



# The (Missing?) Role of Health Information Systems (HIS) in Patient Care Coordination and Continuity (PCCC): The Case of Uganda

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**Abstract.** In Uganda, patients receive care from different health facilities. However, most facilities struggle to exchange patient information across boundaries because their health information systems (HIS) operate in silos. Yet to meet the needs of a patient who receives care from different health facilities the participating facilities ought to collaborate, share and exchange patient information in order to enhance patient care coordination and continuity (PCCC) across the continuum of care. Using qualitative interviews we examine five HIS to investigate the problematic issues that could be raised during HIS active involvement in PCCC across the continuum of care. Results highly indicate that the existing HIS in the country do not enhance PCCC, and below are some of the challenges realized: interoperability objective not given priority during system design, HIS operating in silos, lack of a national standard for the patient record, health facilities exercising ownership of the data and other non-technical challenges. The main implication of these findings is that focusing on the interoperability objective as a design requirement during HIS implementation would potentially repress all other challenges and revive the active role of HIS involvement in PCCC.

**Keywords:** Health information systems ·  
Patient care coordination and continuity

## 1 Introduction

Health information systems (HIS) are increasingly being implemented at most health facilities in order to promote quality healthcare delivery [1, 2]. However, even with increased HIS implementations, health facilities still struggle to share and exchange patient information amongst themselves. An assessment of the current HIS integration schemes, reveals that existing HIS are operating in silos, are fragmented and non-interoperable [3–6] since they do not support information sharing and exchange between each other [3] across the continuum of care. For example, in case of referrals patients repeat tests due to lack of past records to aid care continuity [7]. “Rarely, can

health facilities access electronic medical information from other facilities even within the same geographic setting” [8]. Such lack of coordination among healthcare facilities delays decision making [9], and further impedes patient care coordination and continuity (PCCC) [1, 10].

Therefore, given that patients receive assistance from different health facilities across the continuum of care [11, 12], it is necessary for all participating facilities to be able to collaborate, share and exchange patient medical information [11, 13] in order to enable patient care coordination and continuity (PCCC). According to Haggerty and Lou [14, 15] patient care continuity can be described as the extent to which knowledge about the diagnosis and management of patient health problems is experienced as coherent, connected and conveyed forward in time. In addition care coordination has been defined as “the deliberate integration of patient care activities between two or more participants involved in a patient’s care plan” [16]. Therefore, to achieve PCCC past patient medical information should be coherent, connected and conveyed forward through deliberate integration efforts between participating facilities [14–16].

Expediently, deliberate HIS integration efforts can pave way for PCCC and quality healthcare [17] as seen in well planned HIS that have restructured the way healthcare professionals process and manage patients’ medical information [18, 19]. Moreover, several other studies have highlighted ICTs’ potential in improving the healthcare system and scaling up healthcare initiatives [20]. However, several existing HIS operate in silos, and this has led to the need of research that focuses on: HIS developments that move away from vertical silos to horizontally integrated systems [21], and research that examines the challenges and opportunities for information systems integration in healthcare [1]. Consequently, an investigation in Uganda of 2018, answered by 41 respondents consisting of software developers, system users and ministry of health officials was carried out to establish problematic issues that can be raised concerning HIS involvement in PCCC. This inquiry concluded that almost all the existing HIS within the country could not enhance PCCC and further discussed potential challenges of HIS involvement in PCCC.

This rest of the paper is structured as follows: Sect. 2 presents a discussion of the concept of HIS involvement in PCCC and Sect. 3 highlights the research approach. This is followed by a presentation of the findings in Sect. 4 and a brief discussion of the missing role of HIS in PCCC in Sect. 5. Finally, a conclusion is given and a direction for future works.

