



The Design of Flexible Telemedicine Framework for Healthcare Big Data

Mohd Khanapi Abd Ghani¹, Mazin Abed Mohamed^{1,2}, Salama A Mostafa³, Aida Mustapha³, Hannani Aman³,
Mustafa Musa Jaber^{4,5}

¹ Biomedical Computing and Engineering Technologies Applied Research Group, Faculty of Information and Communication Technology, Universiti Teknikal Malaysia Melaka, Malaysia

² Planning and Follow Up Department, University Headquarter, University of Anbar, Anbar, Iraq

³ Faculty of Computer Science and Information Technology, Universiti Tun Hussein Onn Malaysia, 86400, Johor, Malaysia.

⁴ Faculty of Civil and Environmental Engineering, Universiti Tun Hussein Onn Malaysia, 86400, Johor, Malaysia.

⁵ Nabu Research Academy, Baghdad, Iraq

*Corresponding Author Email: khanapi@utem.edu.my

Abstract

The lifetime health record, which correlates each episode of care of an individual into a continuous health record, is the central key delivery of the Malaysian integrated telehealth application. A lifetime health record for an individual is the integration on his/her life timeline of all his/her electronic health records from healthcare centers he/she has been to since birth. The electronic medical records to be collected that form the lifetime health record, can be gathered from various spectrums of health information systems and healthcare levels, implying the necessity to handle diverse communications and information technology infrastructures. Most important consideration, however, is that the lifetime health record should contain not only longitudinal health summary information, but also the possibility of on-line retrieval of all patient health history whenever required, even during computer system downtime and unavailability of landline telecommunication network. It is only with such comprehensiveness of health records that the risk of inappropriate delivery of care may be reduced, and most of all the true continuum of care may be achieved. This paper develops an interoperable framework for an integrated and distributed telemedicine system in Malaysia, intended to cope with these requirements. The overview on the framework is provided, followed by a concise description of the three major components of the framework.

Keywords: Telemedicine, personal health records, Flexible Telemedicine Framework, continuous care, Big Data.

1. Introduction

Prompt access to a patient's lifetime health record is fundamental for the provision of seamless and continuous care. This can be achieved through the convergence of information and communication technologies (ICT), medical content and healthcare knowledge. This convergence has created many innovative technologies in health information applications (such as telemedicine, telehealth and e-health) for facilitating the delivery of better healthcare services. Through the judicious use of these application technologies, healthcare services could be accessible anywhere and anytime. On the other hand, the fragmented health information applications and paper-based medical records have significant limitations. These include issues such as ineligibility, unavailability, sheer physical volume, difficult transferability and integrability among healthcare facilities, and the difficulty to record the same data many times on different documents [1,2,3]. While recognizing the need to establish ICT in healthcare services throughout the world, healthcare systems are facing major challenges as they struggle to meet rising demand

with limited access to medical records in an integrated and continuous manner [4]. Demographic changes, rising consumer expectations and new medical technologies are all fueling demand. At the same time, considerable problems in prompt, continuous and seamless access to medical records characterize many healthcare systems.

In newly developed countries such as Malaysia, existing problems in accessing medical records and issues of manpower/expertise resources are further compounded by rapid economic growth and increased consumer expectations [5]. In order to mitigate such challenges, Malaysia has started preparing herself through health ICT initiatives such as the Integrated Telemedicine System (subsequently renamed Telehealth) for transforming healthcare services from an illness to a wellness paradigm where the lifetime health record (LHR) is used as the basis for continuous care. The LHR is the central key delivery of the Malaysian integrated telehealth application. The LHR correlates each episode of care for an individual into a continuous health record. The LHR is the summarized health records of every individual compiled from their electronic medical records. The electronic medical records refer to

patient's electronic medical records that are cumulatively derived from the clinical support system (such as clinical information system, laboratory information system, pharmacy information system and patient management system) and it can be collected and gathered from the various spectrums of health information systems and healthcare levels [6,7]. The most important consideration however is that the LHR that should contain not only longitudinal health summary information but also incorporate on-line retrieval of patient health histories whenever required.

