Personal Health Records in Southeast Asia Part 1 – a Way to Computerize Healthcare?

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Abstract

Computerization of healthcare systems and health records in southeast (SE) Asia is progressing very slowly, and there are no indications that it will accelerate in the near future. To alleviate the problems we turn to Personally Controlled Health Records (PHRs or PCHRs). Some places in SE Asia already have approximate PHRs in the form of paper booklets. In the past decade Web-based PHR systems have grown, and they are significantly cheaper and faster to install than entire Hospital Information Systems (HISs).

One problem with Web-based PHRs is that many regions in SE Asia have little or no Internet access. However, regions throughout SE Asia do have many cellphone users and basic cellphone services. Development of a mobile health record for ownership and use primarily by “normal people” has been largely ignored up to now. Therefore, in this paper we propose a PHR system consisting of individual cellphone records (mobile PHRs) synchronized with Web-based PHRs to provide digital health records with or without Internet access. Such a system would be relatively easy to install and would solve many of the current problems of computerization.

The individual components and relationships of such a configuration will be addressed in more detail in subsequent papers: 2 - A Digital Portable Health Record; 3 - Communications with the CCR Standard (about linking to “legacy” systems); 4 – Incorporating Biosensor Data (for self-monitoring); 5 – Incorporating Contextual Information (to allow discovery of external factors in health).

Keywords: Personal Electronic Health Records; Personal Health Records; Mobile Health; Health Information Systems

1 Introduction

1.1 The Problem – Healthcare Computerization in Developing Nations

Countries around the world have been grappling for a long time with the computerization of healthcare. Developing nations have made relatively little progress.

In 1997 the Malaysian government created a “Telemedicine Flagship Application” taskforce as part of its Multimedia Super-Corridor project. The taskforce designed a nationwide “Lifetime Health Record” which was to receive input from all varieties of HISs and related institutions. As of 2011, little progress with the implementation had been made. Of 136 public hospitals, only 13 had almost complete HISs including clinical records, and they were mostly in or near the capital city [1]. The situation is similar in Vietnam [2]. There has been little...
public investment in HISs, even for major hospitals, and computerization at the “commune clinic” level is minimal.

Experience with creating Electronic Health Record (EHR) systems for the developing world is scarce; requirements, priorities and local constraints are less well understood and probably more heterogeneous than in developed nations. It seems impossible to suggest a single EHR architecture and implementation that will fit all environments and needs [3]. Some environments have very limited resources, so if we were to concentrate on an EHR to be usable in developing nations, it must be compatible with minimal hardware, software, networks, Internet access and even knowledge of English [4].

In addition to the technological problems in the developing world, there are the common difficulties which EHRs everywhere face: 1) availability or accessibility – to be available when and where the individual needs it, in a form comprehensible to the individual; 2) maintenance and ownership—whether the EHR is for “normal, average” individuals or for healthcare personnel; 3) compatibility – to at least resemble an internationally recognized form in order to exchange data with other health information systems; 4) cost; 5) ethical issues.

In the following sections we discuss some existing approaches to computerization in health in the developing world – hospital information systems, personal health records, and mobile health. Then we propose a hybrid personal health record system which is suitable for developing countries, especially in SE Asia and most specifically for Malaysia.

1.2 Hospital (Healthcare) Information Systems (HISs)

There are numerous commercial HISs, but for developing nations in SE Asia they are prohibitively expensive. There are only isolated installations in the region.

There are some established free and open-source HISs, most notably World Vista [5]. However, a major argument raised by government ministries against installation of these systems has been the lack of formal, on-site support. This is logical from the point of view of a health ministry, as the main target of such an organization should be the provision of healthcare to the population, rather than the maintenance of large, complicated IT systems.