## 2 HIS Role in PCCC

### 2.1 HIS Role in Healthcare

A Health Information Systems (HIS) is a set of procedures organized to process and disseminate timely information that improves the health care management decision making process [22, 23]. Indeed health information systems have been heavily implemented [1] for their renowned potential in scaling up healthcare initiatives [20]. According to Berg [24], HIS play a great role in bringing about synergy between primary and secondary care hospital roles. These HIS can be categorised under clinical

or managerial HIS [22]. Clinical HIS can enhance patient care activities whereas health management information systems can enhance managerial secondary care activities [2, 25]. PCCC can be harnessed by implementation of clinical HIS like the electronic patient records' system that can process and avail a patient record [26]. Furthermore, [26] states that comprehensive electronic health records can enhance continuous high quality patient care. Subsequently, when HIS take on their role of information processing and dissemination of vital patient medical information across care providers they can certainly enhance PCCC. [2, 7] argue that HIS ought to be interconnected in order to gather and disseminate relevant health information across providers for continued and integrated quality patient healthcare. To have these HIS interconnected, we need 'interoperability' – which is the ability for them to exchange and use that information [27]. This interoperability can at times be facilitated by pre-arranged protocols or a team that works very closely [28]. In such a plan, the patient receives one coherent and logical medical record to inform the ongoing treatment. To this cause, several authors have called for the implementation of integrated and interoperable HIS [2, 22] capable of enhancing PCCC within the continuum of care.

## 2.2 PCCC Role in Healthcare

One of the major processes within primary healthcare, is the 'primary-care-process'. This process according to [29, 30] consists of: access, integration, continuity and comprehensiveness of care. It is within this primary care process that patient care coordination and continuity (PCCC) is pursued in order to aid informed decision making within the continuum of care. PCCC is a term coined to mean care coordination and care continuity. Care continuity according to Lou [15] is when past medical history is conveyed forward in time between the participating facilities. According to Haggerty and Schang [14, 31], care continuity is enhanced by 'care coordination' at both information and managerial levels. The information level ensures that information is recorded and used across the continuum of care while the managerial-coordination ensures longitudinal follow-ups across care providers. This implies that to achieve quality healthcare, patient care should be both coordinated and continued within the continuum of care.

When patient care is coordinated and continued across providers, the patient receives up-to-date medical treatment that is logically informed by their past medical histories [14]. Currently patients need timely updates on their personal health more than ever before [1]. A patient "medical record is a dynamic informational entity that enables continuous monitoring of the health condition of a patient which aggregates all the information from the clinical history and treatments" [2] and this comprehensive patient record supports continuous high quality patient care within the continuum of care [26, 32]. On the contrary, lack of PCCC can delay ongoing treatment as the health professionals seek out for past patient medical information to guide the process [3, 7, 32], or leads to uninformed treatment whereby the later has critical effects of the patients' health as expressed [33] that coordinated care between and across health facilities is often a matter of life and death.

### 3 Research Approach

#### 3.1 Study Setting

The study was carried out in Uganda and is part of an ongoing study that is investigating the interoperability of health information systems used in the country. Health services in the country are offered by both government and private owned health facilities, from the national referral to regional referral through district hospitals to health center levels [34]. In Uganda, patients can visit any health facility for treatment. Apparently, each health facility operates independently and implements its own HIS which has resulted into a pool of HIS within the country [5]. Therefore, this study focused on HIS that are actively used at health facilities. Consequently, the investigation was done by visiting the system proprietors and developers at their head offices, systems users at the health facilities and ministry of health key informants at the Ministry of Health headquarters.

#### 3.2 Case Description

To identify health information systems for the case study, an exploration of the implemented health information systems within the country was carried out during the period of July to December 2017. It was discovered that many systems in Uganda do not go beyond the piloting stage, due to lack of sustainability funds after the funded