This paper proposes a flexible telemedicine framework for Malaysia to maintain patient LHRs seamlessly and continuously, including during possible downtime of computer systems and unavailability of landline telecommunication networks. The central purpose of this paper is to present and describe the key components of the framework in a high-level manner. This research was conducted through close collaboration with the Ministry of Health Malaysia (MOHM).

2. Telemedicine, Patient Health Records and Their Challenges Worldwide

The most common types of telemedicine technologies used recently are interactive tele videoconferencing and store-and-forward technology. Interactive tele videoconferencing uses synchronous connections while store-and-forward technology utilizes asynchronous connections [9,10,11]. The field of internet-mediated electronic medical records (EMR) is in a stage of rapid development. The problem with the two approaches of telemedicine technology - ITV and store-and-forward - is that they are too dependent on the availability of healthcare professionals, computer systems and telecommunication networks. For example, by using ITV, the telemedicine centre and the remote centre have to establish a network connection and a proper schedule in order to conduct the consultation session and both parties need to be physically present in front of the video equipment [12,13]. Without a proper setup and adequate bandwidth, the consultation service cannot proceed. These approaches have not provided alternatives for continuing the consultation sessions during inadequacy of telecommunication network and system downtime; this leads to discontinuity of care and the inability to create, display and store medical records seamlessly. Generally, the recent telemedicine's system does not pay too much attention on the integration and sharing of patient medical records across telemedicine services, healthcare facilities and levels [14]. In New Zealand, research on telemedicine systems diffusion found that the majority of medical records are fragmentally stored in individual hospital information systems within health facility centers [15]. This scenario resulted in a lack of continuity and seamless integration of patient medical information.

By way of another example, the Canadian government - in order to mitigate these issues - has placed a high priority on the convergence of electronic health records and telehealth as critical and integrated components of Canada's health info structure [16,17]. This demonstrates that telemedicine programmers in Canada, which have received investment since 1991, still requires improvement in terms of integration and continuation of medical records. The same scenario occurred with the Malaysian Integrated Telehealth project. Due to a lack of focus in collecting and integrating EMRs for generating centralized patient LHRs, the project suffered from significant drawbacks; this led to suspension of the full nationwide implementation [18].

The Malaysian integrated telehealth system utilized the internet technology as its main transport or communication network [19]. Unfortunately, the telehealth system provides less consideration over the issues of inconsistency and the possible inadequacy of the

telecommunication infrastructure across health facility centres. The system strictly depends on network availability and only works well in big cities such as Kuala Lumpur, Johore Bahru and Penang (Government of Malaysia, 2007). Therefore, the system should take into consideration the situation associated with inconsistency and inadequacy of the telecommunication infrastructure during unpredictable system disasters.

3. Telemedicine Perspective in Malaysia and The Challenges

The Malaysian integrated telehealth project was conceived to fulfil the vision of the Malaysian government, specifically the Ministry of Health, for a more proactive and efficient healthcare delivery to the public. Conceptually, the Malaysian Telehealth project consists of four applications built around the premise of a series of patient-health provider appointments [20]. These meetings comprise of a series of wellness visits (by way of example, immunization events, medical screening events, ante-natal and post-natal events and other health preventive programmes) and some illness visits (by way of example, cough, fever and other related health problems) as illness conditions arose [21,22,23]. The focus of the system will be on people and services, using ICTs as the key enablers to provide an accessible, integrated, high-quality and affordable healthcare system. The Integrated Telehealth pilot projects involved four components [24], namely:

Lifetime Health Plan (LHP)

Mass Customised Personalised Health Information and Education (MCPHIE) – subsequently renamed *MyHealth*

Continuing Medical Education (CME) – subsequently renamed *Continuing Professional Development (CPD)*

Teleconsultation.

