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Scaling across Functional Domains: A Case of Implementing an Electronic HIV Patient Information System in Sierra Leone

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Abstract. With adherence to treatment, HIV positives can live a normal life. Accordingly, investments are made and health systems are expanded to reach those at risk in developing countries, where HIV is reported to be most endemic. At the same time, many developing countries still rely heavily on paper-based tools which are found to be inefficient when large numbers of patients are involved and of limited use to support follow ups and assure adherence to treatment. In this paper, as we move from an existing paper base and to a digital and online information management system, we focus on improving our understanding of how to use an existing system made for collecting, aggregating and presenting population based routine data to support individual follow-up of HIV positives and their adherence to treatment. We approach this through an action research project in Sierra Leone where we have piloted a HIV patient information management system. We contribute insights on health information system scaling with emphasis on building on existing systems in developing new functionalities rather than introducing entirely new systems. Within this approach we observe the need for technological flexibility and organizational collaboration in utilizing existing resources for efficiency gains.

Keywords: HIV/AIDS • Patient information management system • UNAIDS 90-90-90 • Health information systems • Scaling • IS functionality • Electronic system implementation • DHIS2 • Flexibility • Organizational collaboration

1 Introduction

Essential components of HIV (human immunodeficiency virus) treatment are diagnosis, linkage to care, retention in care, adherence to antiretroviral therapy (ART), and viral suppression [1]. In line with this the Joint United Nations Programme on HIV/AIDS (UNAIDS) sets the 90-90-90 goal to help end the AIDS(Acquired Immune Deficiency Syndrome) epidemic by the year 2030[2]. It outlines that by the year 2020, *90 percent of all people living with HIV will know their HIV status, 90 percent of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and 90 percent of all people receiving antiretroviral therapy will have viral suppression*. However, recent UNAIDS data [3] show that many developing countries are underperforming with respect to meeting these targets. Available data for Sierra Leone for example show only 35 percent of people living with HIV know their status and out of that only 26 percent are on treatment. No data was reported for patients on ART who are virally suppressed (ibid).

HIV care expansion strategies towards the UNAIDS 90-90-90 goal tend to pay attention to issues of availability of clinical resources, funding, and logistics supply such as antiretroviral (ARV) drugs (e.g. [4]) which are used in ART programs. But also of equal importance is the development and implementation of the appropriate information management systems for treating HIV as a chronic condition [5] [6]. Such systems potentially ensure correct patient identification during care encounters and linkage to care, and facilitate patient follow-up over time for retention and treatment adherence. From a health monitoring and planning point of view, information management systems are also required to produce the information needed for efficient resource allocation and for scale-up of treatment programs to cover more patients across wider geographical areas. Similarly, appropriate information systems (IS) can help substantiate more accurately the measurement of progress towards the 90-90-90 goals. Based on these and identified inefficiencies of paper systems especially when dealing with large number of patients [7], the World Health Organization (WHO) for example recommends a progressive transition from paper to electronic patient IS starting with high-burden sites [8]. Yet paper-based systems are heavily relied on in many developing countries including Sierra Leone. This is in spite of many information communication technology (ICT) based solutions previously explored in the literature [9]. A common approach in developing countries' setting is the use of electronic medical record (EMR) software, such as OpenMRS (www.openmrs.org) [7] [10] [11] [12]. However, this approach too is found to be problematic due to architectural complexities, and high cost of adoption and maintenance of EMR systems [11][13]. Thus within resource-limited settings, the continuous system adjustments needed for the changing dynamics of HIV treatment in particular becomes more challenging.

