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Personal health record as a backbone for primary healthcare in developing countries

Nana Sarfo Kantanka

Master in Information Systems
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Supervisor: Øystein Nytrø, IDI

Norwegian University of Science and Technology
Department of Computer and Information Science

Problem Description

The student will study how personal health records can support and contribute to the health care system in developing countries especially as a backbone to the improvement of primary healthcare.

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Abstract:

Increasingly, the ability to improve the efficiency, safety and quality of care is being recognized across the primary health sector. Increased focus on "seamless delivery of care", particularly for those with complex care needs, has highlighted the requirement for improved information exchange between health service providers. Personal Health records (PHR) as a transmission of personal health information can be powerful tools for linking the fragmented information that exists between services and allow providers immediate access to essential clinical information.

This research is to make known how personal health records (PHR) can be of a greater support or possible as a backbone for continual of service for primary health care. The acquisition of knowledge by this research is about how personal health records can contribute to the planning of efficient patient’s information which in the long run helps in acquiring the rightful treatment and which also results in the benefit of primary health organization members in the whole.

The results illustrate the conceptions of the need to in cooperate and encourage the use of personal health records which in the long effect can serve as a backbone for the existing primary healthcare.

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Chapter One

1.1 INTRODUCTION

There are many definitions concerning primary care to its accessibility principles, continuity, and coordinated personal care in the context of family and community which are consistent.

According to World Health Organization [1], the concept of primary healthcare is defined as both a level of health service delivery and an approach to health care practice. Primary care, as the provision of essential health care, is the basis of a health care system; Seventy-five to eighty-five percent of the population seeks primary health care yearly.

Primary healthcare is a medical care a patient receives upon first contact with the health care, before referral to elsewhere within the health system. Most consumers and patients receive care from many health care providers, and consequently their health data are dispersed over many facilities' paper- and EHR-based record systems. In view of this there is the need for Personal health record (PHR) to cater for these dispersed and lost medical records or histories. PHR's serves as an information need to patients and health care professionals. Unlike other systems PHR centers on the storage of personal health information. A person's health is greatly influenced by the individual's family, culture and community. In order for continuity consistency in Primary healthcare, there is the need for a reliable source to persist in its healthcare activities hence the need for Personal health record (PHR) as a backbone for primary healthcare

Personal Health record was first mention and heard of in an article published by PubMed [2].

1.2 BACKGROUND (PRIMARY CARE IT SOLUTIONS):

1.2.1 CARE SYSTEM STATUS

These days most developing countries are introducing national health insurance programs and policies to ensure equality of the healthcare in their various countries. The insurance programs are design to ensure that people have adequate access to primary healthcare i.e. medically necessary hospitals, physician services and others. The healthcare system normally includes the provincial and territorial health insurance plans, all of which share common standard health coverage. Roles and responsibilities for a successful health care system are shared between the federal government, private practitioners, non-governmental organizations and others. Health insurance legislation, criteria and conditions are specified that must be satisfied and be met by all stakeholders of health providers.

To further the overall national health policy, governments of the Federation work closely with voluntary agencies, private practitioners and other non-governmental organizations to ensure that the services provided by these other agencies are in line with those of government.

1.2.2 PATIENT RELEVANCE

Teams of health professionals providing standard health services to families, individuals and communities is by way of primary health care. It involves a proactive approach to preventing health problems and ensuring better management and follow-up once a health problem has occurred.

Patients play important role in helping physicians with their daily task of getting into context with their health problems. With regards to personal health records patients play significant roles in keeping data especially with cases of allergies, family health status. This information helps physicians with their decisions making, diagnosing of drugs (physicians would, in some circumstances, search for and read list of diagnoses and list of medication to get a picture of the patient's medical condition or history) and most importantly delivery of good health care. As the Institute of Medicine defines quality as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" [3].

Alternatively, health care services can be provided by Private Institutions (hospitals, clinics, community agencies and others). These Private Institutions in most cases in developing countries provide serves as a supplement or support to the provincials and governmental health services

which in most cases experience shortage in their personnel and also importantly helps in the elimination of overcrowding in primary care Institutions (hospitals, clinics and etc).

The provinces and territories also provide coverage to certain groups of people (e.g., seniors, children and social assistance recipients) for health services that are not generally covered under the publicly funded health care system. In some cases these payments are subsidized by the government (Insurance programs or policies). These supplementary health benefits often include prescription drugs, dental care, vision care, medical equipment and appliances (prostheses, wheelchairs, etc.). The level of coverage varies across country to country

1.2.3 PROVIDER RELEVANCE

Health care is normally provided in hospital, clinics etc (i.e. either by Public (own by the state or government) or Private) which are normally operated by physicians, nurses, physician's assistants and etc.

Primary health care providers can be physicians, nurses, or physician's assistants. Nurses and physician's assistants are trained to perform many parts of primary care. Nurses have to work with a physician in some states, and can work alone in others. They perform regular check-ups and helps in regular patients' routine check in the hospital, clinics and etc.

Physician's assistants must work with a physician, and are also good primary care providers. Almost all physicians' assistants are trained by physicians and they have special licenses. Both nurses and physician's assistants have some limits as to what they are allowed to do.