The LHP is a backbone of the Malaysian Integrated Telehealth system that consists of three main components namely Clinical Support Systems (CSS), Personalized Lifetime Health Plan (PLHP) and Group Data Services (GDS) [20]. CSS is an administrative tool to support healthcare facilities to create the EMRs and finally collate and generate a summary lifespan of EMR called LHR. PLHP is a service to deliver health plans and care plans generated from the LHR. GDS is a data mart to deliver data-mining services and generate relevant health reports [23]. CME offers just-in-time significant information to support decision-making relating to the patient being treated. MCPHIE offers a selection of relevant patient information about the disease that can be further personalized by the doctor and home consumers. Teleconsultation services could be called upon if expert opinion needs to be obtained [23]. As the patient walks in to see the attending health care provider, the attending doctor will access the CSS. All this data under the CSS will be compiled in the EMR of the patient. Upon the patient checking in to the LHP system, his EMR at the point of care is generated. Similarly the patient's LHR and PLHP will be generated and kept within the database.

Upon subsequent visits to the healthcare providers, the LHR and the PLHP of the patient will be called upon and added onto accordingly. In this respect, the patient's records are shared amongst the healthcare providers to ensure a continuity of care. The LHR of the individual where it will be processed and generate a PLHP which can be accessed through MCPHIE via internet (for those with internet access) and, through call centers or through the attending health care provider (for those without internet access). All of the above applications using store-and-forward and internet technologies as a telecommunication medium for delivering the telehealth services. The virtual private network (VPN) is used to link all referral hospitals and health centers. The spectrum VPN bandwidth

requirements ranged from 2 mbps from the hospital to the data centre to 64 kbps from the health clinics to the hospital and 100 mbps for the local area network (LAN) of the hospital [23]. Figure 1

illustrates the interplay amongst components within the telehealth applications to form an integrated solution.

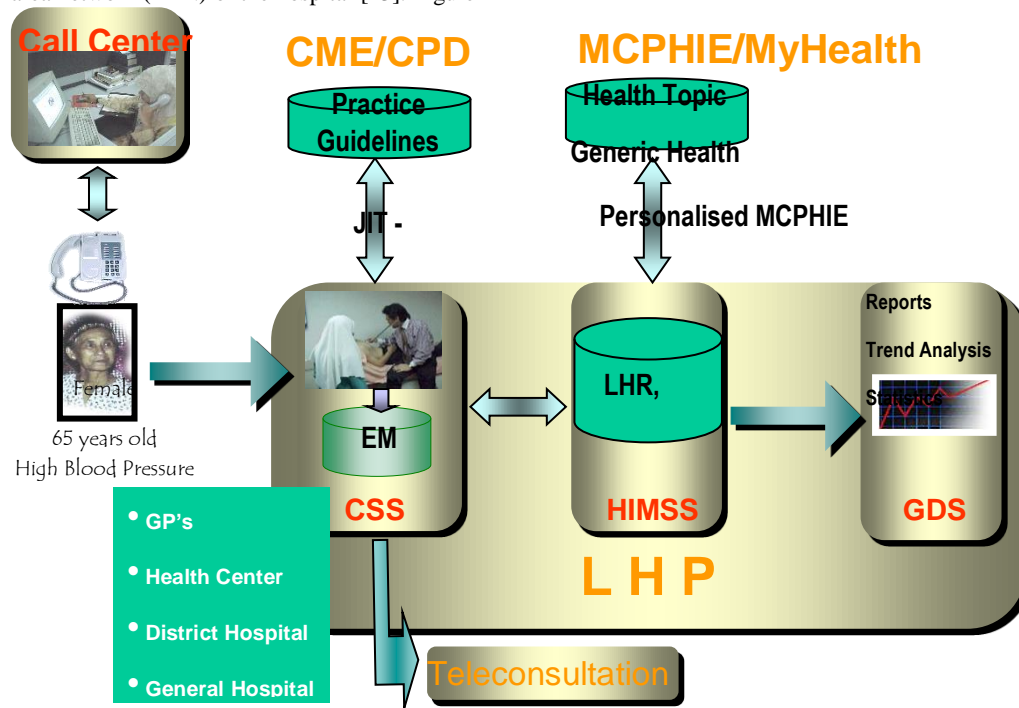


Figure 1. Overview of the Four Components of the Telehealth Application [23].