So to sum up, HIV treatment programs in developing countries are faced with resources availability challenges including lack of adequate funding, and human and material resources. This can also be seen in the lack of appropriate information management solutions. Prior attempts at implementing more efficient ICT-based IS solutions to support patient management too have largely failed to be sustained or be developed further due to resource limitations. Hence taking a different approach we explore in this study the application of an existing system made for collecting, aggregating and presenting population based routine data to also support individual level HIV case based management. With this approach we seek to utilize as much as possible resources already existing in the case context to minimize system implementation and subsequent maintenance costs, and thus potentially enhancing long-term system sustainability. Our conceptual framework is drawn from literature on health information systems (HIS) scaling in developing countries, where *scaling* involves expanding the size, scope, depth and functionality of an IS [14] [15] [16]. Combining this with functional architecting concepts and strategies for scaling functional architecture of software systems [17] we introduce what we call *scaling across functional domains*. We define this as the building of new and differentiated functionalities for previously uncharted domains, starting from an existing install base. This is demonstrated through our case where we have scaled from aggregate health data management system functionality into individual level HIV client management functionality in Sierra Leone. Specific functions covered with the new system functionality are HIV counselling and testing (HCT), ART management and adherence monitoring.

While we find this proposed dimension to HIS functionality scaling to be particularly relevant within resource-limited contexts, how to approach this in practice is lacking in the literature. Therefore our research question is *how to scale functionality of HIS installed base to serve unmet functional need in an adjacent domain.* From this we contribute empirical insights on how to extend ICT-based IS functionality from one functional domain to another. At the same time we identify key enabling conditions to include technological flexibility and collaboration among the various domain organizations involved. The study follows an action research (AR) project covering designing, piloting, and evaluating an electronic HIV patient information management system. This paper gives an account of the first AR cycle reporting from a single pilot site about to be expanded to cover more health facilities. The solution, named HIV Patient Tracker, is built on the existing national health management information system (HMIS) and based on the DHIS2 software platform (see: www.dhis2.org). In the remainder of the paper we describe details of the research project. First we introduce the conceptual framework. After this the research methods are described together with data collection and analysis strategies. This is followed by solution description, presentation of findings, discussions and concluding remarks.

2 The Conceptual Framework

Scaling of health information systems is analyzed in the literature on mainly horizontal and vertical dimensions [14] [15] [16]. Horizontal is in terms of size, coverage or scope, and functionality of the HIS in the same or different setting, and vertical in terms of penetration or depth of the HIS across the health system hierarchy. Within these dimensions, issues of complexity, learning, and adaptations are also analyzed against a backdrop of local and global contexts [18]. For example based on experience from implementing a HIS in primary health care in India, Sahay and Walsham [14] observe that IS scaling is an important issue in the context of globalization. They show how information systems expand within and across contexts and problematize what is scaled as complexity, and conceptualized complexity as a heterogeneous network of geography, numbers, technical systems, data and databases, system expertise, and socio-technical practices including politics(ibid).

With a more particular focus on software components, Nielsen and Sæbø [17] discuss how multiple actors are strategically configuring and re-configuring independent software components to serve functional needs when different systems are integrated. They conceptualize this as functional architecting and identify three different strategies; charting, encroaching and connecting. Charting is a strategy based on extending an existing software component with additional functionality to cover an unmet functional need, in a new and typically adjacent domain. The encroaching strategy is also about extending into a new domain, but where a different system is already offering the functionality. Thus, encroaching is about grabbing the functional role of another software component by duplication, competition or substitution. Where encroaching is about competition, the connection strategy is about coordinating and negotiating the functional role and responsibility of complementary software based in different domains. Turning to the larger literature, scaling of systems functionalities is also seen to occur across dimensions and within local and global contexts. However the focus and approach has predominantly followed a 'replication' logic of sameness of functionalities within and across settings [18].

In this paper, we will use the concept of scaling as our lens to discuss our findings related to how the paper based information system was changed and how the new HIV-system was implemented as an extension of the existing HMIS infrastructure. We term this as scaling across functional domains, which is an attempt at expanding on the functional scaling dimension beyond just replicating same system functionality, to the building of new functionalities for different and typically adjacent domains starting from an existing install base. In our case this can also be viewed as moving an IS into a *new* domain where the move will also potentially strengthen the parts (i.e. the aggregate and population based functionality) that remain in the *old* domain. The installed base which currently serves the old domain and is our starting point consists of the HMIS software, surrounding socio-technical infrastructures, system expertise and other support structures.