**Table 1.** Description of the health information systems under study.

HIS	Description
DHIS2	The District Health Information System-DHIS2, this is a health management system “which provides a coherent platform for data entry and processing, and presentation of data to planners” [36]. It is highly recommended by the MoH for reporting about health indicators to the MoH
HeleCare2x	HeleCare2x was customized for Uganda, from Care2x which is an Integrated Hospital Information System including Surgery, Nursing, Outpatient, Wards, Labs, Pharmacy, Security, Admission, Schedulers, Repair and Communication among others [37]. Current client base are health facilities under the Uganda catholic medical bureau private non for profit ( <a href="http://care2x.org/">http://care2x.org/</a> )
NGANISHA	Nganisha health information system: a comprehensive health facility management information system developed locally in Uganda to provide real time and complete data of a health facility. Current pilots are in government health facilities
UgandaEMR	UgandaEMR is an OpenMRS based electronic medical record system customized for Uganda. It is a system recommended by the ministry of health as the nation’s patient records’ system. <a href="http://emrportal.mets.or.ug/">http://emrportal.mets.or.ug/</a>
Clinic Master	This is an integrated health information management and medical billing software that automates patients’ transactions at the clinic on a visit basis and daily procedures. Current client base in Uganda are private health facilities. <a href="https://clinicmaster.net/about-us/">https://clinicmaster.net/about-us/</a>

project ends [35]. Subsequently looking at system sustainability, system coverage and usage across health facilities and insights from the ministry of health, five outstanding health information systems were chosen for this study. The five systems chosen included: District Health Information System -DHIS2, Clinic master, Nganisha health information system, HeleCare2x and UgandaEMR. The following Table 1 gives the description of the HIS for the case study.

### 3.3 Method

The study followed a qualitative case study approach [38] with an interpretation of the study findings done by the researcher [39]. Through a case study approach, new discoveries were verified with existing knowledge in the area of HIS involvement in PCCC [40]. Data for the study was collected through semi-structured interviews and focused group discussions. Interviews were used for soliciting information regarding the functionality of the health information systems and their role in enhancing PCCC. The study participants included health officials from the ministry of health (MoH), system developers and users from each of the five studied HIS. A total of 5 MoH key informants, 22 system developers and 14 system users were interviewed. Interviews, which on average took 30–60 min, were carried out with the use of an interview guide and an audio recorder, and interviewer took field notes whenever it was necessary. For purposes of validation, at the end of each interview both parties would do a recap of what had transpired during the session in order to have the same understanding.

Furthermore the interviews were transcribed and analysed through the general inductive analysis approach according to Thomas [41]. Guided by this approach we read the transcript over and over and captured brief summaries of categories from the text relating to our study objectives. Throughout the analysis exercise responses concerning each HIS were compared first, followed by comparisons across the studied HIS.

## 4 Findings: Challenges of HIS Involvement in PCCC

From the interviews we found out challenges associated to HIS involvement in PCCC as presented in the subsections that follow.

### 4.1 Interoperability Objective Not a Design Priority

For all the systems studied, it was discovered that the interoperability objective was never considered as a design requirement. Most of these systems were designed to manage and store patient records at the facility level. However, some systems were designed to promote patient information flow within the facility not across facilities. Therefore, for such systems sharing a patient record across facilities becomes a challenge, as illustrated in the following verbatim quote by our respondents.

*“So it was mainly to harbor patient information and use as an information system to manage patient records that was the main aim it did not have anything to do with data exchange before”.*

## 4.2 HIS Operate in Silos

Most health facilities in the Uganda implement independent health information systems that are usually not interoperable. Sometimes different sections of the same health facility implement independent systems. This is in many cases attributed to donor pressure. Respondents stated that most systems in the country serve a section of the care process according to donor needs and most of them are silos as indicated in the verbatim quotes below.

*“There were systems that were running but they were specific to programs, there were not general”. “Systems are silos, which is not talking to each other”.*

*“Another problem why people have different systems is because of the funders”.*

This is further exacerbated by the lack of country uniform HIS implementation guidelines that would certainly lead to standardized systems that are capable of being interoperable as illustrated in the following verbatim quote.

