoring the adherence - health outcome dynamics [41]. It is also stated that currently there is no established "gold standard" for measuring or reporting adherence outcomes [13]. The various methods used in monitoring ART adherence such as patient self-reporting, patient attendance at scheduled visits, pill counts, electronic bottle monitors, pharmacy records, and others are also identified as not effective for all conditions [6, 13]. Moreover, as the treatment of HIV transitions from acute to chronic disease [5] the long-term use of ART will require more strategic solutions that are responsive to the changing dynamics of adherence management in different settings [45].

2.2 ICT in ART Adherence Management

The potential for ICT-based tools to support ART adherence activities has been examined in intervention studies and systematic literature reviews [14-18, 46]. The

advantages of ICTs are identified as their potential for interaction, collaboration, low cost, and use in areas with limited human and material resources [14]. Technological devices like mobile phones can facilitate the ability of health workers for example to track and follow-up patients to provide them with the necessary care. Some specific functions performed with ICT tools in managing ART adherence include reminding patients to take their drugs through phone calls, SMS messages, and pager devices [15-18]. Other devices such as medication events monitoring systems (MEMS) are used to remotely monitor patient-pillbox interactions to help determine medication adherence [45].

Despite these benefits there are challenges that need to be addressed if the full potential of ICT in the area of ART adherence management can be realized. For example the medication events monitoring systems (MEMS), which although efficient at monitoring pillbox events is regarded to be expensive technology [45], and as such may not scale in financially constrained settings. Other web-based solutions used for encouraging medication adherence through the use of social media and similar resource intensive technologies [46] may also not be suitable in some resource-limited conditions. Another dimension also worthy of consideration is the socio-economic and demographic differences in patients which could impact usability of certain technological solutions. But more importantly there are calls to look beyond current solutions which seem to be narrowly focused on the use of single technologies for more comprehensive approaches [6, 13-14, 46]. Such standalone and mostly ad-hoc solutions may not for instance suit public health contexts for the long-term use. Due to information and process overlaps that often exist between different health programs, more integrative and sustainable solutions will be required to reduce information systems fragmentation typical in such contexts [23].

2.3 HIS Integration Strategies

Information systems integration is identified as a socio-technical process involving different actors [27]. Within healthcare integration strategies must take *"the users' needs of the HIS, the purpose of the systems, and the wider organizational perspectives […] and relate those to goals of better efficiency, effectiveness, and co-ordination in organizations"* ([21], p.59). This has also been described as a negotiation process [26] involving technological systems, people, organizations, and cultural practices working toward achieving a more integrated view of information to facilitate decision-making and care delivery. Integration strategies should therefore be able to accommodate changes to the system implementation process [23]. Examples of these include *modular implementation strategies* [31] and *loose coupling integration* strategies [32]. These are also important for preserving evolutionary independence and modular maintainability of the systems involved.

Also depending on the information needs dictating the integration or *interoperability*[3] of a set of systems and actors, the underlying integration processes

[3] In healthcare, **interoperability** is the ability of different information technology systems and software applications to communicate, exchange data, and use the information that has been exchanged. Retrieved November 29, 2016, from http://www.himss.org/library/interoperability-standards/what-is-interoperability

could be pursued either at the *horizontal* or *vertical* levels of the organization [21]. Vertical level integration supports bottom-up flow of usually aggregate data between levels of the administrative hierarchies for higher-level management decision-making. Horizontal level integration on the other hand supports lower-level routine care delivery activities enabled by a single point of access to more granular data from multiple sources. These can include patient data from wards, specialties, and data from other sources like pharmacies and logistics. The horizontal integration approach is therefore suitable for achieving integration objectives proposed in this paper. This could be enabled by ICT platforms capable of supporting the integration of software systems, technological devices, different health programs data and local practices.

2.4 Software Platforms and HIS Integration

Platforms are foundation technologies upon which complementary products, technologies, or services can be developed [29]. Functionalities provided by platforms allow multiple parties to work together to address common problems [29]. Potential benefits offered by platforms include cost and time savings on product development, which can be achieved through half-ready solutions and platform components reusability. They also facilitate the development of highly varied derivative products and services and enable higher levels of products and services customization to meet diverse user requirements [28]. Platforms, by enabling interactions among different sets of actors often result in ecosystems of solutions comprising of human actors, software systems and services working together towards common goals [29]. Examples of software platforms which have contributed to the development of many useful derivative software products and services include Google Android, Apple iOS, Microsoft Windows, and many more (see [29]). The capabilities offered by software platforms can therefore be seen as an avenue through which new healthcare related information systems solutions could be explored.

In the HIS field, the District Health Information Systems 2 (DHIS2) is presented as an example of an emerging software platform (see: www.dhis2.org/technology). Nielsen and Sæbø [33] conceptualize aspects of the platform evolution of DHIS2 as *functional architecting.* Following a number of user adoptions involving the DHIS2 tracker (a software module which runs on top of the DHIS2 platform), they describe three architectural strategies involved in extending DHIS2's platform functionality into different use domains. These are elaborated as *charting*, *encroaching*, and *connecting*. Charting extends a system's platform capability into another domain to fulfil unmet functional needs, encroaching offers alternatives to existing solutions in the domain, and connecting integrates with systems where each has clearly defined roles in the domain. With this conceptualization they demonstrate that software platforms emergence offer opportunities for advancing HIS integration work.