Potential stakeholders include:

Care Providers

- Primary care providers
- Medical specialists
- Emergency department staff
- Hospital and clinic staffs
- Alternative care providers
- Employers
- Schools
- Home health care providers
- Nursing homes
- Pharmacists
- Medical equipment providers

• Disease management companies or care management programs

• Electronic Medical Treatment or paramedics

• Public health care providers

Chapter Two

2.1 PERSONAL HEALTH RECORD SYSTEMS

2.1.1 ARCHITECTURE

Fulfillment of the vision of PHR [4] hinges on establishing a community-level architecture that provides an electronic blueprint for how data will flow to and from people and institutions enabling coordination at the local, regional or national level. The purpose of community architecture is to support user access to and interaction with his or her record. The blueprint should incorporate rules relating to security and privacy, and reflect the agreement to share and use personal health information only with permission from individual PHR users. In addition, there are important design considerations relating to aggregation, analysis and storage of PHR data.

2.1.1.1 Communication

It has been said that [5] communication among various stakeholders and patients are of high importance these days. Email is a wonderful way to leave a note to colleague who is covering a patient for the weekend.

Video conferencing is just beginning to pay demonstrated dividends. Nowadays, it's technically possible to hear a previously dictated radiologist opinion about a patchy infiltrate while seeing movement of a cursor on the image. Integrating such sources of information system will clearly improve a ability to get an instant interpretation of an x-ray image of a patient.

2.1.1.2 Data presentation

Presentation of data about the patient in an organized, comprehensive manner with instant access anytime, anywhere to the data that are needed to care for a patient. Such information include examination and history, drug allergies, treatment and test results, referral reports, problem list, diagnosis, discharge notes and etc. Reliable and accurate data will help save time and reduce errors

2.1.1.3 Knowledge

A highly convenient availability of immediate system, highly cogent sources of additional expertise or knowledge as part of the system use of MEDLINE-based literature searches has been warmly embraced by care givers. Several investigators concluded that its adorable and supportive to have additional information alongside a patient's record. The explosion of information resources on the WWW (internet) promises the desired content.

2.1.1.4 Alerts, reminders and suggestions

Automated generation of alerts, reminders and suggestions and standards of care are not being achieved. All previous three benefits can be achieved to some extend by paper based patient charts, books and telephones or letters. The computer primarily increases the efficiency and convenience of achieving those ends. The mechanism for achieving real-time quality control, however, can realistically be achieved only in electronic environment. The use of manual oversight to encourage compliance is prohibitively expensive and obtrusive and is subject to the same human foibles that one is seeking to avoid.

Second opinions are mandated by insurance companies for some big-ticket examination or intervention, but the manual approach does not match with the myriad hourly tasks and decisions to improve the quality and efficiency of care.

2.1.1.5 Utility/Interface

Compared to the aspects of communication and security, the utility issue attracts much less attention. To date, there have been only few studies evaluating the accuracy or utility of PHR records generated using patient-entered information [6]. A few studies have evaluated the utility

of patient-held summaries of institutional records, documenting significant improvements in levels of compliance with monitoring protocols and immunization schedules [7-10]. A number of recent initiatives have focused on the development of resources targeted to provide patients with direct online access to their own institutional records [11-13].

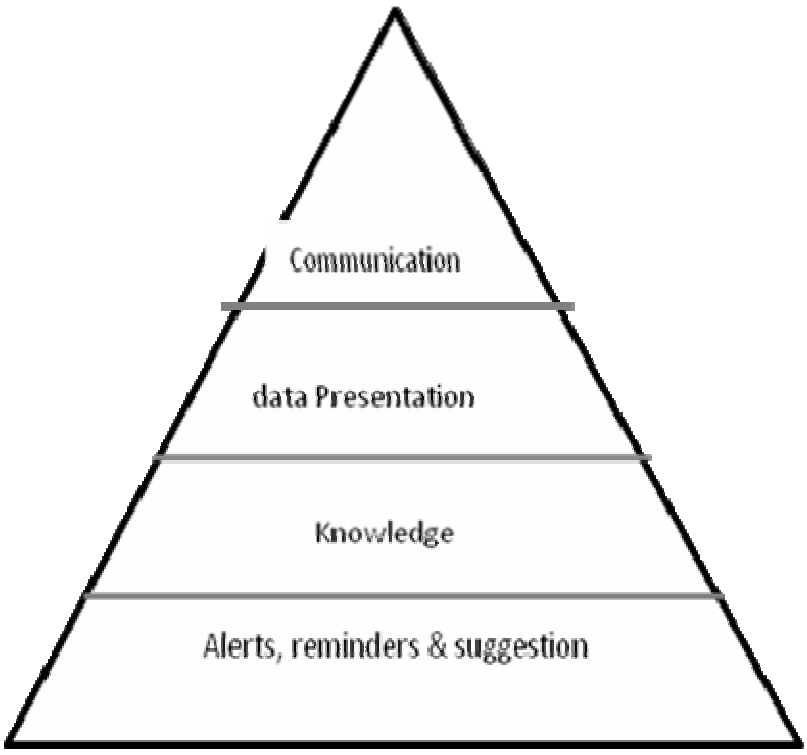

Fig.1 representation of clinical Information system [5].

Though not well studied, the issues of acceptability and usability have become a hurdle to the development of electronic health records. Even in the developed nations with the latest

technology and the best network access, users still complain about non-friendliness: the non-intuitive data input, security procedures, little or inability of (mobile) interaction with the system. The above problems give rise to a series of challenges from the human–computer interaction (HCI) perspective [14]. In particular, specific technological areas that need to be addressed concern input and output devices (e.g. speech interfaces), computer-supported co-operative work intelligent interfaces, user identification procedures, and user interfaces for mobile services [15-17].

