Realising the Value of Information Collected by Community Health Workers

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Abstract: The delivery of health services through health facilities such as hospitals and clinics has been found to be inadequate in developing countries. This is due to limited access to facilities by members in communities, especially in the rural context. To address this, community health workers (CHWs) have been utilised in the South African health system to provide basic health services in communities. Various eHealth solutions, in particular mobile technologies, have been developed and deployed to support CHW in their tasks. Since CHWs often are the first line of contact of patients with the health system, they are the first to register individuals, assess their health status and refer them to health facilities if medical attention is required. The data collected by CHWs is currently stored in separate proprietary data stores. There is an opportunity to utilise the information collected by CHWs in the wider health system through interoperability and applicable standards. This will enable the health system to use the registration information captured by CHWs to reduce the need for reregistration on other systems when individuals present themselves at health facilities, enable clinical practitioners to view assessment results from home visits, track referrals and adherence to referrals and enable sharing or medical summaries between heterogeneous eHealth systems. This paper describes an approach to enable heterogeneous CHW applications and patient management systems to interoperate in a broader, national eHealth system through compliance to defined eHealth standards and a shared foundational eHealth interoperability framework in order to realise the described advantages.

Keywords: eHealth, community health workers, eHealth interoperability

Introduction

The delivery of health services through health facilities such as hospitals and clinics has been found to be inadequate in developing countries (Narasimhan et al. 2004). This is due to a number of reasons including inadequate human resources in the health system and large distances to be travelled to primary healthcare facilities in rural areas (Sumit et al. 2016, Sheetal et al. 2012). Community health workers (CHWs) have been increasingly utilised in low- and middle-income countries to address this gap (Schneider et al. 2016). In South Africa, the deployment of CHWs into communities as part of Ward Based Outreach Teams (WBOTs) is an integral part of the re-engineering of primary healthcare (Mayosi et al. 2012, Marten et al. 2014, Rabkin et al. 2015). CHWs provide basic health services in communities such as home visits, health education, maternal and child health support, communicable disease control, referrals, record-keeping, and collection of data (Perry et al. 2014, Katigbak et al. 2015).

Various eHealth solutions, in particular mobile health (mHealth) technologies have been developed and deployed to support CHWs in their tasks. Mobile health technologies used by CHWS include (1) personal or automated phone calls; (2) text messages including text reminders or messages for community mobilisation; (3) collection of field based health data for health record tracking and clinical decision support; (4) mobile telemedicine devices for patient monitoring and diagnosis; and; (5) information access for facilitation of health education sessions (Källander et al. 2013, Braun et al. 2013). It is also indicated by Braun et al. (2013) that mHealth tools may also be useful to facilitate process improvements and compliance with standards and guidelines.

Since CHWs often are the first contact of the health system with citizens (Walker 2013), they are the first to register individuals, assess their health status and refer them to health

facilities if medical attention is required. CHWs will refer individuals to a primary healthcare facility if a possible health risk is detected. If a person who was referred to a healthcare facility does not adhere to the referral, and this is made know to the CHW, he/she can perform a follow-up visit to the individual and motivate them to adhere to the referral.

The mHealth tools and associated eHealth systems currently used by CHWs store the data collected in separate proprietary data stores. This results in limited or no opportunities for data exchange and/or interoperability between different systems and limits the ability to use and respond to data captured by CHWs to only users of that specific eHealth application. However, the wider eHealth system consists of many different eHealth and mHealth systems. Without interoperability between different systems it will not be possible to reuse data captured in the field by CHWs in other patient management systems or track if a person adhered to a referral if the health facility where the person is referred to uses a different patient management system than what was used by the CHW.

eHealth interoperability refers to "the ability of health information systems to work together within and across organizational boundaries in order to advance the health status of, and the effective delivery of healthcare for individuals and communities" (HIMSS 2013). This implies that information collected by one eHealth or mHealth solution can be shared with and used by another solution through the employment of a common standards based interface. There are many different, and often competing, standards for eHealth (Adebesin 2013). Integrating the Healthcare Enterprise is an initiative that describes standards based health information exchange according to precisely defined profiles that address specific healthcare tasks (IHE 2012). The National Department of Health of South Africa gazetted a Health Normative Standards Framework for eHealth in South Africa in April 2014 (NDOH 2014). In this document a collection of generic eHealth functions are listed with relevant IHE profiles and associated base standards that should be used to enable interoperability within the South African eHealth context. The eHealth functions addressed range from patient identification to update of medical history. There is, however no current IHE profile defined for the exchange of information collected by CHWs.