There is another, unexpected argument against HISs in SE Asia (and other developing countries). Most public hospitals are actually rather small, with only 50 or so beds. A large part of their case load consists of normal births requiring little medical intervention [personal communication from an administrator of a regional hospital in Vietnam][2]. Any complicated cases are always referred to higher institutions. These small hospitals have no need for complex HISs. (Commune clinics in Vietnam declared that they would like to have a computer, only to keep patient records [2][4].)

In many Western countries “general practices” have computer systems. In Malaysia it is estimated that only 700 or fewer out of about 8000 private practices are computerized [1], and among those there is no predominant software package, and few if any include standards-based communications. The Ministry of Health has no authority to compel private practices to install systems [1].

1.3 Personally Controlled e-Health Records (PHRs)

The “availability” problem, which exists not only in developing nations, has been the cause of numerous “health-care networks” and database systems in developed countries. Many systems have been designed to allow integration of individual data from incompatible databases on separate nodes of hospital or other networks. New Zealand has had an integrated healthcare network for over a decade [6], whereby the integration has been achieved via large-scale implementation of HL7 v2.x messaging among healthcare providers. The Australian NeHTA has a similar goal of integration with the launch of its “PCEHR” in July 2012 [7]. Yet these are not suitable for regions with few or no HISs in the first place.

Another approach to the “availability” problem has been the recent development of “personal health records” or “personally controlled health records” (PHRs). These are most clearly represented by “Google Health” (http://health.google.com/, until 1/1/2012) and “Microsoft Health Vault” [8] in the USA. The original one was apparently IndivoHealth [9], installed in the Children’s Hospital in Boston in 1999 – some relationships are shown in Figure 1. These PHRs are Web-based systems open to subscriptions by any and all individuals (within their respective regions or organizations), who can input any information themselves and can control who (else) has access to their records. There are or have been more com-
commercial, government or open-source PHRs, as a search of the Web easily reveals. Their advantages include:

- The records are user-owned and controlled.
- The cost to the user is minimal, often free.
- Being Web-based, they are available wherever there is access to the Web.
- They have security mechanisms, most often password-controlled access. This is an important feature of any health record system in developed nations, but as will be discussed later, it must be weighed against other important features in developing nations.

These are compatible with standards such as ISO 18308, which describes an EHR Architecture [10]. It requires an EHR to be portable, integrated with other data repositories, and viewable in a “problem-oriented” manner, among others. Of course “user-friendliness” is also a requirement.

There are some disadvantages of these PHR systems, especially regarding their relevance to developing nations in SE Asia:

- Most are commercial, i.e. non-governmental and not open-source; of the commercial ones, some claim to be free to the general public.
- Almost all are based in North America, i.e. in the USA, and many are more or less specific to American healthcare.
- Almost all are Web-based; some claim to be compatible with phones, but only by using a phone-based Web browser. However, large areas of SE Asia still do not have access to the Web.
- A few have a smartphone component. Almost none appear to have a “normal” cellphone component or to be accessible via a basic (GSM) cellphone network. [“Cellphone” is a common Malaysian term for “mobile phone.”]
- Almost all seem to use exclusively English. It is equally important to be comprehensible and portable (available) across multiple languages. In Malaysia these include Bahasa Malaysia, Chinese and English.
- Almost none of them describe the implementation of international healthcare IT standards, or compatibility with other healthcare information systems.

An interesting comparison of worldwide Internet usage with a worldwide “disability-adjusted life year – the number of years lost due to ill-health, disability or early death” index shows a clear inverse relationship [11]. Those regions which have the least Internet coverage – including Africa and SE Asia – have higher disability indices.

In contrast to Web-based PHRs, in SE Asia Vietnam and some places in Malaysia have taken almost the opposite approach to the problem of availability. When a person first presents at a hospital, he or she receives a booklet, essentially a school exercise booklet, and all clinical notes, lab results, etc. are entered into the booklet, as shown in Figure 2. The individual is given the booklet on discharge and instructed to bring it whenever or wherever he or she presents again. [Note: this is also practised in some African countries according to a reviewer of this manuscript.] Thus, the booklet represents a “portable” and thus “available” medical record, whereby availability extends beyond the reach of the Internet or other electronic networks. Also, it is not quite a “personally controlled” record because the entries are made only by medical personnel. A portable, personally controlled, digital version of the Vietnamese health care records could be a simple, easily implemented step to computerization of at least health records in developing nations.