Sun [18] developed a model for comparison of Personal Health Record sites and identified a series of elements to evaluate the PHR utility. These elements taken together serve as an indication of the PHR interface quality, which include:

- Ease of navigation
- Time to complete tasks
- Ability to find desired information
- Site presentation and layout
- User's satisfaction level
- Percentage of tasks completed correctly
- The number of problems encountered
- The amount of assistance required

In the view of the author, this list is not complete as to be a sufficient utility indication for PHR applications. Besides the above points, several other bullets should be added in. Shneiderman's [19] 'eight golden rules' provides general guidelines for PHR interface design as well. In particular, the following two issues can make a big difference in the ease of PHR use:

- to offer error prevention and simple error handling
- to enable shortcuts for frequent use and emergent use

2.1.1.6 Security

Security [4] is one of the major concerns which rise up whenever there is the issue of information system. The issues of privacy and sensitivity of data's and systems raises it the first major issue to be concern with.

Security approaches designed for electronic commerce, a trade known for security weaknesses for limited financial liability, are not sufficient for personal health data, where the personal damage caused by unintentional disclosure may be far more serious.

Moreover there are lot of policies and legislations protecting the privacy and security of personal health records [4]. HIPAA and privacy groups (such as HIEthics) provide a general expectation for protecting privacy.

To facilitate the analysis and design of health information systems, a layered security model has been developed which seems to be now established and well accepted. Figure 2 describes the technical application security services on a level of higher granularity [20]. Any electronic health record security solution must fulfill the basic principles for open interoperable systems' design, such as conservatism, minimality, simplicity, generality, relevance, flexibility, and scalability.

2.1.2 OPPORTUNITIES

From Brownstein [21], the issue maintainability and affordability creates facilitating health system which will also create an expansive market for enabling technologies. The solutions identified will generate understanding of how to integrate and employ emerging information processing technologies, sensors, computing structures, displays, communications networks and information management software all rises to the concern of its affordability, and sustenance. This infrastructure will enable new classes of

economical health care maintenance and support services across a broad spectrum. At one end are information services for patient provided assistance and informal social support. At the other end is close-coupled interaction between patient and professional medical personal.

In exploring the system from medical care view, there is the need for reliability, safety and easy use, control and access to the system and other infrastructures. In view of this there is the need for affordable systems for assessing other information processing applications that share a common domain or infrastructure.

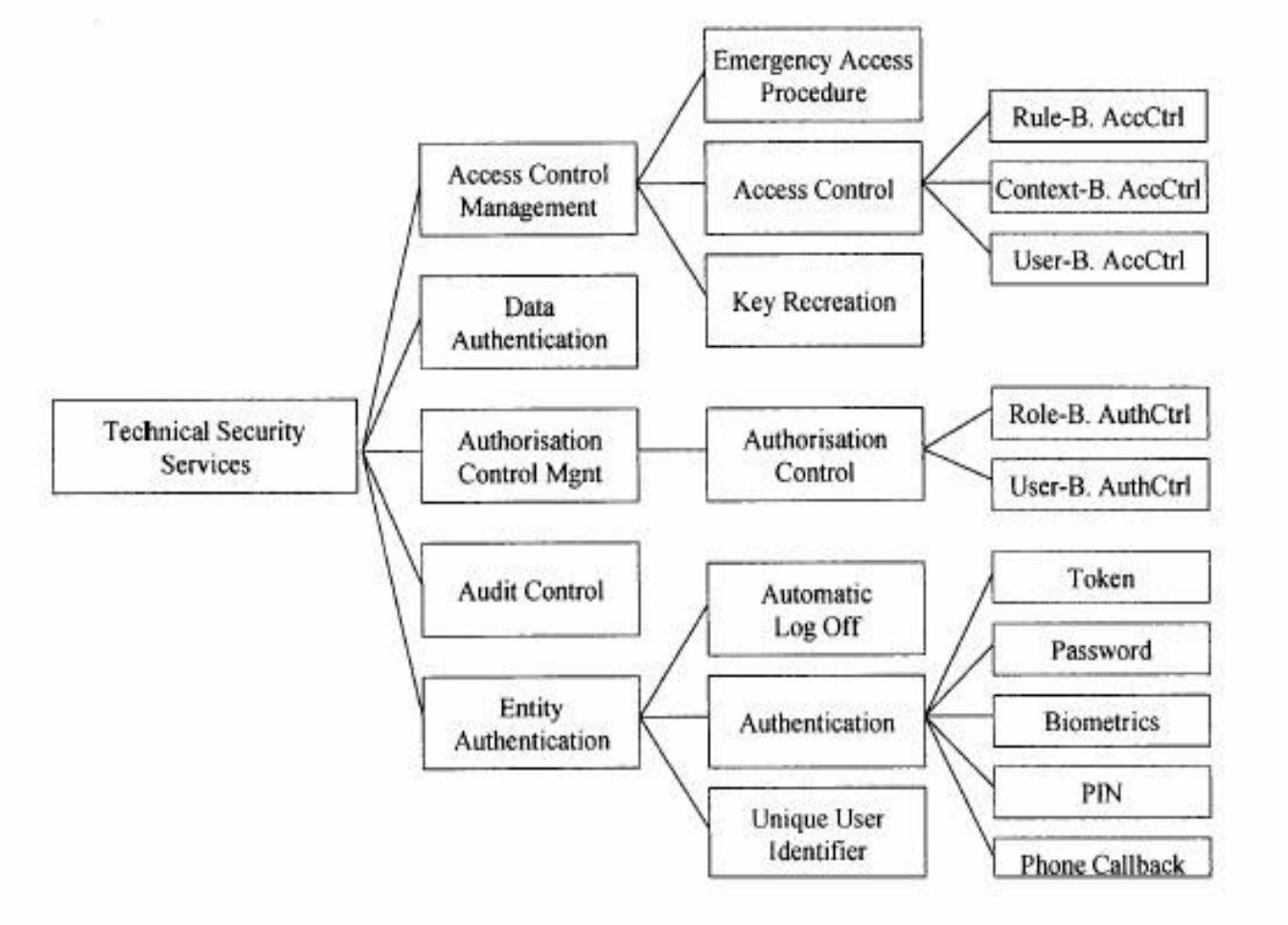

Fig. 2 Technical application security services on a level of higher granularity

It is also known that [22] wide spread and availability of internet access in various developing countries, also generate care providers and other IT institutions with employment opportunities. Institutions such as the National Library of Medicine and a variety of commercial sources provide substantial information to the public through the web.

