The Role of Health Informatics in Volunteer Supported Healthcare for Underserved Populations

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Abstract: This paper examines the role of health informatics in bridging the gaps and augmenting volunteer supported healthcare services to underserved populations in urban, rural, conflict, minimal resource and disaster settings worldwide through the experiences and vision of AarogyaSeva, a non-profit flexible micro–volunteering sustainable platform offering services in 7 countries. Due to the rapid increase in volunteers and patients, as well as an ever-increasing need for healthcare service delivery in underserved communities globally, we address the requirements for a robust health informatics system, addressing the challenges of availability of information to multiple healthcare providers, patient privacy, interfacing with multiple platforms, robustness, ease of use by people with limited technical skills, and extensibility.

Keywords: Health Informatics; Electronic Medical Records, Electronic Health Records; Healthcare Volunteers, Micro-volunteering, Public Health; Doctors For Seva

1. Introduction

Vast numbers of people do not have adequate access to quality healthcare, despite the existence of resources and healthcare providers. This challenge needs to be tackled at multiple levels that include public policy-makers and administrators. Meanwhile, organizations supported by volunteers can help address the urgent and immediate needs of millions of people. These efforts can be significantly assisted by the careful use of state-of-the-art technologies including sensors and mobile telecommunication devices (BinDhim and Trevena 2015), inexpensive computer hardware and storage devices, and easy-to-use software interfaces.

Such efforts necessitate a robust software framework that facilitates the growth of a healthcare access provider organization with severe cost constraints, with particular focus on electronic medical/health records (EMR/EHR) management. We presume that any such system includes all available health information concerning patients, since prior medical incidents are often relevant in diagnosis and treatment.

The benefits of a well-designed system include avoiding pitfalls such as loss of privacy, the invocation of unsustainably expensive technologies or products, repetitive testing, loss of patient-related information due to the use of multiple volunteers, and the accumulation of mutually incompatible technological components.

Section 2 introduces the work that has been done in recent years by other organizations, and the potential for integration with government-supported authentication systems. Section 3 describes the organization that our efforts serve, and its recent healthcare initiatives and experience with a pilot information system. Section 4 summarizes the software requirements, and discusses a proposed software architecture.

Section 5 discusses the impact and deployment considerations of an appropriate system. Concluding remarks are presented in Section 6, including a brief discussion of near-term plans.

2. Background

Numerous efforts have been in progress, addressing various aspects of global health informatics, e.g., (Jordanova and Lievens 2012). Studies in Africa include (Gladwin, Dixon and Wilson 2003), (Fenenga and de Jager 2007), and (Smith, et al. 2008).

The rest of this section discusses some results of the work done in India. In an overview, (Athavale and Zodpey 2010) discuss public health informatics in India, identifying advantages such as reduction of errors in medical care, maintenance costs, accessibility, accurate diagnosis and follow-up care. They also address challenges such as the lack of financial investment, unavailability of trained manpower (resulting in extended periods of interrupted service), need for interoperability standards, resistance from healthcare professionals, and concerns about confidentiality and security of data.

The All India Institute of Medical Sciences introduced a computerized Health Management Information System, using a name-based retrieval approach, at Ballabgarh in 1988; (Krishnan, et al. 2010) have discussed the impact of their work over a 20-year period, concluding many positive outcomes such as savings in record keeping and report generation efforts. They estimate that the savings imply a two-year recovery period of capital costs for computerizing a primary health center. Potential cyber-security issues were addressed by isolating the servers from the internet, and rigorous record-keeping to track accesses by internal users.

In a recent pilot study (Radhakrishna, et al. 2014), physician encounters with patients in a primary health center in the village of Mugalur (India) were recorded using a web-based EHR template, and also made available to participants using a USB memory card which served as another portable mechanism that could be used in future interactions with other healthcare providers; SMS text interactions were also performed. Data was stored centrally at a hospital's servers, facilitating analysis for epidemiological purposes. The greatest obstacle arose from electric power cuts that affected the usability of the hardware platform, impairing interactions with patients.