There is an opportunity to utilise the information collected by CHWs in the wider health system through interoperability and applicable standards. This will enable the health system to use the registration information captured by CHWs to reduce the need for reregistration on other systems when individuals present themselves at health facilities, enable clinical practitioners to view assessment results from home visits and most importantly, track if a patient referred to a health facility, adhered to the referral. Through referral tracking it will be possible to identify individuals who did not comply with referrals and schedule follow-up home visits. It is particularly important to follow up in cases of maternal and child health as well as suspected communicable or non-communicable diseases.

The aim of this study is to describe how eHealth standards and interoperability can be utilised to (1) reuse the information captured by CHWs and (2) track referrals and adherence to referral over heterogeneous mHealth and eHealth applications. This study will be of interest to institutions implementing or using eHealth and mHealth applications interested in establishing interoperability in order to benefit from the information collected by CHWs and other eHealth systems.

The requirement for privacy and security of patient information and specifically clinical information in the context of health information exchange is crucial. However this is not the focus of this paper and will not be described in detail.

The rest of the paper is structured as follows: The research method utilised in the study will be briefly described in the next section. This will be followed by a discussion of the interoperability platform for standards based exchange of information collected by and useful to CHWs. The paper is concluded in the last section.

Research method

The study described in this paper has been conducted according to the Design Science Research method. It was selected because design science research facilitates studies where the anticipated result will be an artefact such as a concept, model, method or instantiation that can be applied for a practical purpose (March et al. 1995). The resulting artefact should be relevant, by solving an important problem, and novel, by solving a problem in a unique and innovative way (Geerts 2011, Hevner et al. 2004). The research described in this paper fits in the adaptation quadrant of Gregor and Hevner (Gregor et al. 2013) since it extends known solutions, i.e. establishing eHealth interoperability through the application of eHealth standards, to a new problem area of exchanging information collected by CHWs.

The following processes are required by Design Science Research: (1) Preliminary study or analysis of the problem; (2) Development of solutions or prototypes; (3) Evaluation and testing; and; (4) Assessment or reflection (Reeves 2006, March et al. 2008, Wang et al 2010). The study presented in this paper addresses all four of the required processes. The preliminary study was conducted by investigating the problem area and the articulation of the opportunities of exchanging information collected by CWH between heterogeneous eHealth and mHealth applications. The development of solutions process is reflected in the conceptual design and implementation of the platform to enable standards based exchange of information collected by CHWs. The study is currently in the evaluation and testing process. The designed platform has been developed and is being tested in a simulated environment in a laboratory. The platform will be deployed in at least one district in South Africa within the next 4 months for real-world piloting and assessment as required by the last process of Design Science Research listed above.

Hevner (Hevner 2007) and Pirenen (Pirenen 2009) outlined three inherent research cycles required in Design Science Research namely relevance, rigor and design. The study to conceptualise, design and implement an interoperability platform to enable standards based exchange of information collected by CHWs addresses all three cycles as described below:

1. *Relevance cycle*: Design Science Research is initiated by researching the requirements and criteria for the conceptualization of the platform for standards-based exchange of information collected by CHWs.
2. *Rigor cycle*: The research is grounded in the study of relevant research literature to ensure a firm understanding of existing research and work to guide the conceptualisation and design of the platform.
3. *Design cycle*: The design cycle is facilitated through the design, construction and refinement of the platform for standards-based exchange of information collected by CHWs.