1.4 Mobile Health

Most of the world now has basic (GSM) mobile phone networks. The geographical coverage by
GSM in East Malaysia (northern Borneo) extends far beyond that of the Internet [12].

The field of mobile applications is evolving rapidly, and in developing countries is giving cellphone users access to and control and/or ownership over services they have never had, such as banking. These applications require only access to the cellphone network, which in developing regions is much more extensive than the Web.

Mobile health or healthcare applications are also evolving rapidly. They have concentrated on data collection by health workers, sometimes using digital bio-sensors or such, then transmission to a central service for monitoring or diagnosis, again by a healthcare professional (see reviews [13][14][15] and many others). Examples of these include openMRS [16], SANA [17] and H’andy sana210 [18] among others.

The openMRS project [16] focusses on remote data collection with portable devices such as PDAs and cellphones. The collected data is transmitted to the online system via broadband networks, i.e. not via a low-bandwidth GSM network. It is then accessible only through the Web, i.e., it does not remain on the remote devices, and is accessible only to registered users, not directly to the patients themselves (who mostly do not have access to the Web anyway). This approach is quite successful where there is a broadband network, but very few cellphones or PDAs. OpenMRS has made very significant progress in recording and tracking HIV-AIDS patients in several African countries. The SANA project [17] extends the openMRS remote data collection to Android smartphones, but the procedures and transmission protocols are similar.

In Korea a similar approach, focussed on diabetes management, has been reported by Cho et al. [19]. Patients used smartphones to collect and transmit blood glucose levels, which could be reviewed by medical personnel. In Malaysia MobileHealth2U [20] offers a “mobile” interface to its Web-based PHR (http://m.mobilehealth2u.com). Subscribers can view data from their hospital visits (if they were treated at the hospital belonging to the parent company) and enter data from home, including manually entered data and data from portable bio-sensors which is semi-automatically sent to their Web-based PHR. In Kenya, the country where the cellphone-banking revolution first took off, another new (2011) mobile application is MedAfrica from Shimba Technologies [21] and Safaricom [22]. This provides useful links to and information about numerous health services. The description does not mention keeping a longitudinal health record (PHR); it seems aimed at providing health-related information when and where needed.

The systems reviewed above leave a gap. That is health records

• which are maintained by individuals (not mainly by healthcare providers),
• which are ubiquitously available, i.e. even where there is no Internet access,
• and which are compatible with other health record systems.

2 Proposal: Solving the Problem with PHRs and Mobile Health Applications

As seen above, there are several concepts of the individual health record. We propose differentiating the PHR concept into a Web-based WWW-PHR and a matching cellphone-based portable PHR or “PPHR”. Our goal is to provide a simple, available, cheap, digital health record mainly for individuals, but also for healthcare providers.
In developing countries such as those in SE Asia this approach could provide digital health records at a cost far below that of HISs. Healthcare providers in the developing world are much more likely to have access to the Internet than to have a HIS.

The PPHR is a simple mobile phone application with an interface in different languages, thereby addressing the availability problem. By “attaching” the health record to the person, at least in the form of the ever-present cellphone, it becomes almost always available, wherever the person is. It is owned and used by cellphone users, who of course may choose to make it available to healthcare providers. Its interface is designed for the general, non-medical public. The PPHR extends the initiatives described above (openMRS, SANA, etc.) by including low-end cellphones and the most widespread transmission network, GSM.

The WWW-PHR can be an installation of any existing Web-based PHR system (see above) which can process CCR standard messages. It serves as a back-up for the PPHR, but it is also available via the Web to medical personnel and institutions, so entries may adopt more precise terminology such as encoding with ICD-10 etc.