3 Methods

Under a broader action research project of the Health Information Systems Program (HISP, see www.hisp.uio.no) at the University of Oslo in Norway this study was initiated. HISP engages in health information systems design, development and implementation in developing countries [19]. The AR cycle [20] of *problem diagnosis, action planning, action taking, evaluating*, and *specifying learning* was followed. This approach was chosen as the research was prompted on a request by Global Fund (www.theglobalfund.org/en/) and the Ministry of Health and Sanitation (MOHS) of Sierra Leone to extend the functionality of the existing HMIS platform into a patient level information management system for the HIV program. This study also follows up the research project as earlier proposed in Adu-Gyamfi and Nielsen [21]. The project is funded by the Global Fund with the MOHS as the owner, and the University of Oslo (UiO) as the implementing partner. Other local stakeholders are the National HIV/AIDS Secretariat (NAS) in Sierra Leone, which has the strategic responsibility for the HIV/AIDS program in the country, the National HIV/AIDS Control Program (NACP) which is the program implementing agency and owner of the HIV patient information management system being implemented, and the Directorate for Planning Policy and Information (DPPI) which is responsible for the ministry's entire information systems infrastructure including the HMIS system.

An interpretive paradigm of IS research is used in this study[22]. Research data was collected and analyzed through qualitative means [23]. Data collection methods included participating in system conceptualization, setup and customization workshops, on-site visits, meetings, discussions, semi-structured interviews, email conversations, review of relevant documentations, and user training sessions. The empirical work spans a period of about 9 months between September 2017 and May 2018. All four authors were involved in the field work at various times but the first author stayed longer in the field (about 6 months in total) to collect more data while following up on the project implementation.

3.1 Data Collection and Analysis

The research team engaged with NAS, NACP and DPPI in meetings and discussions to understand and define the problem. The problem was defined as a lack of efficient, centralized and widely accessible information management system for the HIV program. Three selected HIV clinics were then visited to ascertain the problem scope. At all three clinics visited semi-structured interviews and discussions were conducted involving a total of 15 HIV counselors and ART nurses, 2 HIV medical doctors, and 1 electronic data entry clerk. Paper registers for HIV testing, ART, and aggregate reporting were also reviewed. These helped in identifying prevailing resource challenges, work processes and end-user requirements. After this, we held a weeklong system conceptualization workshop in Norway with DHIS2 developers and system consultants. Workshop activities included system design and customization planning, and learning from experts involved in similar ongoing projects in other developing countries. Later in the workshop we had a conference call with WHO representatives in Geneva for their feedback on the preliminary system design with respect to the WHO guideline recommendations [8]. This was also significant because our work informs early efforts to making a WHO reference configuration of DHIS2 for case based HIV information management (see e.g. [24]). We then embarked on a field trip to Sierra Leone to finalize the solution customization. Once on site, the HIV program personnel also reviewed the proposed solution and gave their inputs for further customization.

The next set of activities involved preparing training materials, developing system user guides, training of users and subsequently testing of the system at one clinic in the capital city. The test clinic has the highest case-load of ART patients in the country, which is about 4000 out of the 20000 registered patients countrywide. Challenges encountered during the system testing mainly related to internet service availability, which was resolved by the HIV program management. Two months into testing a first review meeting was held where we presented the system solution and progress on the implementation to 23 participants from NACP, NAS, DPPI and partner organizations. In May 2018, the system testing was ended and piloting with real-life patient data started. Program indicators were defined so the data entries could be supervised by the program management. We then conducted pilot expansion feasibility assessment for 8 more HIV clinics, and the findings together with preliminary results from the ongoing piloting were shared in a second project update meeting with 18 participants in attendance. This marked the end of the first AR cycle as we withdrew from the site to reflect on the results and prepare for the next cycle expected to focus on expanding the pilot to cover more HIV clinics. By end of September 2018 about 4200 HCT registrations and close to 400 ART patient enrollments had been recorded on the new system for the pilot site.