The interoperability platform for standards based exchange of information collected by and useful to CHWs

The interoperability platform for standards based exchange of information collected by and useful to CHWs is described in this section. The description will start with an articulation of the problems, opportunities and criteria an appropriate platform should address. This is followed by the design of the conceptualised platform. Finally, a discussion of the evaluation of the platform against the criteria is presented.

Problem description and criteria

CHWs are the first contact with the health system for many citizens in middle- and low-income countries, especially in rural communities. CHWs are increasingly equipped with a range of mHealth applications to support them in their work. Specifically, there exist numerous mHealth applications to assist CHWs to register households, register household members and record health assessment results. Although this information is very useful to

users of a specific mHealth and associated eHealth solution, its use is limited to only that solution and cannot be utilized in the wider eHealth context.

The following problems or limitations are identified in this scenario:

1. When a person is registered by a CHW in the field using a mHealth application and this person goes to a clinic using a different patient management system, the person must be registered again on the other system.
2. If a person was referred to a clinic by a CHW and the person presented at a clinic using a different patient management system, it is not possible for the CHW to track if the person did adhered to the referral or not.
3. If a patient is referred to a hospital by a clinical practitioner in a clinic, and the patient goes to a hospital using a different patient management system, it is not possible for the clinic to track if the patient did adhered to the referral or not.
4. A referring health facility (e.g. a clinic) does not have access to the results of a referral if the facility the patient was referred to (e.g. a hospital) used a different patient management system.
5. In both instances of referral described in points 2 and 3 above, the CHW cannot be mobilized to perform a follow-up visit to the household member in the case of non-adherence of a referral.

The criteria for an interoperability platform for standards-based exchange of information collected by and useful to CHWs are as follows:

1. *Exchange of registration information*: Household member registration information captured by CHWs must be reused by other patient information systems to eliminate the need to repeat registration for every new system the patient encounters.
2. *Referral tracking*: Tracking of referrals and adherence of referrals must be possible over heterogeneous patient management systems.
3. *Sharing of medical summaries*: Sharing of medical summaries between referring and referred to health facilities must be supported.
4. *Standards based exchange*: All information exchange should be performed through eHealth standards to enable any compliant third part application to participate.

The use case the platform for standards based exchange of information collected by and useful to CHWs should support is described in the following section.

Use case for interoperability

The use case of the proposed platform is described in the context of maternal health, but is generalizable to support any medical condition. The maternal health referral tracking use case is depicted in Figure 1 below.