The innovations under study in this effort require capabilities that cut across the device, network and information spectrum, but in edge environments. These will require innovation and represent new opportunities for communications, computing, software, hardware and information services providers. The greatest opportunities for innovations are in information technology applications that combine new computing structures such as inexpensive sensors and processing devices with robust communications capabilities linked to high capability information processing and wide area communications in economically and functionally scalable systems.

The growing demand will create opportunities for new services offering to meet the medical needs and demands of consumers or patients, care providers, and the government. Many technologies and services will compete in the health maintenance marketplace. All will benefit from the opportunity offered by personal health record.

2.1.3 RELATED WORK

The system as proposed above, which was first articulated in this form in [23], marries the well-established technology of public key encryption with a number of ideas which have been described previously in various guises.

A suggestion from ISO stated that [24], the key features of the PHR are that, it is under the control of the subject of care and that the information it contains is at least partly entered by the subject (consumer, patient).

There is a widespread misapprehension in the community, including among healthcare professionals, that the PHR must be a completely different entity from the EHR if it is to meet the requirements of patients/consumers to create, enter, maintain, and retrieve data in a form meaningful to them and to control their own health record. This is not correct. There is no reason why the PHR cannot have exactly the same record architecture (i.e. standard information model) as the healthcare provider EHR and still meet the entire patient or consumer requirements listed above. In fact there is every reason to ensure that a standardized architecture is used for all forms of to enable sharing of information between them as and when appropriate, under the control of the patient or a consumer.

The PHR can then be considered in at least three different forms:

1. A self-contained EHR maintained and controlled by the patient/consumer;

2. the need for a third party such as a web service provider to maintain it;

3. A component of a EHR maintained by a healthcare provider (e.g. a General Practitioner) and controlled at least partially (i.e. the PHR component as a minimum) by the patient or consumer;

4. It should also be maintained and controlled completely by the patient or a consumer.

According to ISO 18308 [25] it was stated that, before building a computer program for an electronic health record (EHR) system (or for any other application) it is imperative to have a clear and detailed set of user and technical requirements. Equally, it is imperative to develop a clear and detailed set of requirements for an EHR architecture for using, sharing, and exchanging electronic health records, independent of the technology used to implement the EHR system. It should also be independent of current organization structures. Many health informatics experts and healthcare professionals believe it should be possible to develop an international standard for a comprehensive and widely applicable architecture for the EHR globally. However, this cannot be achieved until the requirements for such a standard have first been specified and agreed. That is the principal purpose of this draft Technical Specification. There has already been a large volume of work done internationally over the past decade on public domain EHR architecture requirements. In very broad terms the requirements for a truly global EHR should ensure that it can be used, shared, and exchanged between clinicians of all disciplines, across all sectors of health, different countries, and different models of healthcare and healthcare delivery. It should

also support secondary uses such as research, epidemiology, population health, health administration, financing, and health service planning. Finally, it should facilitate the evolution of existing systems as well as the construction of new systems.

Firstly, the idea which prompts mind is identifying the support of Health records systems in developing countries. According to [22] the implementation of electronic medical record systems (EMR) faces challenges and barriers which is also the case of the developed world which have better technologies and sophisticated systems. They went on to state that it is impossible, therefore to suggest a single EMR architecture and implementation that will fit all environments and needs. But moreover, some settings in the developing world are similar to a European or US healthcare environment and can use similar system features. These researchers also stated that despite the difficulties involve in these systems in developing world, others have successfully integrated into clinical workflows, while others represent a complete or ideal solutions.

Martínez et al [26] in their article presented the three studies in dealing with information and communication needs in developing countries. They suggested;

1. *the need to recognized healthcare related needs,*

2. *the social and economic context and*
3. *lastly, the communication-based solution of telemedicine that has to be install and design.*

Byne and Sahay [27] further state that, an important step in trying to address successful health information systems (IS) is to enhance the participatory of all the various stakeholders involved in the process. Again, in acknowledging the contribution of the various research participatory in the design of IS, they suggested the need to reconceptualize the idea of participation in IS design from human rights perspective. In their discussion and review they made known the need for four important key points or factors

1. *the obligatory nature of the community involvement,*
2. *the need to develop capacity for participation,*
3. *the politics of participation and non-participation and*
4. *the need for a multi-level and multi-sectoral approach*

Chapter Three

3.1 Methodology [25]

The research was about Personal Health Records (PHR) as Backbone for Primary Healthcare Continuity in <suitable limiting domain> and as such, a review of the literatures contributed to the identification of a useful PHR system including broadly based systems, tools and support features, and barriers to the use of the system. Some contacts were made with Moterio and Nytrø [28] for his views and suggestions. The main concern was to be able to gain much understanding in the IS (Information System) that will be suitable and also support the daily health of patients or consumers. Another idea was to show how patients or consumers can be better engaged with their own care and relate to key issues such as ownership and security. Moreover support stronger partnerships of patients and physicians and at the same time promote personal health records. And lastly Support integrated provisions and evidence-based educational materials

The method adopted during this research was to break down the methods into various categories, identification of Information Systems (specifically in healthcare) careful examination and review of various health systems (PHR, EMR, EHR, and others) development of a consolidated set of requirements based on the first two methods.