3 Research Approach

This paper introduces a longitudinal action research project planned to span several years. Using a canonical action research methodology [34] several cycles of research

iterations involving *problem diagnosis*, *action planning*, *intervention* (action taking), *evaluation* (assessment), and *reflection* (learning) are planned to be executed. The research work done so far covers the first iteration of problem diagnosis and action planning. This is informed by an ongoing conversation between HISP UiO team and project partners in Sierra Leone. From this the research objectives have been identified and the initial requirements for the proposed solution have been analyzed. Additional data about the problem context has been gathered from sources like the *National AIDS Progress Response Report*[4] for 2014 and other relevant documentations. DHIS2 platform documentation including the implementers guide (see: www.dhis2.org/documentation) have been instrumental in planning the solution implementation roadmap. Also experiences have been drawn from similar HISP projects including a recent DHIS2 tracker implementation for a national malaria control program in Zimbabwe [47], in which one of the authors of this paper participated. In Sierra Leone, HISP UiO's involvement in health information system strengthening through the implementation of DHIS2 in since 2008 [22] have also served as the groundwork in the build up to this current research. The next phase of this research process will focus on initiating planned field intervention activities at the research site.

3.1 Problem Diagnosis and Solution Description

The research problem is diagnosed as high fragmentation of information systems currently used for managing the HIV treatment program. The fragmentation is identified as: 1) the information systems used in managing the ART programs have been deployed as standalone systems and spread across localities in HIV clinics. And the lack of a common information platform makes patients monitoring challenging across localities, and 2) the information systems for managing HIV related health programs such as prevention of mother-to-child-transmission (PMTCT) for HIV pregnant women have been implemented as 'silo' systems. This lack of communication between systems also affect efficient delivery of care to patients who may be enrolled into other health programs which need to be managed together with HIV treatment. These problems have contributed to making adherence monitoring challenging, and impacting negatively on the effectiveness of the ART program.

A solution based on a software module on the DHIS2 platform known as tracker capture, is hereby proposed to address the identified challenges. The tracker capture module utilizes the DHIS2 platform's data warehousing functionalities to enable enrollment, management, and tracking of patients in specific health programs (see: www.dhis2.org/individual-data-records). With this approach the currently fragmented systems will be absorbed onto one instance of the tracker capture hosted on the DHIS2 platform. End users at the health facility level will then be able to access the centralized system via web-enabled devices such as computers and smartphones through the internet. Allied health programs like malaria and TB can also be deployed

[4] Sierra Leone National AIDS Response Progress Report 2014. Retrieved October 8, 2016, from http://www.unaids.org/sites/default/files/country/documents/SLE_narrative_report_2015.pdf

as separate instances on the same platform and configured to share data into the HIV system. Data sharing is also possible between third party systems through interoperable interfaces supported by the DHIS2 platform. With this, a more holistic view of patient data can be achieved for effective monitoring and treatment adherence promotion. It will also improve health worker mobility through the DHIS2 tracker capture App available for deployment on Android-based devices.

3.2 Challenges with Managing ART Adherence and Why DHIS2

Complexities of ART treatment regimen and guidelines pose major information management challenges for care providers [6]. To manage patient adherence effectively requires continuous monitoring of multiplicity of events associated with the treatment process. These include for example the ability to access the right information to determine what ART regimen a patient is eligible for. While undergoing treatment a patient's progress have to be monitored continuously to inform subsequent actions. Other events such as viral load and CD4 count measurements, diet restrictions, drug resistance and side effects, and many other HIV associated complications also have to be monitored. This puts a huge information management burden on care providers instead of having more time for patient care. With current unavailability of more efficient information management tools the effects of ART adherence programs have been reported as generally weak, and underpowered [6, 40]. Also in adherence promotion, activities like patient education, treatment tracking and provision of follow-up services by health workers require the support of ICT tools. And lacking these tools can hamper their ability to effectively conduct adherence monitoring. In the contexts of developing countries under consideration, the viability of the needed supporting ICT tools will depend on factors such as systems availability, accessibility, and flexibility. This is where the DHIS2 platform is seen as a more viable solution. It is currently available and being used at various levels of health information management in 47 developing countries including the one under study (see: www.dhis2.org/inaction). The main strength of DHIS2 is its strong support base of researchers, system developers, system implementers, and users. This international support network is actively engaged in the continuous development of the DHIS2 platform and modules to meet the changing needs of health information management [20]. The platform has generic functionalities that can readily be customized to suit the requirements of the particular context. In the particular case of ART adherence management, platform modules such as the tracker capture and event capture can be used to manage patient information and related treatment events. DHIS2 also integrates internet technologies, SMS services, and Geographical Information Systems (GIS) which can support patient follow-up activities in the communities for adherence promotion purposes. One caution though, is that because DHIS2 was traditionally developed for aggregate data its security regime is currently less developed. Hence extra measures should be taken to safeguard data privacy when dealing with patient level data.