The existence of a third-party authentication process can substantially assist efforts to develop a secure EHR system. In particular, the government of India is implementing the world's largest biometric ID system, *Aadhaar,* to address concerns such as fraudulent use of scarce resources. Each individual's Aadhaar card will be linked with a *Digi-Locker* with 1GB data storage that can be used to store medical records and other documents; so far, this has been implemented for 2 million users. Similar digi-lockers with larger storage amounts can be offered by other entities. Health ministry officials are preparing to use Aadhaar in government hospitals; patient records linked to Aadhaar can later be retrieved from any location. The use of Aadhaar is also being required in all health insurance schemes subsidized by the government, facilitating data collection efforts.

Public health efforts would be assisted by such steps to obtain reliable data to track epidemics. Health-care research would also be assisted by keeping track of the degree of success of interventions by the government, medical researchers, or NGOs. For the application being addressed in our work, the main difficulty in the utilization of Aadhaar is the limited availability of biometric authentication hardware at health clinics, especially in rural areas, where internet connectivity or even electrical power supply may be absent or failure-prone; this can be addressed if volunteers who assist patients can be provided with appropriate portable and battery-operated hardware, with storage and communication capabilities that do not rely on potentially inadequate infrastructure.

3. Aarogyaseva Global Health Volunteer Alliance

Aarogyaseva[1] is a non-profit NGO based in Bangalore, conceptualized in 2010 and founded in 2012, which provides a flexible micro-volunteering platform and participates in extensive collaborations with other organizations for improving healthcare access. Volunteers are the key drivers to achieve the objective of ensuring that every individual has access to quality healthcare.

Some recent initiatives of Aarogyaseva are listed below:

- **Doctor at School** is a comprehensive program serving children in government schools, orphanages, institutional homes and slums. Volunteers have been working to eradicate easily treated ailments such as stomach worms, and have been able to improve the quality of life and improve access to education for children at no cost to the children or the schools.
- **Eldercare**: Providing access to healthcare at several "old age homes" serving senior citizens in India.
- **Doctors in the Community**: Providing free medical services to migrant workers who have recently migrated to India's big cities.
- **Mental Health Initiative**: Providing access to trained psychiatrists, psychologists, counsellors and therapists, for mentally ill patients.
- **Rural Health Initiative**: Providing basic health facilities to rural areas where no physicians or hospitals are available.
- **Disaster Management**: Training readily deployable volunteers, and providing logistical assistance for relief efforts during calamities such as the floods in Chennai and the Nepal earthquake.
- **Women Empowerment Program**: Producing and disseminating primary health and hygiene materials to rural and urban women.
- **Prosthetic Hands for Children:** Producing 3D-printed upper limb prosthetics with basic functionality, to be provided free to children who do not have access to commercial prosthetics.
- **Healthcare Hackathons:** Organized with the theme of Digital Innovations in Healthcare Volunteerism.
- **Rwanda:**
  - A periodic medical mission to provide medical care through a global network of volunteers.
  - A leadership program for people living with HIV.
  - A tele-medicine program.
  - A maker-space to encourage entrepreneurship.

Section 3.1 describes the deployed health information system, and Section 3.2 discusses some of the limitations and practical challenges addressed by such deployment efforts.

3.1. Health Information System Deployed

A pilot information system was used to capture patient data from remote villages in Chamarajanagara District (about 150 miles from the city of Bangalore). This helped us capture the basic data of 4000 residents with the help of volunteers using a tablet computer. The data was stored on secure servers with security measures in place.

Information collected in a spreadsheet included past history and current complaints, collected by non-medical volunteers, and other details filled in by medically trained professionals, including physical examination results, any available investigation results (such as blood/urine tests), diagnosis—provisional and final, and management plan (including medication dosages and timings). There are designated types of logins with different levels of access permissions for doctors, health workers and non-medical volunteers. After the data is entered and submitted, any modifications are recorded with time-stamps and the initials of the authors of the modifications.

This effort provided baseline data for the patient database, and also helps the volunteer team of doctors access the patient history and treatment information continuously during follow up visits. Patient history records are particularly useful since the medical volunteers visiting for follow up may change every month.