Stage 1: identification of Information Systems (specifically in healthcare)

An extensive search of the literature and direct contact [25] with domain experts in many countries has been undertaken to identify as many existing sources of EHR requirements as possible. Material from over 30 primary sources was obtained.

This included 20 sources originally collected by the EHCR Support Action Project (EHCRSupA) in Europe. This project was established to support the work of CEN in developing a four part EHR communication standard, CEN 13606, 2000 [25] and one of its deliverables (SupA1.4, 2000) was to provide *"…a consolidated classification of the requirements for the Electronic Health Care Record (EHCR) and EHCR architecture (EHCRA)*".

The primary EHR requirements documents used by EHCR-SupA came from sources that included relevant projects from the EU's Third and Fourth Framework AIM programs and more recent documents from the United States, Canada, Australia, and New Zealand have provided further sources of requirements.

Characteristics of this material include;

a) Most of the literature materials and sources were from Europe and United States and few materials were found about personal health record but basically there are a lot of materials on Electronic medical records and other medical systems relating to it.

b) Most of the sources were under the sole sponsorship of governments and by publicly funded projects and with few others relating to the private sector.

c) Large majority of available PHR requirements a developed from a case point of view, which are suitable for a particular medical domain at a point in time.

d) Most of the material has originated from medically-oriented projects although there has been multi-disciplinary input (e.g. nursing and allied health professions) into a number of these projects and some of the source material relates specifically to EHR requirements from a nursing and community allied health perspective.

e) There appears to be a reasonable spread between primary and secondary (i.e. hospital, specialist) healthcare sector EHR requirements.

f) Most PHR requirement made so far are not obtained directly from any patient or consumer representative group. Although there exist projects which have had consumer representation and many PHR requirements relate directly to the consumer or patient perspective.

g) There are different cultural requirements which persist within the healthcare models and have been identified in some sources but are not generally prominent.

Nevertheless, it is hoped that over time, standardization of PHR requirements for other healthcare models and other healthcare professions will emerge. It will also be essential to have more direct input from consumers and from minority ethnic and cultural groups within countries and healthcare communities. These new source requirements may:

1. *Add validation to the existing requirements,*
2. *Necessitate changes to some requirements, or*
3. *Result in the need to add new requirements.*

Stage 2: Collation of existing EHR requirements source material careful examination and review of various health systems (PHR, EMR, EHR, and others)

Collation of a large number of requirements from many different sources with varying perspectives and differing formats is a difficult and problematic task. The first challenge was to devise or adopt a suitable hierarchical framework of headings which will suit the purpose. The characteristics of a good framework for this purpose are:

a) it should be detailed enough to separate requirements which are clearly different in type;

b) it should facilitate the location of particular types of requirements by the user of the standard; and

c) it should not be so detailed as to make the job of compliance testing against the standard overly difficult.

A classification system for EHR requirements implies a statistical usage and should embody the concepts of mutual exclusiveness and exhaustiveness which are not required for the purpose of this Technical Specification. Moreover, the objective has not been to produce a “perfect” framework (if such a thing exists) but to produce a set of hierarchical headings which are comprehensive but easy to use.

A decision was taken early in the early part of the project to adopt an existing framework of EHR requirements headings which was devised by the EHCR-SupA project. This framework was used

in the first Working Draft of this Technical Specification (ISO/WD 18308 Version 1.0, 2000-10-6) which listed over 600 source requirements. The EHCR-SupA framework provided an excellent starting point for the collation of a broader set of ISO EHR requirements. However, it became apparent after further review by ISO/TC 215 WG1 and also by the Standards Australia IT-14-9-2 EHR working group, that the EHCR-SupA framework had some deficiencies which would make it unsuitable for an ISO requirement Technical Specification. A process of modifying the framework was therefore begun which resulted in a new version (V2.0) and 4 subsequent sub-versions (V2.1-2.4) of the framework.

an adequate range of EHR requirements had been identified and that the framework had been sufficiently refined to provide a sound basis for their consolidation.

Stage 3: Development of a consolidated set of EHR requirements

The final stage of the development process for this Technical Specification was to produce a consolidated set of EHR requirements for each heading and sub-heading of the framework, using the 590 source requirements of V5.3

as “raw material”. There are several reasons for needing to produce a consolidated set of requirements:

1. *Many of the 590 source requirements are actually compound statements embodying two or more specific requirements;*
2. *Many of the source requirements are either too wordy or are very brief phrases which do not stand alone as valid requirements statements;*
3. *Many of the source requirements within a particular category or heading have overlapping or identical meaning;*
4. *Most of the source requirements are expressed in terms of the EHR/EHCR/EPR/PHR, rather than in terms of EHR architecture;*
5. *Many of the source requirements are actually system requirements rather than record requirements and therefore do not belong in this Technical Specification.*

The development of the consolidated set of requirements has been an iterative process of refinement and agreement. The framework has also inevitably changed somewhat during this process. The consolidation stage began under the *aegis* of Standards Australia following the London ISO meeting in August 2001. A two day workshop involving six experts was held in Sydney in October 2001 to produce a first draft set of consolidated requirements. This draft was updated following review by the Standards Australia IT-14-9-2 EHR working group. A second more representative stakeholder workshop was held in Sydney in December 2001. This

one day workshop had over 20 participants from 16 diverse stakeholder organizations. The objective of this workshop was to subject the second draft to detailed scrutiny from the perspective of a broad range of stakeholders including consumers, clinicians, academics, consultants, software vendors, health insurers, and government health and legal representatives. A third draft was produced as a result of this workshop and was further reviewed by the workshop participants, other stakeholders who were not able to attend the second workshop, and IT-14-9-2. The resulting fourth draft was reviewed by ISO/TC 215 WG1 and discussed at its meeting in Johannesburg in April 2002. Approval was given for progression to the Committee Draft (CD) stage with the incorporation of a number of suggested changes. There are now 123 consolidated requirements, which is a very significant reduction from the 590 source requirements in the first working draft. This is a reduction of over 75% and the more consistent and concise requirements statements will hopefully make the document more readable and more useful. Furthermore, most of the requirements statements are phrased in the form “The EHRA shall…” which more easily supports a future normative implementation of the Technical Specification.