*“We lack regulations that determine the design of electronic systems at least by Uganda national bureau of standards.”*

## 4.3 Lack of a National Standard for the Patient Record

All the existing health information systems in the country are developed without uniform standards and so the patient information is recorded in various formats that are non-interoperable. Consequently, each system holds some kind of patient record different from the others and so there is no standard patient record for exchange. One respondent stated that:

*“If we are to share what should we share and what should we not share”*

The situation is worsened by the lack of a national patient identification that would help in identifying the patient as the same across the continuum of care.

## 4.4 Data Ownership by Health Facilities

Each health facility records its own data in its own format, and therefore has sole ownership over the data. Respondents perceived this as the common practice especially in private health facilities that have no will to share patient data as illustrated in the following verbatim quote.

*“Currently the client base is private everyone wants to keep their information for themselves, they wouldn’t want the sharing....private hospitals want their data”.*

With such mentality, it becomes hard to harness HIS to improve PCCC across the continuum of care.

## 4.5 Non-technical Challenges

There are a number of challenges encountered in the use of HIS for PCCC. For example, challenges to do with cost of purchasing and maintaining computing

equipment is usually high for health facilities. In developing countries, infrastructure is still a big challenge, with intermittent and inadequate internet and electricity supplies. Others include lack of skilled technology savvy personnel as indicated in the respondent's verbatim quotes.

*"They cut off power even before we completed the pilot"*

*"We left because there was no equipment and support"*

Another respondent noted the presence of the policies that do not support patient data exchange across facilities.

*"But the challenge comes, in with policy, policy of Uganda especially health does not allow clouding patient information. That means it does not allow remote access of patient information but rather have patient information strictly at health centers."*

Yet another challenge is resistance to change from the old way of doing things to new ways of using technology.

## 5 Discussion: The Missing Role of HIS in PCCC

By their nature, information systems should facilitate information processing from data creation to information dissemination to all relevant stakeholders for purposes of decision making [1, 22, 23]. Indeed, they have been heavily employed in processing health data in order to promote quality healthcare. One example is the electronic medical records system which according to Heavin [1] provides a unified single view of patient data, and they have currently restructured the way patients' medical data is handled at a given health facility.

However, amidst rapid HIS implementations, there are challenges encountered that have led to the missing role of HIS in PCCC, as discussed below. Findings reveal interoperability issues as being the greatest challenge of HIS involvement in PCCC [32, 42]. Though several state policies address interoperability issues, in practice system implementers do not consider interoperability aspects during HIS implementation. In Uganda policies that support system interoperability are under development though the current ones do not support exchange of patient data across facilities [35, 43]. The lack of active interoperability policies, standards and implementation guidelines, leaves health facilities no choice but to implement independent HIS, that end up operating in silos and not capable of exchanging data [3–5, 35, 43]. Consequently, all systems are developed following different implementation standards [42] and therefore have no uniform patient record to exchange across the continuum of care for PCCC. Therefore, the missed interoperability objective during HIS design potentially leads to the missing role of HIS in PCCC, as patient records will be dispersed and not exchangeable across the various health facilities [10].

Additionally, since health facilities implement their own independent HIS, they tend to own their data and are not willing to share it across facilities. Hence these particular HIS will not actively participate in PCCC. These challenges combined with other non-technical challenges like: lack of technology-savvy labour, high costs of

computing equipment, poor infrastructure [34, 44, 45], and inadequate policy guidelines [35, 43] all together justify the missing role of HIS in improving PCCC.

## 6 Conclusion and Future Works

This study set out to discover the missing role of health information systems (HIS) in PCCC. This was carried out by discovering the problematic issues of HIS involvement in PCCC. Certainly, through an empirical case study approach, the study validated both new and previously known challenges through a discussion of the missing role of HIS in PCCC. Important to note is that internal interoperability in some health facilities existed but interoperability across facilities emerged as the greatest challenge, hence the missing role of HIS in PCCC within the continuum of care.

Amidst an array of challenges, HIS have ended up missing their unique and fundamental role of enhancing PCCC. Therefore, there is a need for future research to revive this great role of HIS involvement in PCCC, by investigating how these challenges can be overcome and most importantly, on how interoperability across facilities can be achieved and prioritized.

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