Data collection and analysis strategies employed during this research included daily field notes compilation and reflection in the form of a research diary. Both the research problem and data were analyzed and tackled iteratively through consideration of *the interdependent meaning of parts and the whole that they form* [23]. This informed subsequent data collection and analysis by identifying emerging themes and patterns. Further analysis was also prompted against the extant research literature to foreground issues of HIS scaling in developing countries and help position our research contribution in the broader context of HIS research and practice. This was facilitated through the chosen conceptual framework.

4 System Description

The resulting HIV patient tracker solution infrastructure consists of a DHIS2 server instance deployed on cloud-based server which is accessible via internet. This is deployed as a separate DHIS2 server instance different from the existing HMIS instance, with own database, server address, and user access policies due to sensitivities associated with HIV patient data. A secured link is to be established for automatic aggregate data transfer to the HMIS server. The design of the HIV case based surveillance (CBS) system and how it connects with the national aggregate HMIS server is shown in Figure 1. Two software modules of the DHIS2 platform namely Event Capture and Tracker Capture were customized for managing HIV client related services provided at HIV clinics which are HIV counselling and testing and ART services. The Event Capture is used for capturing data on counselling and testing including capturing Tuberculosis (TB) screening and testing information. The Tracker Capture module is used for managing adult ART, PMTCT, and Pediatric ART services. It consists of an *enrollment register* followed by four program stage registers in order of *initiation*, *visit*, *follow-up*, and *exit*. Additional features are included to enable scheduling of ART patient care events in advance, view events that are open, due, or in the future, and missed events which need to be followed up. All two modules were modelled according to local requirements and in line with WHO guideline recommendations on person-centered HIV patient monitoring and case surveillance [8]. The CBS system also inherits the reporting functionalities of the aggregate system plus its own individual events reporting functionalities.

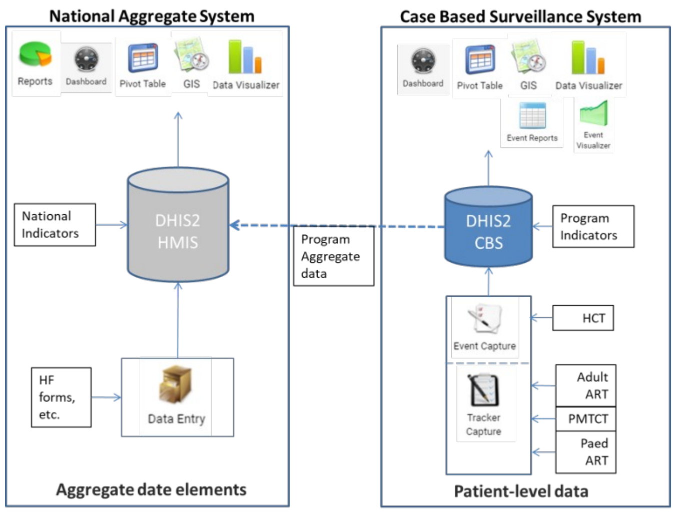

Figure.1: Design of the existing national aggregate system and the new HIV system

The new HIV patient tracker setup alongside the existing paper-based system is also shown below in figure 2. For now the two setups are running in parallel while the new electronic system is gradually integrated into the routine care delivery processes.

