



Individual Identification Tied to Health Records

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1.0 Introduction: What's Needed

Not long ago, the use of Electronic Health Records (EHRs) in developing nations was thought to be unrealistic. What projects existed used either expensive commercial software in large organizations or user-developed software for specialized purposes, such as to manage a specific disease. Since then, several successful EHR systems have been implemented in developing countries, due in no small part to the increase in the availability of information technology in these areas. These factors, along with recognition of the benefits of EHRs in improving quality of care in developed countries, have created a broad interest in the use of such systems in the management of diseases such as HIV and drug-resistant Tuberculosis (TB). There are examples of successful implementations of such systems, such as the AMPATH project in Western Kenya, the PIH (Partners in Health) projects in Peru, Haiti, and Rwanda, the Baobab Health systems projects in Malawi, and the CIDRZ (Center for Infectious Disease Research in Zambia) project [eHealth 2008].

In many places, some kind of legacy, paper-based EHR system will already be in place. But throwing it out and replacing it with an electronic system may not be so simple, or appropriate. It can be difficult to shift the concerned parties in lockstep from the paper-based system they know to an electronic system you know. More likely, any new system will have to be a hybrid of electronic and paper-based tools. This adds to the difficulty of designing a system because the records will have to work in both a paper and an electronic world. Simply scanning paper into electronic form does not address the real issues, nor does it correct errors that may have been embedded earlier.

At the same time, there are serious concerns over the slow adoption of EHRs in developed countries such as the United States and the United Kingdom. A recent report claims that very few acute care hospitals in the US have even a basic EHR system [Jha 2009]. Moreover, there is little real research that clearly articulates the benefits of such systems in comparison to the costs of developing and operating them. How can we find ways to create and deploy such systems for the most vulnerable populations while avoiding the major pitfalls and high costs that have plagued the United States and many other countries?



2.0 Environmental Description

An accompanying problem is the lack, in many developing countries, of a system for accurately obtaining unique identification of every person for whom a health record is created. Identifying each and every individual accurately is not only a major problem at healthcare facilities in developing countries, but a most difficult task. Obviously, knowing who is who avoids potentially harmful, even deadly, errors, and allows for continuity of care and sound management of drug use. It also helps eliminate unnecessary procedures and reduce fraud, thereby lowering costs and improving a system's efficiency.

Accurate individual identification is also necessary if a facility is to contribute to the epidemiological statistics gathered by the national government. If you don't know who you've been treating, the prevalence of illness—such as malaria, TB, or HIV/AIDS—cannot be counted accurately. Measuring the baseline health of a country, and any improvements in health, is difficult if not impossible.

Name confusion leading to mistaken identity is a special problem in communities where most people's names are not unique, as you may find in a developing country. This is especially so within smaller settings such as tribes and rural and remote communities. In extreme cases, individuals may have no useful identity to offer at all; their culture or literacy may prevent them from accurately reciting their identities with consistency. Tying records to individuals without a stable means of identification (name, address, etc.) can be a great problem

3.0 Shorter-term Challenge (about one to two years)

A key challenge is to develop a system for healthcare facilities in developing countries that correctly identifies individuals so that accurate medical records (paper or electronic) can be processed and stored. Such a system is needed for something as simple as a wristband that identifies a patient in a hospital, as well as for long-term administrative purposes such as follow-up care, managing drug use, disease control and developing health-related statistics.

Designing and implementing a reliable individual ID system could be a worthwhile short-term project. But this cannot be done in a vacuum: it must be tied into whatever overall health record system the country may already have, even if it's only a small pilot project, and the overall health strategy of the country. This last point is particularly critical; the design of the



system must reflect the intended use, whether it be a public health/disease surveillance system or one for assuring the continuity of care for individuals.

Any individual ID system must answer the following questions:

- Is this person who he/she claims to be?
- Has this person accessed health services previously here or elsewhere in the system?
- What services has this person received?
- Is this person a member of a household or in a relationship that could have some effect on the condition, such as HIV/AIDS, that brought him/her in for healthcare?

In preparation for developing an individual ID system, it will be helpful to:

- Make an inventory of ID and health records methods already in use in your target country, including those implemented by NGOs and other entities not within the country's healthcare system that could be applicable.
- List the identity needs: short term for individual ID, disease and disaster control and medical statistics, or long term for keeping healthcare records.
- Identify the problems of melding an individual's ID with perhaps a national or other ID that your country may already have.
- Identify how you might provide ID for people in remote locations or for populations with literacy issues.
- Find out if your country has any regional variations in the preference for one means of identity or another.
- Find out if there already are ID methods in your country for such things as money transfer or micro-banking, and if there are any regional preferences for one system over another.
- Calculate the cost and resources needed to provide accurate individual identification and the tradeoffs among different options.
- Identify the importance of various disease treatments in your areas, and the need to accurately identify individuals needing such treatment. Errors in some cases could be fatal; at the least, they represent a waste of time and resources.