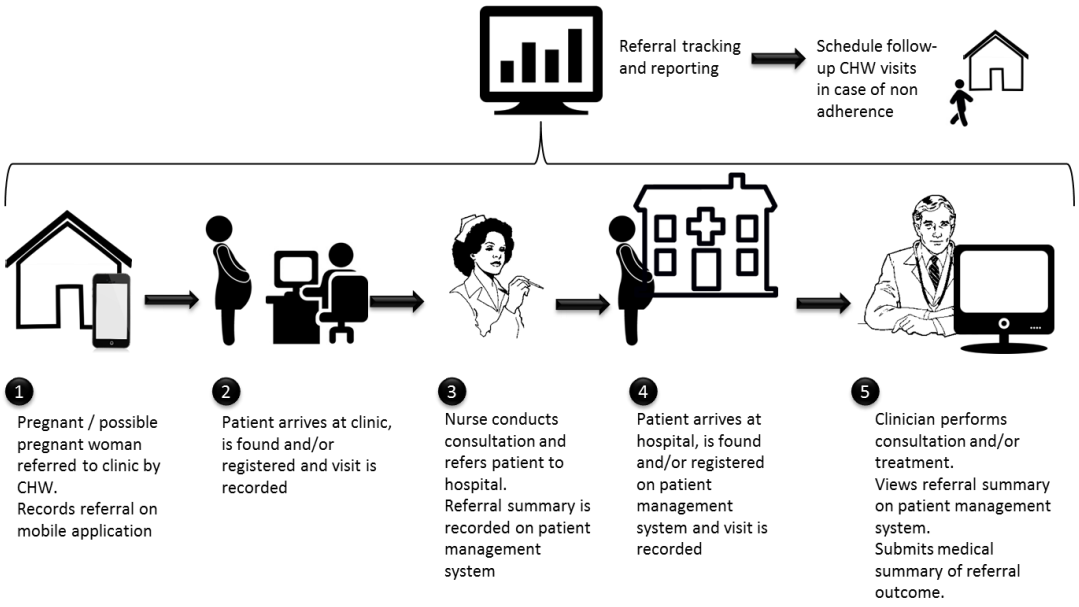

Figure 1: The maternal health referral tracking use case

The use case is initiated when the CHW visits a household in the field and identifies a pregnant or possible pregnant woman. It is standard operating procedure that any pregnant or suspected pregnant woman found in the community should be referred to the clinic. The CHW registers the woman, records the assessment of pregnancy or suspected pregnancy and the referral using the mobile application.

When the patient arrives at the clinic, the clerk at reception searches for the patient using the patient management system deployed at the clinic. Since the patient has previously been registered by the CHW, the patient detail is found and no re-registration is needed. The visit is recorded on the patient management system and the patient proceeds to the consultation room.

The clinical practitioner at the clinic (e.g. a nurse) conducts the consultation. If referral is required, the nurse refers the patient to the hospital and records the referral using the patient management system.

When the patient arrives at the hospital, the clerk at reception searches for the patient using the patient management system deployed at the hospital. Since the patient has previously been registered by the CHW and the information was confirmed at the clinic, the patient detail is found and no re-registration is needed. The visit is recorded on the patient management system and the patient proceeds to the consultation room.

The clinical practitioner at the hospital conducts the consultation and provides treatment if required. A medical summary of the outcome of the referral is recorded in the patient management system at the hospital.

The clinical practitioner at the clinic can view the medical summary of the outcome of the referral at any time.

Reports and visualization of referrals and adherence of referral can be viewed over all referrals and visits recorded.

Referrals not adhered to within a predetermined time period can be identified and follow-up visits from CHWs can be scheduled to the identified patients and households.

The design for a platform for standards based exchange of information collected by and useful to CHWs that supports the use case articulated above is described in the following section.

Platform design

The interoperability platform to support the use case described in the previous section is depicted in Figure 2 below.

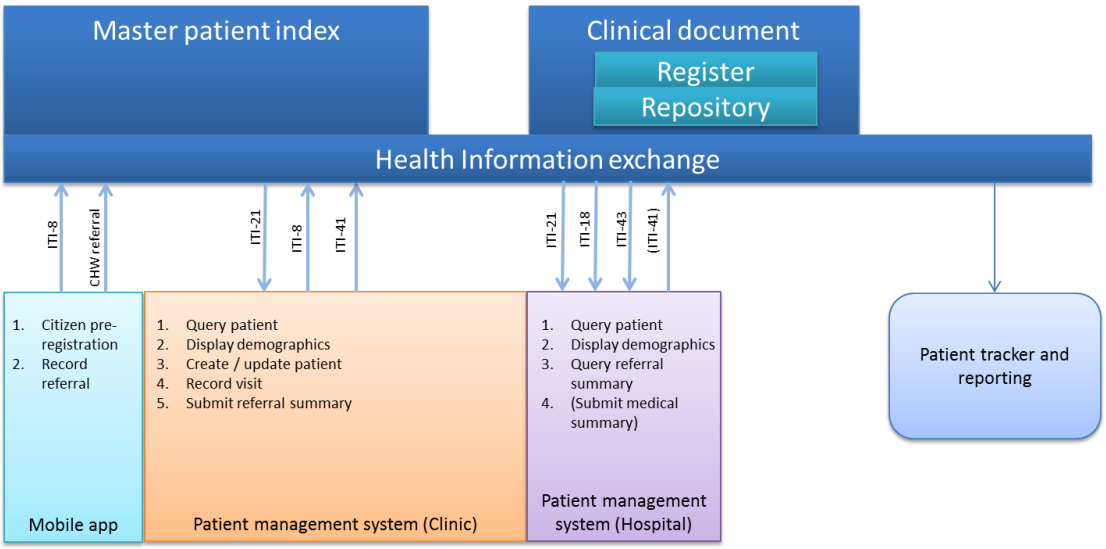

Figure 2: Interoperability platform design

The proposed platform consists of the following shared components: A Health Information Exchange, Master Patient Index , Clinical document register and repository and a Patient encounter tracker and referral reporting component. The components are briefly described below:

1. The *Health Information Exchange (HIE)* enables the electronic exchange of patient information between disparate healthcare information systems while preserving the meaning of information being exchanged. The purpose of information exchange is to facilitate interoperability by providing access to and retrieval of relevant data to support improved quality and continuity of patient-centered care. The HIE implements the norms and standards as defined by the Health Normative Standards Framework (NDOH 2014) through controlling and mediating standard-based messages between compliant consumer applications and shared registers and repositories. The standards implemented through the HIE are based on Integrating the Health Enterprise (IHE) profiles associated with defined functions to be performed in the health system. The IHE also provides security and auditing services to ensure the privacy, security and integrity of information exchanged and stored in the shared repositories. Authentication and authorisation services are included to prevent unauthorised access to information and services. This includes auditing, user authentication and node authentication.
2. The *Master Patient Index (MPI)* is the definitive and authoritative source of patient demographic and identity information. It enables authorised third party applications to search for patients using demographic or identity detail, create patients and update patient demographic and identity data.
3. The *Clinical document registry and repository* is used to store and provide controlled access to clinical information of patients related to healthcare encounters. The document registry keeps record of all clinical documents stored in the repositories and where they are located. The document repository will contain the actual clinical documents. All clinical documents are stored in the format of

HL7 Clinical Document Architecture (CDA). Third party applications must be able to submit their clinical documents in this format to the HIE as well as retrieve, consume and display CDA documents in order to effectively exchange clinical documents through the platform.

4. The *patient tracker and reporting* component will intercept messages submitted through the HIE related to referrals and medical encounters and store it in the patient tracker and reporting module. This will enable users to view reports on referrals and referral adherence as well as the ability to track patient encounters between health facilities.

Third party applications will interact with the interoperability platform through the IHE profiles and transactions as depicted in Table 1 below. The table lists the type of application, the tasks the application needs to perform with the associated IHE profile and transactions.

Table 1: Applicable IHE profiles and transactions

Application	Task	IHE profile	Transaction
CHW mobile app	Register citizen	PIX	ITI-8
	Record referral	Custom profile	Custom transaction
Patient management system	Query patient	PDQ	ITI-21
	Create/update patient information	PIX	ITI-8
	Submit referral summary	XDS-MS Referral	ITI-41
	Query referral summary document reference	XDS-MS Referral	ITI-18
	Query referral summary	XDS-MS Referral	ITI-43
	Submit medical summary	XDS-MS	ITI-41
	Query medical summary document reference	XDS-MS	ITI-18
	Query medical summary	XDS-MS	ITI-43

It is important to note that there is no existing applicable IHE profile for the exchange of CHW assessment results and referrals. In this case a candidate message structure was designed based on the minimum requirements defined by the National Department of Health for information to be collected by Ward Based Outreach Teams. This will be refined and extended based on experiences in the field.

In order to preserve the security and privacy of patient information when shared through the interoperability platform, the Audit Trail and Node Authentication (ATNA) profile and associated transactions as specified in the HNSF must be implemented. As described earlier, the HIE implements these profiles and will ensure that 3rd party applications accessing the information through the interoperability layer is trusted and that any access and change to patient information is logged. The requirement to log all access into an audit trail is required to enable investigation into who accessed the information in the event of queries regarding unauthorised access. In addition to the implementation of the ATNA profile in the HIE, it is also required that any 3rd party application must have appropriate access control implemented and must have an audit trail of local access to patient information.