Previous versions or parts of this work have been presented: Seldon [4] described a primitive PPHR which ran as a Java application on any USB storage device. Seo [23] described a cellphone-based health record with terminology derived from the Continuity of Care Record (CCR – ASTM [24]), but that prototype was not viewed favorably by test users. Sutanto & Seldon [25] demonstrated a translation module for HL7 v2.x and the CCR, to allow communications between CCR-compliant PHR systems and HL7-compliant HISs.

3 The Proposed PHR System

It must be emphasized that a Personal Health Record is what the name implies. It is a record owned and maintained by the Person, an individual. Therefore, we do not talk about the “Patient” or the “Doctor-Patient” relationship. The main purpose of a PHR is to assist a Person to record and monitor his or her own health – to encourage “self-monitoring.” Of course use of the record by medical personnel and the inclusion of information from medical records should be possible, but that is not the main purpose.

Of course the diagram in Figure 3 is a very simplified schematic. In reality a PHR system would have more components, as shown in the following Figure. The single arrow connecting the PPHR with the WWW-PHR is really a “network” with communication servers which, as an added benefit, also allow communications with HISs. The main parts are the phone-based PPHR and the Web-based WWW-PHR. The Person – the most important item in this diagram - uses the phone or a Web server. The main parts are linked via simple communication channels and servers, which can also connect HISs. Possible message types between the PPHR and the “network” are shown, as are standard healthcare message formats within the network (HL7 v2.x [26], CCR).

3.1 Components of a Dual PHR System

3.1.1 Cellphone-based PHR for individuals - PPHR

As mentioned above, almost all “mobile health” applications have been written for healthcare providers. The goal of the PPHR is to be a simple, portable, digital record to represent the health history of one (or maybe more than one) person, and to be compatible with a WWW-PHR. It must be emphasized that the PPHR is intended for all individuals, and not just for medical personnel, so it should not be judged by criteria for a “medical record”.

A PPHR prototype is discussed in detail in another manuscript (Seldon HL, Moghaddasi H, Seo WJ, Wee JoNah S. Personal Health Records in SE Asia Part 2 - A Digital Portable Health Record), so it will be only briefly described here. The code (in Java Micro-Edition or J2ME) is available...
Figure 5: Entering data, Bahasa Malaysia

Figure 6: Viewing the whole record, English
at Google’s open-source repository http://code.google.com/a/eclipselabs.org/p/hmapper/. It intentionally uses simple coding to maximize its compatibility with older or less powerful cellphone models. A dilemma in this project is to create an application which is simple enough to be used by most cellphone users with no requisite training, yet rigorous enough to provide useful information to medical personnel who encounter it. Sample screenshots from the NetBeans 6.9.1 (http://www.netbeans.org/) emulator are shown below.

Because the PPHR is intended for use on minimal devices, the PPHR stores data as “name – value” pairs, an organization which is also included in ISO 18308 [10], and uses the ICPC-2e vocabulary (International Classification for Primary Care version 2e [27]).

3.1.2 Web-based PHR – WWW-PHR

There is a choice of existing WWW-PHRs, as seen above, so there is no need to develop another one. The WWW-PHR must at least accept data from a PPHR. Like a few existing ones, it may also support at least the possibility of uploading health data from existing systems (HISs). This implies that a WWW-PHR may support some internationally standard healthcare message formats (see below and e.g. Microsoft Health Vault [8]). Some existing WWW-PHRs also allow encoding of health data using the international standard vocabularies SNOMED-CT, ICD and LOINC. Existing WWW-PHR systems also have their own mechanisms for data presentation, security, privacy and confidentiality.

As noted above, most of the free WWW-PHR systems are based in the USA and target the USA market, with few concessions to international or more specifically SE Asian subscribers. Therefore, SE Asian initiatives must install WWW-PHR systems aimed at their own populations.