Now you may be ready to develop a plan for identifying individuals using a mix of technologies.

4.0 Longer-term Challenge (about three to five years)

EHRs allow for the longitudinal collection of health information generated by any number of visits of an individual to a health facility. They provide the knowledge needed to enhance the quality, safety and efficiency of health care [Maryland 2007]. These records, which can include demographics, problems, diagnoses, medications, vital signs, past medical history, immunizations, laboratory data and radiology reports, are legal records that must be accessed securely by authorized parties.

However, implementing an electronic health record system is a long-term project, and can take many years, even in countries without the infrastructure challenges facing developing countries. You should design an intelligent data model for multiple sites, and you must also consider what functions will be needed in the future. Otherwise, it will be difficult to scale up a flat-file data model to a larger relational-model clinical system or one that can be deployed to other sites.

Again, accurate individual (and provider) identification is the backbone of an effective EHR system, whether manual or electronic. Problems abound, though, and may include such issues as the lack of standard terminology in the country, including how clinical data is to be entered [WHO 2006]. Another concern is a staff lacking appropriate training. This could affect the quality of data entries and the information in general. For example, staff members may not know how to classify diseases. The staff could also be resistant to computer technology, in part because they're not computer literate. They could also be concerned that information will not be available when they request it. And everyone – healthcare professionals, individuals and the general community – is likely to be concerned about individual privacy. It is essential to involve the healthcare personnel and facility administrators with your project as early as possible.

In remote areas, the system for storing and retrieving EHRs should be as simple as possible. Even so, developing such a system is likely to be expensive, considering the cost and complexity of acquiring computers and computer systems, as well as the need to maintain and upgrade them. Computer installations also have an environmental impact [Scott 2009] and involve practical implementation issues such as the quality of the space needed to house the



computers, the supply of electricity and the electrical wiring. (Note that the electricity supply relates directly to the Reliable Electricity Challenge.)

Once you've recognized the potential problems, you can move on to:

- Identify the key benefits of migrating to an EHR system with respect to local and global disease control and management, and the long- and short-term healthcare benefits.
- Identify best practices, along with the problems (such as data migration from legacy systems [Scott 2007]), for implementing data storage and retrieval of EHRs in remote locations. (Note: this relates to the IEEE Data Connectivity Challenge.)
- Identify regional variations in your country's approach to EHRs, including cultural, regulatory and political constraints.
- Identify potential misuses and gaps in handling EHRs.
- Identify examples of systems for storing and retrieving data that could be applied in your area, and how your community could benefit.

Each EHR must use a standard format for compatibility in coding, storing, transmitting and retrieving information. Without standardization, staff members will be unable to retrieve information or, once it's in hand, interpret it correctly. So here again your job is to do more detective work and survey any legacy EHR systems in use in your region. Investigate what passes for standards not only in your region but in the entire country. Identify key interoperability and integration issues among systems, as well as the kind of terminals being used and the systems' compatibility for storage and retrieval.

As you do this, assess the pros and cons of achieving interoperability among the systems. Try to calculate the potential cost implications versus the local and global benefits gained from interoperability, as well as issues that need to be addressed when sharing records among healthcare professionals and inter-jurisdictionally [Khoja 2008].

5.0 Applicable Technologies

A number of technologies are applicable to an individual ID system, as well as to storing and retrieving EHRs. Possibilities include a combination of biometrics and human-readable alphanumeric characters such as a name and a number, barcodes, RFID tags. Biometric



techniques can be chosen from among fingerprint systems and facial, voice, and iris recognition. A generic biometrics system captures, usually in real-time, the characteristics of an individual, then processes and stores the record in a database. Another possibility is making use of the SIM cards many individuals have in their cell phones to use a phone as a platform for validating the person's identity (although shared use of cell phones may compromise this approach due to confidentiality issues).

One example of an architecture already in place for verifying an individual's ID is a system in Crete [Lees 2000]. The Lees paper describes a set of middleware services that facilitate access to the island's telecommunications infrastructure and integrates electronic records from multiple systems. The middleware provides three kinds of services. One is a directory that identifies individuals based on commonly used information, and includes such information as the addresses of facilities in the system. The system also provides security for certification of users and encryption of the records and a glossary of terms that can be helpful for translating among different standards. Unfortunately, the approach to correlating individual ID relies on information such as name and address, which is unsatisfactory for this challenge. But the system's architecture could be used with other techniques such as biometrics.