Chapter Four

4.1 Feasibility

As with EHR adoption [29], the impediments to PHR adoption are not limited to technical ones. In addition to the economic and technological challenges, organizational and behavioral issues can delay PHR adoption. Barriers exist both at the environmental level and at the level of individual health care professionals and consumers. Education and research focused on the personal health record can facilitate adoption.

4.1.1 ENVIRONMENTAL BARRIERS TO PERSONAL HEALTH RECORDS ADOPTION

Health information on each patient now resides in multiple locations; integrated PHRs must reach across organizational boundaries to interface with multiple EHR systems. The lack of ubiquitous EHR usage currently presents the greatest environmental barrier to such integrated PHR adoption. A related problem is that EHRs must not only exist in individual offices and hospitals but must also be able to communicate with PHRs. Nonetheless, lessons learned from early PHR usage can inform future PHR development. Understanding the types of patients and consumers who use PHRs, what functions they use the most, and what changes in health-related behaviors arise from using PHRs would contribute to productive future development.

There are inadequate infrastructures which persist within most developing countries and as such hinder the implementation of PHR's. Alongside the issue of infrastructures another problem which exist as to whether there are trained users or personnel to constitute to the usage of personal health records. Though a lot of rapid development of in IT have reduce the costs of the setting of information systems [22], the question as to whether users or consumers can afford also prompts in. moreover the number of people having personal computers are limited in number throughout developing countries and as such pose as a great environmental barrier

Economic and market forces are obstacles to PHR (and EHR) adoption. Many vendors offering stand-alone PHRs have not been financially successful; numerous products and companies are no longer in existence. This may create a business climate that undervalues the potential of future, more ideal PHR systems and hinders their eventual development.

Other barriers to PHR adoption involve legal concerns on the part of providers and the privacy concerns of individuals. Providers are wary of the legal implications of PHRs. For example, courts might apply negligence standards in cases where practitioners rely on inaccurate patient-entered PHR information to make suboptimal decisions about care. While consumers appropriately desire protection of their private health information, aggressive protection measures might hamper PHR access by patients and clinicians and impede optimal care.

4.1.2 INDIVIDUAL LEVEL BARRIERS TO PERSONAL HEALTH RECORDS ADOPTION

At the level of the individual, health care consumers must understand and accept their roles and responsibilities related to their own health care. The developers and users of EHRs and PHRs must understand individuals' and clinicians' mental models of health care processes, and the related workflows. An individual's PHR can only be useful if the person understands the importance of maintaining and coordinating health-related documentation and activities with health care providers. Consumer-related interface, technology, and access issues specific to PHRs are not yet well understood.

It is possible that PHRs will threaten the control, autonomy, and authority of some health care providers, based on traditional provider–patient roles. Providers and patients will need to develop different mindsets and levels of trust. Providers must learn to encourage patients to enter the information accurately and to trust that information appropriately. Consumers must trust that providers will only use the information for the individual's benefit.

Behavioral change is a difficult problem for PHR adoption; change management issues involve providers, consumers, and regulators. First, there must be a motivation to change. While it is intuitive that PHRs can help to improve health by offering additional information when it is

needed, better objective evidence of efficiency and effectiveness of PHRs may be required before consumers, providers, and regulators will move toward the goal of PHR adoption.

Chapter Five

5.1 Results of The Project Evaluation and Discussion

There are a lot of projects going on in developing countries nowadays with the sole intention of improving the quality of healthcare. As a result most of the concentration is basically shifted on electronic medical records (EMR), electronic health records (EHR), computer based information systems (CIS) and others . much attention have not been focus on personal health records due to various challenges and barriers

1. Maintains a comprehensive, accurate, privacy protected, multi-sourced record about an individual's health
2. Provides endorsed, understandable knowledge, advice, and health status data for an individual to act upon
3. Promotes access and portability of personal health information
4. Facilitates a personalized experience, promotes health and wellness, and supports the health care of an individual
5. Facilitates asynchronous communication between a patient, authorized stakeholders (e.g., family members, other informal care givers) and the health professional(s) who are providing care services

6. Allows individuals to see much, if not most, of the information that health professionals have and use to support the patient's care
7. Allows the patient to add personal health information to the provider's formal EHR and to 'flag' potential error(s)
8. Accumulates a 'longitudinal' electronic health record that incorporates a 'memory' of essential communications among all involved parties
9. Allows individuals to create a unique health identifier for purposes of more efficient and safe authentication
10. Allows the patient, should they so choose, to be contacted for possible participation in approved biomedical or social research projects