3.1.3 Communications (Transmission, Message Formats)

Standards lie at the heart of communications. There are three categories which are relevant to the PHR system: transmission standards, message format standards, and message vocabulary standards.

The relevant transmission protocols are mostly those which are supported by cellphone networks. The speed and variety of these protocols is increas-
ing, but one must remember that they are not all available throughout remote regions of SE Asia. Therefore, the basic GSM network and SMS messages must always be included. The SANA project [17] makes clever use of available transmission protocols. The “PPHR Communication Server” (Fig. 4) listens for the various types of messages which may come from PPHRs, i.e. for SMSs via a SMS Gateway, for packets via a TCP/IP channel, etc. As the incoming messages may have various formats, the “PPHR Communication Server” also standardizes them to a common, recognized format (see below).

The relevant message format standards are HL7 version 2.x [26] and the Continuity of Care Record (CCR) [24]. Many HISs use HL7 (mostly version 2.x). The CCR is a patient-oriented description, written in XML and resembling a source-oriented health record – see the partial list below (derived from CCR Figure A2.2). One advantage is that it allows varying degrees of atomicity in its elements, including un-coded plain text. PHRs such as (formerly) Google Health and Microsoft Health Vault can use the CCR [24]. As the HL7 v2.x and CCR formats are quite different, the PHR system must somewhere have a means to translate between them, to allow health data to be transmitted from existing HISs to the WWW-PPHR (Fig. 5, lower right). That is the purpose of a “message gateway”. Such a “translator” is described in another manuscript (Sutanto JH, Seldon HL. Personal Health Records for SE Asia Part 3 – Communications with the CCR Standard). The code is available at Google’s open-source repository http://code.google.com/a/eclipselabs.org/p/hmapper/.

- <Body>
- <Functional Status>
- <Problems>
- <FamilyHistory>
- <Social History>
- <Alerts>
- <Medication>
- <Medical Equipment>
- <Immunizations>
- <Vital Signs>
- <Results>
- <Procedures>
- <Plan Of Care>
- etc.
- <Actors><Actor>...<Person>

Although international healthcare vocabularies such as SNOMED-CT [28], ICD-10 [29] and LOINC [30] have existed for a long time, they have not been implemented in many healthcare IT systems, especially not in affordable or free ones suitable for SE Asia. Their importance lies in removing ambiguities in healthcare communications – e.g. “glucose test” is an often used but relatively vague term, but LOINC supplies codes for very precisely defined varieties of “glucose test”. The WWW-PPHR must implement these where possible; most of those listed above do not seem to do this. Implementing the vocabularies on a cellphone would be extraordinarily difficult at best, but it is relatively easy to map the ICPC-2e terms used by the PPHR (see above) to other vocabularies. Indeed, WICC [27] has already done this, indicating ICD-10 correlates for ICPC-2e diagnosis terms.

3.1.4 Privacy and Confidentiality

For most of the population of SE Asia, privacy and confidentiality are quite different from the developed Western nations, both in personal lives and in health records. The paper health records described above are deemed sufficient, also in terms of privacy and security, although they are clearly susceptible to loss, unauthorized viewing, modification or theft. Likewise, individual cellphones contain a wealth of personal information; yet although most cellphones contain some security mechanisms, such as password-controlled access, almost nobody uses these. It could be argued that as SE Asia develops economically, the attitude towards privacy and confidentiality may become more “westernized,” but this is speculation nowadays; many Asian customs have not changed despite the increasing economic wealth.

We concur with Fraser et al. [3] regarding developing nations – “it has been suggested that the very limited access to health care makes it critical to avoid barriers that might be created by excessive adherence to principles of confidentiality.” In other words, in SE Asia access to any healthcare has priority over any security or privacy mechanisms which might interfere with this access. Therefore,
the PHR system described above allows available security mechanisms to be used, but should not and does not impose additional barriers.