Above all else, an EHR system for a remote area should be simple [Maryland 2007] and have a user interface that adapts to the local culture and language(s). It will be of great help if you consider systems that have already been successfully deployed in challenging environments, especially if you can find systems with ample evaluation data. A summary of recent efforts to create EHR systems in developing countries is found in [Fraser 2005]. This paper discusses projects in Kenya, Peru, Haiti, Uganda, Malawi and Brazil. It describes system and network requirements, as well as organizational, user and security concerns. It includes basic cost estimates for various kinds of systems, along with an extensive bibliography. Open source systems and initiatives already under way such as OpenMRS or CHITS [Seebregts; Marcelo 2009] could lead to reliable technology at reduced costs.

Any technology platform you deploy must be practical for the intended environment and its end-users. It must integrate hardware, software, instrumentation and communications efficiently and cost-effectively. Such a platform must also complement and integrate with existing or future hospital, laboratory, healthcare and clinical systems, making adherence to recognized standards important. Several technologies may be deployed in a single



environment; some may be available commercially [Alvin 2005] or from nonprofits [OLPC], while others could be based on proposed new approaches [Zhang 2007].

Availability and cost effectiveness are the two key issues to be considered at this stage, along with standards and the country's culture. An example of a low-cost computer-based approach is the One Laptop per Child (OLPC) non-profit project [Laptop], and its target \$100 laptop (this particular project may not be applicable to our needs). At the same time, wireless technologies such as cellular communications and smart phones are becoming more widely available, and there is at least one initiative using them for remote diagnoses and data collection [VitalWave 2009]. This technology is power efficient, programmable, and generally reliable in terms of devices and communication connectivity.

Of course, introducing information systems to remote sites with no communications facilities may prove of little use. Wireless communications from reliable local service providers can facilitate telemedicine consultations and lead to fewer patient transfers from a remote to a better-staffed facility. It is vital to set realistic targets for what technologies can be deployed, and what level of deployment is possible. The low level of adoption of EHRs in developed countries, for example, indicates that change management, policy, and strategy issues are the primary problems, rather than technology [HFMA 2006, Jha 2009, Khoja 2008]. Training and managing healthcare staffs to deal with technological systems are significant issues [RCN 2009]. Adopting electronic records without significant changes in the way doctors and medical facilities operate will not result in improved quality of care or lower costs. You must make sure your system will support new work processes and true interoperability.

6.0 Financial Considerations

The costs and benefits of new EHR systems to both individuals and society are prime considerations. Some costs—for hardware, software, training and so on—may be offset by cost savings. First, consider in terms of cost what is needed to:

- Request, issue and assign a unique individual identifier.
- Store health encounter information—either on paper or in EHRs.
- Train the medical staff to look up and review individual information and support that access once they are trained.



- Link information from different services (laboratory, pharmacy, hospital, rural health center) to form a complete health record, either episodic for disease management or longitudinal for continuity of individual care.
- Operate and maintain the system over time.

Expenses could also increase depending on what you expect from the healthcare workers. Will a better trained staff be needed if staffers must now identify an illness and provide appropriate care instead of presumptively treating an individual with drugs regardless of signs and symptoms? Will more staff be needed to handle the extra workload? (This has been anecdotally observed for lab staff in some places.)

Other considerations include the extra expense of deploying a system at health centers away from urban areas or an established hospital system where there is no modern infrastructure. And there's a cost to integrating your system into an existing EHR system.

On the other hand, cost savings could be achieved through such benefits as avoiding duplication of individual records and eliminating fraud. An EHR system can help reduce costs further by helping provide the appropriate treatment and avoiding unnecessary drugs and tests, and reducing errors that could lead to expensive remediation. The system could also produce better epidemiological data for the country's public health activities.

Costs can be divided, of course, into fixed and recurring. But it is important to recognize the potentially significant cost for training and supervising staff and buying computer supplies, etc. that go beyond the initial investment.

Benefits for the individual may not necessarily translate into direct cost savings but into better care. For example, what's the worth of reduced morbidity and mortality and improved quality of life? Both the individual and system may benefit if, for example, the health system efficiently identifies each individual and provides appropriate services. Costs may go down as rational drug dispensing goes up and unnecessary procedures are reduced or eliminated. Individuals also benefit if they can seek health care at the closest facility because their health records are available from anywhere in the system. This can reduce the need to travel long distances for care, which is a direct cost benefit to the individuals and their families.