[1] Roughly translated as "service for health"

This project involved 120 volunteers, including 25 healthcare providers and 16 technical personnel; the number of patients screened was 3950. The host partner was a local organization, the *Karuna Trust*, and the technology partner was a software company. Institutional partners included *MMCRI, JSS University* (Medical and Pharma), and the Karnataka state Department.

The patients attending the clinic were informed about the electronic medical records in detail along with information on storage, use and security. This information was provided by the primary health worker, trained health volunteer and consulting doctor. The patients were also given a paper copy of their records.

In the deployed system, the physical data storage media are owned by the healthcare provider. The personal data details of a patient, contained in the records, are owned by the patient himself/herself, with the electronic records being held by the healthcare provider in trust on behalf of the patient. The healthcare provider will have to change, append, or modify any record in relation to the healthcare of the patient as necessary, with a complete documented trail of such change.

Each patient provided oral consent for this process and further implied consent by providing information to be filled in the EHR system, and actively seeking free healthcare consultations. Patient-specific information is not provided to any other individuals or organizations; we emphasize that this was a healthcare effort, not a sponsored research study.

This simplified EHR system was designed by a software company, and current efforts are exploring the use of *openEMS* as well as *eClinicalWorks*. Some lessons learnt during the pilot deployment are outlined below:

- It is sometimes necessary to record the data offline and then upload at periodic intervals.
- The system needs to be integrated with a user authentication system.
- It is necessary to keep the parameters simple, and use a smart-phone instead of a tablet.
- There is a need for a teleconsultation feature.
- Capabilities for interactions with other software components are necessary, e.g., in order to interact with a mobile app, prescription system, diagnostics reporting, and our volunteering app that can be used by doctors who offer virtual consultation and reviews.

3.2. Limitations and Challenges

This section describes some of the practical limitations and challenges addressed in the deployment of an EHR system in a rural area, and solutions that we implemented.

First, the volunteers and health workers needed to be trained in the use of the EHR system and various hand-held devices. Some of these volunteers worked for other organizations that collected health data for the government. Hence each form to be filled in was designed to be very simple and easy to work with, and consistent with terminology and fields used in other health data forms used by the volunteers.

Many rural residents had low levels of literacy and were also unfamiliar with English medical terminology, some of which is not easily translatable to the local language. This implies difficulties in ensuring reliable data entry, since EMR/EHR systems have not been developed using local languages. Efforts were made to keep the language of interactions simple, with questions in multiple choice formats, and fields that accept free notes that are transliterations of the local language.

Since the scope of the medical interactions is very large, the EHR system was extensive and the record-filling process was time-consuming, especially due to open-ended input modes. Options such as drop down menus and multiple choice answers make the process faster, though more effort is needed in the user interface design.

We depend on the internet to use the software and store data, and abilities to communicate with the internet are often impaired due to infrastructural limitations. The deployed system permits data capture by devices with local storage, which is later uploaded to the server when internet access becomes available.

Electric power is notoriously unreliable in many rural and urban regions in the developing world. Hence, servers, storage and communication devices need considerable power back-up resources. In the deployed system, the hand-held devices have a battery life of 8-10 hours, and are charged overnight at the end of the day when the health workers return to their base camp or headquarters. Solar-powered battery system solutions can be very useful in future deployment efforts.

Data security is a perpetual concern, from both privacy and data integrity perspectives. Currently, the Aarogyaseva organization follows the guidelines developed by the Indian government, with secure servers physically located in the region of deployment.

Finally, in order to be usable, follow-up medical visits need to be assisted by easy recall of prior patient data, notwithstanding potential communication challenges due to electric power or internet unavailability constraints. Currently, since the health records can be offline, the most recently updated data is made available for recall and follow-up, even if the device is not connected to the internet.

The next section describes the requirements of the health informatics system needed for this application.

4. Software Architecture Requirements

The central task to be addressed is an Electronic Medical (or Health) Records system, facilitating storage and retrieval of patient data. As stated by Rector, et al., "the requirements for a medical record must be grounded in its use for patient care. The basic requirement is that it must be a faithful record of what clinicians have heard, seen, thought, and done." (Rector and Kay 1991) Critical areas identified in addressing interoperability requirements[2] include interactions with users (e.g., e-prescribing), communication standards, information processing, and other systems and applications (e.g., tablet PCs).