4 Discussion and Future Work

As mentioned at the start, SE Asian countries face an almost insurmountable task in trying to computerize their healthcare systems. The PHR concept offers a much easier option to computerize personal health records, the most or one of the most important components of any healthcare system. The proposal here is to extend the PHR concept, normally associated only with Web-based systems, to mobile technology, specifically cellphones.

By adopting the PHR approach we endorse the concept that the individual owns his or her health record and is responsible for its maintenance, as also indicated in the Wikipedia definition (http://en.wikipedia.org/wiki/Personal_health_record, 17 Dec 2012). More precisely, the PPHR and its Web backup are a personal diary, owned by a person; this resolves or bypasses the question of “health record ownership” because healthcare providers may not be involved at all.

The PPHR differs from others. Whereas most mobile health devices and systems are intended for use by health workers – e.g. SANA, the Korean “Ubiquitous Life Care Research Center” system [31] (more high-end ubiquitous sensor technology and networks), the Taiwanese electronic medical record [32], etc – the PPHR is intended for use by non-medical individuals.

Many mobile health devices emphasize recordings from bio-sensors – e.g., H’andy sana 210. There is an increasing number of portable, or even wearable, physiological measuring devices available on the market; some of them can use the Bluetooth transmission protocol. The PPHR text version mentioned above uses only text input, thereby making it available for the many cellphones which do not have connectivities such as Bluetooth. An “upgrade” of the PPHR to allow input from biosensors, cellphone cameras, etc., will be described in a future manuscript (Simon S et al. Personal Health Records – Incorporating Biosensor Data), but that version – like all others with wireless or other non-text input - will not be available to low-end cellphones.

Such a PHR system can also collect health-related data which is not normally collected in hospitals or other acute healthcare facilities. This can even range to wellness information, which is being emphasized more strongly even in SE Asia, epidemiological and environmental information from news channels or Web sites (e.g. HealthMap [33], WikiMapAid [34] and others), and more. A future manuscript will discuss this feature (Ahsan et al., Personal Health Records: Incorporating Contextual Information).

Other cellphone-based health record packages assume or require broadband connectivity - for example, SANA, openMRS / openRosa [16]. The suggested PPHR requires only a basic GSM network, which is the (only) one available to all cellphones. A future version will allow communications via other channels if such are available, but will always retain the capability to communicate via SMS.

Most mobile health systems have some kind of central server and/or database, but they are custom-made or “proprietary”; that is, they are not designed to be compatible with or inter-operate with a variety of health information systems. They are designed as “stand-alone” systems, even if they appear to be quite complete. The PHR system suggested here would use the international standard CCR (or HL7 v2.x) healthcare message format for individual health data, so that any system which also uses CCR messages can interact with the PHR system. This would include systems such as (formerly) Google Health and Microsoft Health Vault.

Few existing PHR systems devote time to discussion of standard vocabularies such as SNOMED-CT, LOINC and ICD-10, but these are required for any system which may interact with others, even others such as government ministries. Therefore, a WWW-PHR for SE Asia, as suggested here, must allow the use of these, as well as using the CCR message format, and be free (and open-source); this severely restricts the list of existing ones.

There is one as yet unresolved barrier to any PHR system in Malaysia (and other parts of SE Asia), and that is culture. Especially the rural population has no history or culture of health records or of western-style professional healthcare. Yet it is especially the rural individuals with chronic diseases who would benefit the most from a PHR system, both to monitor their own health and to be able to present a long-term record to any healthcare provider they may encounter.
5 Conclusions

Conceptually and technologically simple PHR systems, based on the Web and simple cellphones, could be used to create and manage digital personal health records in developing countries such as those in SE Asia. One must remain aware that including more advanced phone features would come with a trade-off against compatibility with less capable cellphones. Thus, a basic text version should be retained until people throughout the developing world have more powerful cellphones.

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Conflict of Interests

None.

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