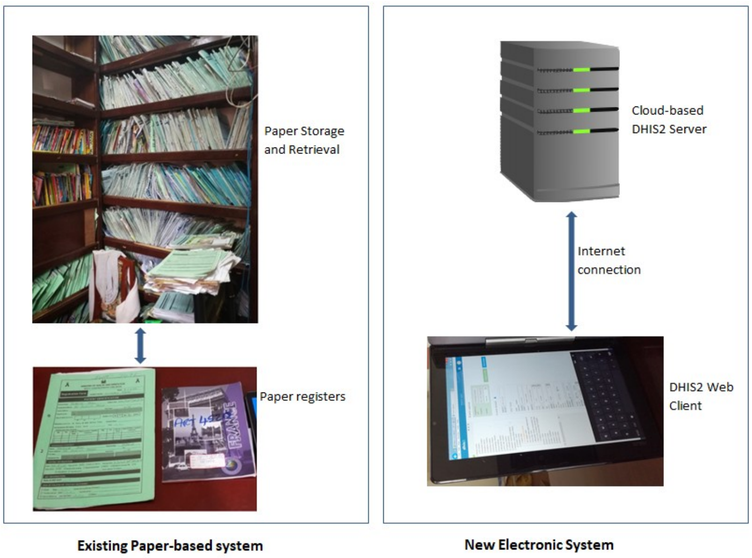

Figure 2: Paper vs. Electronic system for HCT and ART Management at the HIV clinic.

5 Findings

During the research we found the HIV service workflows across the clinics visited to be generally identical and adhering to WHO guidelines to a large extent. Testing for HIV is offered as a routine service, notably for tuberculosis patients (as co-infection is common) and all pregnant women, as well as in some other programs. If the test is positive, the patient is enrolled in ART. Treatment consists of a mix of various drugs, which may be changed over time due to adverse effects or less efficacy. Patients on ART thus regularly come to a health facility to measure the effect of treatment and to get a new supply of medicines. CD4 count and degree of viral load suppression are also measured (CD4 count is used to monitor response to ART, and viral load is suppressed at a level where the disease is chronic but not deadly and risk of passing the virus on to others is limited). Special programs target pregnant women to prevent transmission to the unborn child, and there are also special child programs where nutritional status is included in addition to ART management. Due to these different treatment configurations, an information system needs to cater for both larger populations for irregular testing, and a smaller population on life-long treatment with scheduled visits. Key challenges relate to duplication of records and patients who default on ART. One area contributing is patient movements across facilities and service points without accompanying paper trail. This point was reiterated by the HIV program manager explaining that "*a client can default and even be reported as lost to follow up at one facility, while taking treatment in another facility*". This also affects ART enrollment data credibility and has implications for efficient resource planning and allocation.

Gauging from the national list of facilities offering HIV services it can be said that care is reasonably well distributed across the country. However shortage of skilled health workers coupled with the inefficient paper-based information management system pose challenges for efficient service delivery. The paper systems by nature cannot support automation of tasks needed for effective patient monitoring, such as automatically scheduling patient visits and follow-ups with auto-reminders. The many associated manual processes also consume time and attention which should have been given to patient care. In addition, with increasing complexities and size of data, relying on paper tools alone makes it difficult to detect and correct data quality problems. In fact the ongoing system piloting has revealed discrepancies between data aggregates from the HIV patient tracker and that of the paper-based tools which feed into the HMIS. Furthermore as we plan to increase the coverage of the solution to include more health facilities the need for unique patient identification system has been expressed. This is required to facilitate ART patients' follow-ups and also minimize incidence of multiple registrations.

Lastly, on the system implementation, we find team flexibility necessary in adapting plans and system choices, and aligning multiple stakeholder interests and resources towards project goals. The state of local infrastructure should also be taken into consideration. For example while it would have been possible to deploy the patient IS solution on a local server infrastructure, an existing offshore cloud server was used. Although this option was to guarantee higher system availability due to generally unstable electricity supply in the country, the downside is that without internet connectivity the system cannot be used. Hence an offline usability feature of the DHIS2 system should be explored further.

6 Discussions

Our discussion of the findings so far in our project relate to three main points; the characteristics of the technology that made this scaling possible, the benefits of the installed base related to the specific technology, and the need for organizational collaboration to grow in a sustainable way.

First, our case is one of proven, though limited, success. The DHIS2 was successfully scaled to cater for the recommended WHO guidelines on case based management [8], while allowing customization to suit current work practices in the Sierra Leone hospital. Preliminary results point to quick adoption by staff at the hospital, and potentially improved aggregate data quality compared to the paper-based reporting structure. On the technology side, this can be attributed to the design and architecture of the DHIS2 itself. Having gone through a decade of *generification* [25], it can now be applied for a wide range of use cases [26], especially applied to management of aggregate and patient data in the health sector. The generic nature of the software also means it needs to be customized and configured before it can be used, and can be considered as half-ready product [27]. The possibilities for customization are great, giving it the flexibility needed to first accommodate the WHO guidelines, and when there were requests for additional data to be collected in Sierra Leone, this could be added on the fly. While the tracker and event functionalities have been applied for HIV management in other countries, Sierra Leone was the first place it was adapted specifically building on the WHO guidelines[8].