Since patient information is potentially shared between systems and facilities, a patient must provide consent to enable the sharing of information. If the patient does not give consent, the information will not be submitted to the interoperability platform and will not be shared.

The evaluation of the interoperability platform is discussed in the following section.

Evaluation

The interoperability platform for standards-based exchange of information collected by and useful to CHWs described in previous sections was implemented and evaluated in a laboratory environment. The introduction of interoperability between different 3rd party applications (i.e. CHW mobile applications and patient information systems deployed at health facilities) does not influence the basic functionality of the applications. The applications function as originally developed. Interoperability only enables sharing of information to provide more information to end-users users and eliminate recapturing of information already available. The deployment of this platform into an operational environment is dependent on commercial third-party patient management systems to be adjusted to 1) be compliant to the stipulated IHE profiles and base standards; 2) be able to consume and display information received through the interoperability platform; 3) implement the minimum authentication and auditing requirements; and 4) manage consent from patients to share their information . This requires investment in terms of funding and time on the part of third-party service providers which can cause a delay in implementation. In order to fast-track the evaluation of the platform independent from the dependency on external parties, the platform was deployed in a laboratory and in-house simulations of compliant applications were used.

The platform was evaluated against the criteria defined for the platform as described in the section on the problem description and criteria. The result of the evaluation against the stated criteria is depicted in Table 2 below.

Table 2: Evaluation against criteria

Criteria	Evaluation
Exchange of registration information	The registration detail of the household member captured by the CHW is stored in the Master Patient Index. When the patient presents at a clinic or hospital using a different patient management system, the system queries the MPI through the PDQ profile. The detail returned is used in the patient management system. No re-registration is required.
Referral tracking	Since the referral from the CHW mobile application as well as the clinic patient management system is submitted and stored in the Clinical document registry and repository, the referral tracking component can access and track all referrals. In addition, since encounters are recorded by the patient management systems and also stored in the Clinical document registry and repository, adherence of referrals can be tracked and non-adherence can be identified for follow-up visits by CHWs
Sharing of medical summaries	Since the medical summaries of patient encounters are submitted to and stored in the clinical document registry and repository, any authenticated patient management system able to query, consume and display clinical documents in the format of HL7 DCA will enable authenticated users to view medical summaries of encounters with a patient.
Standards based exchange	All messages are according to IHE profiles and associated

	transactions. The messages regarding CHW assessment results and referrals are in the format of a candidate message structure according to the minimum requirements of the National Department of Health and will be refined and extended as needed.

Through the evaluation of the interoperability platform, the following challenges have been identified:

- The quality of data from different types of applications varies, therefore differentiation had to be made between applications from which updates of existing information in shared registries will be accepted and those from which updates will not be processed.
- Due to the unreliability of connectivity in rural areas, is not possible to assume always on connectivity between applications and the interoperability platform. It is crucial that applications should not be dependent on the availability of the platform to continue functioning. Investigation into queuing of messages to the platform to be submitted when connectivity is reestablished must be performed as future work.

Conclusions

This paper presented the problems encountered and the unrealized potential when the information collected by CHWs using mobile applications is not shared in the wider eHealth system. A case is made for standards based interoperability between heterogeneous eHealth systems to enable standards based data exchange, information reuse, referral tracking and sharing of medical summaries. A description of an interoperability platform for standards based exchange of information collected by and useful to CHWs is presented including descriptions of the use case and the design of the platform. The IHE profiles and transactions to be used for the different tasks are defined.. The resulting platform was implemented and evaluated against a set of criteria in a simulated environment in a laboratory.

Future work is to deploy the platform in at least one district in South Africa in the next 4 months. This deployment will integrate operational third party CHW mobile applications and patient management systems compliant to the prescribed standards. The deployment will be used to further refine the interoperability platform and assess the level of interoperability achieved. The candidate message structure for CHW assessments and referral will be assessed and refined.

This study has shown that it is possible to achieve interoperability between heterogeneous mHealth and eHealth applications to realise the value of information collected by community health workers.

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