4 Discussion

Looking at the literature, the majority of the available studies are conducted as clinical trials with the primary aim of promoting ART adherence in HIV-positive patients. These studies do not necessarily focus on the ICT tools themselves involved in the intervention activities. Where ICT tools are the focus of analysis it is mostly about what activities they were used to perform [e.g. in 14-18] or assessing their effectiveness in systematic literature reviews such as in de Lima et al.[14] and Muessig et al. [46]. But generally speaking, studies on how more appropriate technological tools may be developed are still lacking. There is a need to take into account particular contextual needs, including resource limitation concerns such as lack of local expertise and financial resources and relatively poor state of technological infrastructures to support such activities. In recent times however, access to ICT services has improved considerably in many developing countries due to the proliferation of mobile telecommunication networks. This together with emerging technologies like software platforms and associated services in the health domain, now makes it more feasible to implement more effective ICT solutions to address information management challenges identified with ART adherence programs.

In this paper we emphasize leveraging the capabilities of software platforms due to several potential benefits that can be gained. The most fundamental capabilities software platforms offer are based on their architectural design principles The *platform* aspect which is *the extensible codebase that provides core functionality shared by the modules that interoperate with it and the interfaces through which they interoperate ([28] p.675)* is designed to be stable. The other aspect, a complementary set of *modules* is designed to vary. A module is *an add-on software subsystem that connects to the platform to add functionality to it (ibid)*. Benefits that can be gained from this include providing a foundation on which information system solutions can be grounded in the context of adoption. This can contribute to local institutionalization and participation in the systems development processes. The current ad-hoc and off-the-shelf use of technologies do not provide the mechanisms necessary for enabling local participation. Implementing a platform upon which solutions can be developed and or tailored [42] can help generate local knowledge bases around such tools to ensure their long-term sustainability. Also important to long-term sustainability is the ability of platforms to interface with other systems to enable interoperability. In the context of HIV treatment this ability to share data across different systems is critical for treatment effectiveness due to complexities associated with ART regimens [6]. Platforms can enable different technological solutions to be pooled together for rapid innovations and experimentation to address the changing dynamics and information needs involved in ART treatment. This can also contribute to research by encouraging ART adherence studies to examine the effectiveness of combining different technological tools rather focusing on single technologies as is common currently.

With free and open-source software platforms like DHIS2, an added benefit in the context of developing countries is the lower economic barrier to entry. Liberal

licensing regimes such as *Berkeley Source Distribution* (BSD)[5] license for DHIS2 for example, contribute to expanding access to platform services. Under such arrangements users have the freedom to use, share, change, or improve the platform and complementary services without the licensing overheads often associated with proprietary systems. Additionally platforms enable integration of services such as SMS, email, internet, maps, etc. to support development of innovative solutions, for example to support geo-spatial disease surveillance activities. Platforms like the DHIS2 also provide data warehousing and data analytic functionalities which can be helpful in addressing difficulties with monitoring and measuring adherence programs efficacy [45]. Also designed into platforms are security mechanisms for safeguarding data privacy. This is important because loss of patient privacy, confidentiality, or secrecy can lead to HIV patient stigmatization with negative consequence on ART adherence [14, 44].

Finally, concerning lack of local capacity or expertise for platform or module development and maintenance in developing countries, platform governance mechanisms [30] provide strategies to address such challenges. This is done through global community collaborations where responsibilities for development and maintenance are shared among platform owners, module developers, and users. This collaborative approach is especially characteristic of open-source software projects like the DHIS2 (see for example: www.dhis2.org/contact). Within such global communities, different types of expertise are available to provide assistance when needed [38].

5 Conclusion

The main idea explored in this paper is that the software platform phenomenon emerging in the health information systems domain presents new opportunities to develop ICT-based solutions to better support healthcare management. The specific area within healthcare management focused on in this paper is HIV treatment and ART adherence monitoring for HIV-positive patients. Current research studies involving the use of ICT in ART adherence programs tend to focus narrowly on the use of specific technologies such as mobile phones. There also seem to be a lack of studies exploring how to design or develop ICT solutions specifically for supporting ART adherence programs. We therefore call for more studies to focus on technological solutions themselves involved in ART adherence management and monitoring. This means more IS research practitioners have to recognize the need to adequately engage in addressing this research problem. This can be pursued through the development of new ICT based solutions or innovative use of existing technologies. Proposed in this paper is a more integrated solution based on DHIS2 platform to integrate technological and non-technological actors, and processes to support ART adherence monitoring activities for the case of Sierra Leone. To improve chances of success the paper proposes the use of suitable IS integration

[5] BSD license definition. (2005). Retrieved November 25, 2016, from http://www.linfo.org/bsdlicense.html

strategies in the problem context. These are flexible implementation processes that are adaptable to role negotiations among the actors involved. Through the use of concepts and strategies discussed, this paper argues for the opportunities software platforms offer and how their capabilities can be leveraged to develop more effective and locally relevant solutions. Going forward we hope to begin work on planned field intervention activities to investigate further the viability of the solution proposed.

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