The ISO has developed requirements for such systems. (Schloeffel 2002) Although not a complete specification, ISO 18308:2011 defines EHR architecture requirements, "formulated to ensure that these EHRs are faithful to the needs of healthcare delivery, are clinically valid and reliable, are ethically sound, meet prevailing legal requirements, support good clinical practice and facilitate data analysis for a multitude of purposes"[3] (ISO 2011). Beale and Heard[4] (Beale and Heard 2008) present an overview of the architecture of *OpenEHR,* an open-source electronic health records management system supported by the nonprofit *Open EHR Foundation,* based on research and experience over many years around the world. There are some *Generic Care Record Requirements,* including expectations of any such clinically oriented software. In addition, patient records must support data entry of different types and formats, e.g., without requiring the use of a specific language.

Since records must be shared, additional requirements include maintenance of patient privacy while permitting sharing and being compatible with accepted communication standards and systems. They must also permit both fully automated and partially automated interactions. Emphasis is on holistic patient-centric record-keeping, and clinical decision support. To maximize adaptability, OpenEHR relies on a two-level modeling approach (Beale 2002), in which a "reference information model" is implemented in software, leaving the definitions of clinical content to the archetypes and templates that may change with time. This philosophy suggests that stable models are to be implemented in software, clearly separated from representations of dynamic entities.

EHR systems are usually developed with the expectation of their use by patients and medical care providers. Our application requires additional functionality features, such as the following:

- Patient data (including images and audio signals) may be obtained remotely using a sensor attached to a mobile phone, and transmitted wirelessly with no local storage; so the system must permit simultaneous acquisition and storage of such data, appropriately labeled or annotated, along with a recording or transcript of a conversation that occurs over the mobile phone. The system must account for noise, incomplete data, and data corruption, with annotations describing any uncertainty with sensor readings.
- Four classes of entities may access the system: patients, healthcare providers, volunteers, and administrators. Each of these would have different access permissions. The patient (or a patient's representative) would initially be expected to sign off on access permissions which may be broad, e.g., permitting any volunteering physician associated with the organization to view his/her record, since it may be impossible to determine *a priori* which volunteering physician may review a specific patient's case at a given time.
- Many security concerns exist: privacy preservation is the first, to be addressed through authentication and access control mechanisms. In addition, protocols must be established for emergency medical assistance which may require documented overrides of access control requirements.
- To optimize the use of limited resources, the desired system must receive data wirelessly using mobile phones or other devices. This requires explicit protocols for data transmission. In addition, there will be scenarios where smart phones or wireless bandwidth is unavailable to the patient and the assisting volunteer; mechanisms must be developed to acquire data in such scenarios.
- A frequently used scenario for assisting patients involves a volunteer physically accompanying a patient to a physician's office. This often requires excess time that could be critical in some scenarios. The software architecture must allow for data and communications (such as instructions and feedback related to CPR efforts) being recorded in transit, with associated expectations of noisy signal characteristics.
- When multiple volunteers are dispatched to take patients to different healthcare providers, a schedule and routing computation system is required. A simple scheduling algorithm has been implemented, which requires access to the availability information of physician volunteers, e.g., Dr. X may announce that she is available to see upto five cardiac patients on a given day between 1PM and 6PM; available volunteers must then be assigned to pick up and take patients with cardiac complaints to Dr. X's

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[2] www.healthit.gov/providers-professionals/faqs/what-ehr-interoperability-and-why-it-important

[3] www.iso.org/iso/catalogue_detail?csnumber=52823

[4] www.openehr.org/releases/1.0.2/architecture/overview.pdf

office during the specified time period. Once a schedule is constructed, Dr. X must be provided access to the electronic health records of patients being brought to her office, preferably prior to the actual medical examination. In some cases, Dr. X may decide that a patient needs to be seen immediately rather than wait for the scheduled appointment. In some cases, the physician may not have access to the internet (e.g., due to unreliable power system infrastructure), and protocols must be established for recording and storing the patient-physician interactions.