5.1.1 RELEVANCY OF PHR'S

From the problems of performance of health information systems in developing countries, Lungo and Nhampossa [30] reports on the restructuring of health information systems. In Tanzania for instance, the former President of the United Republic of Tanzania His Excellency Ali Hassan Mwinyi in a speech presented on 8th June 1990 was quoted as saying, "we need to improve our

health information systems in order to enable individuals and the government to make sound decisions based on correct information". Similar health information systems eform efforts have been reported from South Africa, Zambia, Uganda, and Mozambique. The important health information system reform in Mozambique occurred after independence in 1975. However, those efforts were deteriorated by the 16 years (1976 - 1992) civil war. The socio economic reforms in Mozambique shows that, "with the peace agreement in 1992 and the democratic elections in 1994, the new government designed an economic, and social programs, emphasizing National Reconstruction and Rehabilitation of Economic and Social Infrastructures". Peace time in Mozambique has made it possible for people to re-establish effective communication with the population in areas formerly cut off by the war and to collaborate with the communities in planning and implementation of programmes intended to help them to improve their lives. While restructuring health information systems, many countries focus on decentralising their systems to empower the lower levels in the HIS hierarchy. The national health information systems are built up from the informational activity carried out in multiple, minuscule, often hierarchically insignificant points in the geographical structure of a country, these points are generally districts. The administration structure of many developing countries includes the community (village), district, provincial and national levels. The national health information systems in many developing countries have been strongly based on Primary Health Care (PHC) and the district becomes the most appropriate level for co-ordinating top-down and bottom-up planning, for

organising community involvement in planning and implementation, and for improving the co-ordination of government and private healthcare. Being the information and physical hub between the community and the national health information system, the district consists of a large variety of interrelated elements that support the health system in a specific geographical area. A district includes the health care workers and facilities, up to and including first and second referral hospital levels. From the above we realized there are a lot of measures being laid down from country to country to improve upon their healthcare which in most cases involves patients and consumers. To support these, WHO [31] makes it known that there is the need for countries to recognize the role of essential health technologies vertical and horizontal programs and plan their use within a sectoral approach. However, in order to be used effectively, health technologies should be adapted to the national context, and not merely copied.

The following were some five key elements which were identified as contributing factors to the success of the project [32].

1. extensive training and publicity to all OAUTHC staff in general,
2. management's involvement and support;
3. Development of an entire network of supporting activities (dedicated operator team, software and hardware maintenance);
4. regular clinical feedback ; and

5. international contacts.(With experts, etc)

In order to face current challenges and enhance the use of essential health technologies, it is planned to update normative guidelines, define specifications, and prepare training material on essential health technologies; strengthen mechanisms for efficient data collection and dissemination to Member States; and to set up mechanisms to maintain and increase installed capacity and training in all areas relating to essential health technologies, including the adoption of good clinical practices.

5.1.2 REGIONAL

5.1.2.1 Potential Need for Adding Central Revolvers

Tang et al [33] showed if PHR's cannot exchange data with other health care systems, PHRs will become "information islands" that contain subsets of patients' data, isolated from other information about patients, with limited access and transient value.

As a result, integrated PHR systems will have to interoperate with other systems throughout the entire health information environment. At a minimum, PHRs must export data to and import data

from other systems in a standardized way. More advanced PHRs will at some future time function as seamlessly integrated, interoperable "components" of other health systems. To provide interoperability, PHRs must support the same communications (Asynchronous), messaging, and content encoding standards as other health information systems.

Beyond an individual's personal data, PHRs may include relevant information about family members, caregivers, and home and work environments that are important to the individual's health. A PHR might, for example, interact with other health system such as (EMR's, EHR's and others) to obtain information about contagious diseases detected among family members. A related concern is how to allow individuals to specify which of their own data they will allow to be shared with other health information systems.

Authentication presents a particularly vexing problem for PHRs. A stand-alone PHR device may be safe if it is constantly under the control of the owner, unless its contents are unencrypted and the device is lost in a public area. However, as soon as the PHR becomes a component in an interoperable health care system, authentication becomes very important. On a regional base, before another health information system shares data with a PHR, it will need to verify the identity of the PHR's owner. In addition, the difficulty of authenticating a patient in a stand-alone PHR creates a de facto unique patient identifier that may actually increase threats to the patient's privacy. In an integrated PHR, the provider's system might authenticate the patient

5.1.3 PERSONAL HEALTH RECORD FLEXIBILITY

5.1.3.1 Infrastructure

Ring found that [34] despite the benefits and opportunities that come with personal health record's (PHR's), yet its flexibility in developing countries is minimal. With the poverty rate existing and varying from various countries, [35] it raises the concern of its affordability and maintainability, adequate infrastructures to support a propose system.

Basically the problem of trained staff manage functions related to the creation and administering of such infrastructure and in determining the motivation and policies properly to ensure that maintenance and upkeep of infrastructures are carried out on timely bases but cost efficient hinders its progression.

Also according to McDonald [36] the physical infrastructures, are perhaps the most obvious barrier which varies dramatically from country to country. State-owned telecommunications systems in most cases inhibit the rate of infrastructure diffusion. Similarly state-owned health care systems in most but not all cases tend to reduce variation, innovation, and technology adoption. Ultimately, even with the rapid diffusion of the technology, human resources remain

the greatest barrier to success. Developing human infrastructure is often the rate determining step in health informatics.

5.1.4 COMPETENCE

There is the need of education and expertise knowledge to constitute task in maintaining the infrastructure, as well as the skills of those who are to use it, for example, McDonald [36] stated that Clinics for delivering primary care, combined in some cases with facilities for the provision of minor surgery, dentistry, ophthalmic, dispensary and maternity care. Next in priority should come district medical centre, based on the cottage hospital concept, where longer term care and more radical procedures could be carried out under the supervision of senior medical and nursing personnel. In many developing countries it is appropriate to create a network of mobile clinics and specialist treatment units, able to provide medical aid to outlying districts and isolated settlements. Finally, perhaps, a teaching hospital, nursing schools and universities can provide countries with a suitable academic background and education. Culture and socio-ecological factors play important roles in development processes [32].