Second, the intended approach was to build on the installed base to limit the amount of technologies needing support. In our case the answer to this is inconclusive, as there has been limited interaction so far between the owners of the HIV patient IS and the owners of the HMIS. However, there are also some obvious efficiency gains. There has been no introduction of new technology, and the cloud server used for the HMIS was partitioned to serve also the HIV system. There is an in-country person who can assist in maintaining both. There is also a strong base of local level staff in districts that routinely use DHIS2, which will provide a local support structure for future national roll out of the HIV system. Indeed an important aspect would be to grow the total user base, of both administrators and end-users, which will mitigate some of the known challenges of staff turnover and political changes. As the users of the different systems are different, the growing of both will limit the risk of losing key capacity related to the technology. Integration of information systems is another key challenge in the field [28], which has not been explicitly covered in this paper. However, using the same technology across two functional domains this integration is achieved by default. As the case based HIV system covers more health clinics, aggregate statistics derived from it can supplant the manual reporting of the same data to the HMIS. An added benefit of this will be fewer manual aggregation and data entry steps, improving data quality. Building on the installed base does not only have potential benefits for the new system introduced, but also strengthens the existing system it is built upon.

Thirdly, as the discussion above points to, while increasing the capacity of one technology to support several systems has potential benefits, it needs to be coupled with corresponding growth in organizational cooperation [29]. The benefits of increased user base, increased scope for specialization, and mutual support between user groups can only be achieved if the system owners (the organizations) enable and promote this. If this is not achieved, we have two organizations using the technology independently, building their own capacities irrespective of their complementarities, and independently facing the same challenges to implementation and sustainability. At the moment, there is only limited collaboration between DPPI and NACP. While DPPI have made available hardware for the pilot (tablets) and assigned their staff at the hospital to support the entry of backlog data, a closer collaboration between DPPI and NACP needs to be fostered, so that they can pool resources for common requirements such as server maintenance, hardware procurement, and end-user training.

Theoretically, we have in this paper approached the complexity of scaling by focusing on functional architecting[17]. Our case is an illustrative example of charting, in terms of the HMIS system being extended with additional functionality to cover an unmet functional need related to HIV treatment. As shown, with the flexible DHIS2 software the WHO guidelines could be adopted and additional local requirements from Sierra Leone implemented. While Nielsen and Sæbø [17] primarily focus on different approaches to strategically positioning of different software components, we have in this paper highlighted how scaling functional architecture also depends on coordination and cooperation at the organizational level. We also emphasize building on the installed base so as to maximize efficient utilization of existing resources. But to release the full potential of this strategy the social, technical and political complexities of the context of scaling must also be taken into consideration [14] [15].

7 Conclusion

In our research we sought to investigate how we can scale an existing IS across two domains. We approached this through building on the existing Sierra Leone HMIS to cater for case based HIV management also. HMIS and case-based management represent different domains of care and information management. Where HMIS is routine reporting and analysis of aggregate data for general health management, the HIV system is focusing on continuous individual case-based management. We chose this approach because the alternative of introducing a new information system based on a different technology will require creating all the institutional and organizational structures needed for sustaining the solution. By instead building on a technology already present and supported in the MOHS, we aimed with this choice of architecture to reducing the costs and complexities related to the implementation and further development. Flexibility of the installed base technology enabled its functionality to be scaled for the different use case. Cooperation between the owners of the two systems (domains) though currently limited was vital. Additionally, implementation team flexibility helped achieved practicable and potentially more sustainable solution with the prevailing resource situation. In future research fostering of deeper collaboration between the owners of two systems for long-term project sustainability will be investigated further.

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