However, costs to the system can also rise if treatment is linked to diagnoses. Eliminating presumptive treatment could reduce drug costs and avoid unnecessary prescriptions that could increase drug resistance on one hand, but this could raise the cost of laboratory kits, reagents and consumables on the other.

7.0 Related Humanitarian Needs

In addition to retrieving accurate health information, individual ID and EHR systems contribute to important societal needs, including:

- **Vital statistics:** Unique identifiers and accessible health records enable the capture of vital events, such as births and deaths. But this will require resources to train people to capture cause of death information according to accepted global standards, such as the World Health Organization’s ICD-10 International Classification of Diseases.
- **Public health:** The system could detect and track epidemics and emerging diseases, as well as help tailor an appropriate response from the health system.
- **Decentralized distribution of unique identifiers:** Many programs beyond health share the same identification problems. Implemented correctly, the EHR infrastructure could be shared across many ministries.
- **Standardized forms/data elements/reports:** Programs utilizing EHR technology should be applicable to capture, store, analyze and report data on a much larger number of standard indicators of societal conditions.
- **Public sector planning:** Knowing how many individuals are in a community could, for example, aid planning for schools, sewage, water supply and other public services.

8.0 Relevant Activities Already Underway

A number of activities are already in place that could provide you with useful information as you go about planning your system.

IntraHealth International, a nonprofit that has served developing countries for 30 years, describes itself as “a catalyst for public health and open source in Africa” [IntraHealth]. The organization is dedicated to providing health care workers around the globe with the training, support and infrastructure to solve their communities’ critical public health issues. “We believe



in a world where all people have an equal opportunity for health and well-being,” notes the IntraHealth Web site.

The Cisco Connected Health framework, in use in developed countries, is designed so that healthcare professionals can share vital medical, clinical and individual information. This model now needs to be applied to issues facing developing countries. Connected Health provides critical health information anywhere, anytime. It includes hospital management and healthcare services for both public and private hospitals. It supports technologies such as individual ID systems, electronic health records, bar coding, picture archiving and communications systems, and diagnostic and support services. It also supports secure messaging and electronic order entry and results reporting. Remote telecenters can plug into a country’s health centers, medical research facilities and universities—enabling employment of the best talents and specialists available around the world [Drury2007].

9.0 Non-technical Solution Constraints

Collaboration and Validation

In deciding what EHR systems to develop and deploy in developing countries, promising ideas are not enough: they must first be validated in the field. It’s important to look closely at systems that have been deployed successfully in challenging environments, and any reliable evaluation data that may be available.

The introduction of IT systems to remote sites with no communication should provide an opportunity to evaluate the impact of the data management and communications tools you introduce. Outcomes should be measured [Ovretveit 1998], such as the time to modify patient treatment in response to new lab results, or whether patient compliance is now being monitored more closely.

Improvements in drug-supply management applying medication data from EHR systems could offer the most measurable cost benefits; a well-managed drug supply also improves the availability and quality of individual care. Furthermore, it makes little sense to recreate the same functions and tools from scratch at each site. Collaborative development between projects using an open source model (even if the underlying operating system is not open) has great potential to improve software quality and reduce costs.



Infrastructure

Clearly, the individual ID and EHR challenge requires integration with both the Data Connectivity and the Reliable Electricity challenges being considered by the IEEE Humanitarian Technology Challenges. If these two challenges are unmet, any linking of individuals to their health records will be only possible locally. The system will be unable to reach its full potential. Relevant issues from these challenges include deciding on the communications network for issuing IDs and tracking individuals, as well as exchanging information among healthcare systems. And, of course, you need to know what basic utilities, particularly electrical, are available for your system to work, and what redundancy may be required.

Issuing IDs

Most developing countries will need to create a system for issuing unique IDs, and to capture information in a standard format across diseases and locations. This raises significant management questions. For example, who in the government is responsible for the definition, methodology and issuance of IDs to people? And who has the legal authority and the moral and popular support to lead such an effort?

Protection and privacy

As solutions for unique individual ID are developed, we must remain aware of the need for legal and ethical protection of information. It is necessary to differentiate between uniquely identifying a person walking into a clinic versus the privacy requirements associated with retrieving the person's personal information from a computer system. We also must take care that a unique identifier isn't going to be used incorrectly. Can we be confident that an ID issued by the government will only be used for health-related ID purposes? We must consider the need to protect an individual's identity from being misused by dissociating the actual identity of the person from the record identity. In this way, a match can only be pieced together with the consent of the individual. And, we must consider mechanisms to combat identity fraud. None of these are simple tasks.

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