According to Pellegrini [32] maintains that technology should be considered appropriate when its introducing it into a community, can creates a self-reinforcing process internal to the same

community, which supports the growth of the local activities and the development of indigenous capabilities as decided by the community itself. Hence appropriate development is an indigenous aspect of the capabilities of a community to decide on its future and implement its decisions. Therefore technology can be acquired and adapted, but not transferred, for it to be appropriately developed. That is why countries to adapt and develop their own information systems based on their own needs and structures, using their own methods and practices. However some Arabic cultures restrict access to the World Wide Web and in particular to certain medical illustrations of the human body. In other cultures such as Cuba or China, information flow is more restricted for political purposes. Although in all of the above, the trend is to increased information flow.

5.1.5 AVAILABILITY OF CARE PERSONNELS

According to Lærum, Ellingsen and Faxvag [37], technology alone is not sufficient for clinical change, they review the following from their findings. “Our general findings of computer use conform to the traditional division of labor in hospitals—with writing associated with secretaries, mediation of requests associated with nurses, and reading associated with doctors. None of the electronic medical records systems seem to have stimulated the development of new or more advantageous ways of doing medical work; they have simply reinforced existing routines. This indicates that technology alone is not sufficient to achieve a well functioning electronic

information system; organizational aspects must also be taken into account. This indicates that there is the need for competent care personnel's constitute to the new development of the health sector. Yet their availability is less or in shortage developing with the increase in population size.

The WHO report [31] indicated that the shortage of trained medical personnel is frequently a barrier to the provision of effective health-care services. In some countries, nurses, health technicians and other health personnel are obliged to take on roles that elsewhere are assigned to physicians. This makes it all the more important for the choice of health technologies to be determined by the primary needs of patients and by the level of service that can be provided by the human resources available. There is also a need for greater interdisciplinary collaboration to evaluate essential health technologies.

5.1.6 FUTURE DIRECTION

As revealed by *Healthcare Informatics* [4] "Medical Care Goes Home" becomes a clear healthcare trend in future. It indicates provision of health services to homes with new innovative services such as personal health monitoring and support systems and user-friendly information systems for supporting health education and awareness. The trend is towards more involvement

of patient in receiving information, in decision-making and in responsibility for own health. The prime feature of this trend is to shift from healthcare-institution-centered care to the patient-centered care and from prevention to rehabilitation. PHR that enables patients to record and maintain their own health records plays a significant role in this trend.

Moreover, standardization [4] will play a more and more important role in PHR development. The main challenges from the technological point of view refer to the storage, maintenance, communication and retrieval of multimedia information in different technological platforms and heterogeneous database systems that may be geographically distributed. Integration and interface of multi-vendor platforms and the development of health sector specific middleware and applications have recently received lot of effort by research and development projects. This integration effort is critical since the number of systems of different purposes (administrative, insurance, clinical, nursing, etc) is rising. The standardization issues among all types of electronic health records, including PHR, EMR, etc. become more and more important. The standardization issues can be grouped into the following categories [38].

1. *Standards for record architecture*

It is an agreed structure that can accommodate all types of data and support different views and at the same time preserve the meaning and the context. This standardized architecture should be a general model of the record so it can enable the development of many different systems with a particular instance of this architecture.

2. Standards for terminology

It is necessary to preserve the meaning, for proper coding of diseases and classification of medical procedures, for any possibility of multilingualism and possibilities to link and update other knowledge sources. The work on terminology is long lasting and difficult and requires the concerted effort of many disciplines and countries.

3. Standards for communication

Communication of the records among the different users is one critical feature of the PHR and any other types of electronic health records. This means technical interoperability independent of provider, format, medical specialty, geographic location, country systems, and legislation, etc. Currently, six different approaches are competing

for being a platform for interoperability. They are OSI, CORBA, GEHR, HL7 CDA, OpenEHR, and the generic XML or Ontology approach.

4. Standards for security

Security features such as digital signature, digital keys, and other authentication systems need to be standardized. Most of the security applications and technologies are not health sector specific and the development is mainly pushed by the large financial or military institutions. The issues of security are closely related to the requirements of the confidentiality that are inherent in the definition of the electronic health record and will also be legally required by the national legislation.

Usability becomes the key to success in the heated competition in the PHR market. As mentioned above, there are only few patient-oriented research projects targeted to evaluate the performance and usability of PHR application. As shown in the preliminary analysis above, there is still much space for interface and usability improvement for the current PHR applications.

As the field matures, increasing effort will be focused on the interface and utility issues. High requirement on the accuracy and completeness of patient-entered health information pose

particular challenges for PHR interface design: how can the RHR interface effectively guides health data entry, validation, and information display with minimal user efforts? The large variety of health data types and health data terminologies add more complications to this challenge. In addition, the future PHR applications would serve as a significant component of the 'shared health setting', linking hospitals, laboratories, pharmacies, primary care and social centers. The PHR interface should be competent in adapting to different types of users and situations in such a broad healthcare scenario.

While there has been a welcome expansion of research on the use of PHRs and PHR systems, there are key areas of evaluation and development that deserve attention. For example, targets of additional research and development include [39]:

1. Identifying and understanding the applications and devices that hold the greatest transformative potential
2. Evaluating models of care delivery that are integrated with PHRs and PHR systems
3. Continuing to develop integrated PHRs as a promising model for health communications and care.

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