- The availability of resources (medical and non-medical volunteers) may constantly change over time, along with emergency situations for people who cannot be reached by Ambulance vehicles (e.g., for patients in locations with no drivable road access). Incremental resource allocation and adjustment algorithms are to be implemented, which may occasionally require pre-empting or over-riding prior plans. The implementation of such changes is non-trivial (e.g., the volunteer traveling with a patient may be temporarily inaccessible by phone or email, since he is driving a vehicle) and the software system must be aware of the distinctions between desired and actually implemented changes, so that the right patient information reaches the right healthcare provider.

Such a system has many autonomous components that collaborate, and may be considered to be a "system of systems." (Maier 1996) To maximize flexibility and interoperability, we propose to use a multi-blackboard architecture (Engelmore and Morgan 1988) in which data is stored in a set of repositories (tables or collections of records), each of which is accessible to the external entities with necessary permissions to read, write, or modify the contents of that blackboard. Since all interactions will occur through the repositories, different software modules may be contributed by different authors using different programming languages or tools.

Unlike the "Repository" model, the Blackboard model assumes that active computation modules are also associated with the repository,[5] e.g., alerting a cardiologist when data is received (over a mobile phone) that indicates arrhythmia in a cardiac patient. An additional layer of security must be implemented via anomaly detection software that runs in the background, checking local and global consistency of data whenever changes are made by an external entity, with periodic check-pointing to permit rollback to a previous version if necessary, since some anomalies (e.g., successive changes to multiple patient records by the same entity) may not be detected before the first undesirable entry is recorded.

The system administrator's role includes granting and verification of access to various repositories from requesting entities. An oft-ignored consideration is the purging of unneeded access permissions, e.g., when a volunteer or employee ceases to be associated with the organization.

[5] www.tutorialspoint.com/software_architecture_design/data_centered_architecture.htm

5. Impact and Experience

In many communities, the population does not have access to quality healthcare, due to the lack of infrastructure, large distance from the nearest specialist facility, poverty, conflict (political and armed) and lack of skilled human resources. In such dire circumstances, the periodic interventions by teams of volunteers provide a highly valued service. However, the individual volunteers visiting these centers are different during each visit even though they belong to the same medical specialty.

Every time a new volunteer sees a patient, problems arise due to the unavailability of case notes, prescriptions, lab reports, *etc.,* as the villagers are unable to retain paper forms due to various reasons, such as destruction due to improper storage. This leads to a lack of continuity of care, delay in history taking and examination, repetition, missing diagnoses, repeat investigations, and missed/wrong prescriptions.

The introduction of an EHR system drastically improved service delivery in the Chamarajapura region. The data for 4000 patients stored in the system permitted doctors to access patient history during every visit, with saved time during consultations, proper follow-up, saved time and cost in repeat investigations. These resulted in substantial improvements in medication processes and monitoring outcomes. Similar results were observed in the *Doctor at School* program, in which medical personnel visit schools periodically. Student data can be available year after year to measure the growth of each child, as well as to conduct broader analysis of the student populations in the school/region.

An unexpected benefit was that all the doctors polled indicated that they would be more willing to sign up to volunteer if EHR systems could be used, due to improved health outcomes and hence the value of the volunteering experience. The primary increase in their effort was an increase in the duration of their initial consultations by approximately 7 minutes when compared to consultation in camps without electronic record-keeping, on a sample size of 30.

6. Conclusion

Aarogyaseva's experience with a simple EHR system revealed the need for a system with substantially enhanced capabilities. We have examined the requirements of the software system that can serve such scenarios, and plan to implement a blackboard-based software architecture with multiple repositories, emphasizing security and accessibility considerations.

AarogyaSeva provides an open source platform for the development and deployment of medical technology through collaboration and innovation. This platform facilitates engineers, designers and innovators to participate in the development of affordable medical technology. By sharing research, processes, and results across multiple stakeholders, we hope to develop solutions that are safe, effective, appropriate, affordable, accessible, and usable by other organizations.

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