4. Implementation Issues and Challenges

The implementation of telehealth application would naturally necessitate the development of national repositories for LHR, the former for storing integrated medical records of individuals to date. Such a huge collection of critical data would certainly allow for various forms of statistical studies and data mining (referred to as GDS) which would result for better health planning at the national and state level. Such a collection of services including GDS, LHR and together with PLHP may collectively be classed under the generic title of HIMSS. The development of national repositories for LHRs would in turn necessitate a nationwide effort in the collection of EMRs at various health centers or institutions (General practitioner, health centre, district hospital, general hospital and tertiary centre). The EMRs not only have to be integrated in terms of chronology but also across health centers to form corresponding LHRs. This entail the development and deployment of various CSS at the participating health centers, where the CSS would come in the form of a set of integrated clinical applications comprising of various systems such as the Hospital Information system, the laboratory information system, the radiology information system, the picture archiving and communication system, etc. [26].

An overall view of the telehealth project given above shows the ultimate telehealth service that requires the use of the LHR repositories, both of which also contribute to the provision of GDS via the HIMSS and also shows that LHRs are built from EMRs that are collected via CSS. The point here is how to make sure the collection and the generation of patient health records could be maintained during unavailability of landline network and downtime of computer system. Obviously CSS and HIMSS need to be active at all times because LHR contents need to be updated with every new encounter at various healthcare centers. Therefore, it was

critical important to have a flexible framework for ensuring the health records of patient could be captured, viewed and stored continuously and seamlessly. The next section discusses the issues and challenges in implementing the pilot telehealth system in Malaysia and continues to the proposition of the framework.

4.1 Continuity and Seamlessness of Health Record

The continuity and seamlessness of medical patient information is a major problem in the Malaysian Public and Private Healthcare Facilities and is also a critical issue in other countries such as the UK, USA, Australia, Canada and others in mainland Europe [27,28,29]. It has been demonstrated that access to paper records is generally problematic and resource intensive [30]. A study carried out on cervical cancer patients in Malaysian women [31] found that only 30% of patient records were fairly complete and accessible, with another 30% of records being available but not complete and the remainder of records lost or not retrievable at all. This would relate to the need for generating EMRs that can be shared across different healthcare facilities. Although the information system has been implemented and used as a means to support the medical practice in day-to-day operations, the continuous and seamless access to patient medical records is still inadequate. The three major information system projects in Malaysian Public Healthcare Facilities, namely Tele primary care, Total hospital information system and Telehealth are still unable to share and link the patient health record from one facility to another [32,33]. The different technologies, the fragmented setup of ICT infrastructure and the fragmented solutions lead to highly challenges for achieving the solution integrity between applications and services and finally for gathering and generating the LHR centrally.

4.2 Telecommunication Infrastructure

Telehealth or e-health systems involve geographical information and the use of telecommunication technologies in providing healthcare services to the patients. Telehealth applications can be implemented in healthcare facilities or provide services direct to patients through the internet. In Malaysia, the network infrastructure may not be consistent across the country and among healthcare facilities. For example, in 2005, the average internet penetration in Malaysia was around 14% [34]. Internet penetration in large cities such as Kuala Lumpur is around 50%. These issues and challenges need to be addressed before the telehealth or e-health system is fully implemented in healthcare facilities nationwide. Inadequate telecommunication infrastructure would jeopardize the availability, accessibility and the continuous upkeep of the patient medical record.

4.3 System Integration

The integration issues on health information systems (HIS) are well known throughout the healthcare industry. In 2005, approximately 80% of healthcare providers in the US were still using paper-based medical records in their day-to-day consultations; from the systems that do exist, few are interoperable [35]. The Malaysian Public Healthcare Facilities are also facing the same situation where systems operate independently and are unable to share patient medical records with one another. Uncoordinated planning and legacy and proprietary systems with limited or no networking capabilities present major challenges to systems integration [8]. The integration challenges include formulating and developing health informatics standard (such as a clinical code set – e.g. patient identifier, clinical terminology, drug code, disease code classification and administration code set), information system architectural standard (such as software, hardware, operating system, middleware, network communication protocol, database system, data model and information communication protocol), making eventual use of available open source code [36], and standard operating procedures (such as care pathways, clinical professional guidelines and operational policies). It is therefore of critical importance that existing systems are upgraded and the future HIS adopts standard solutions and integrity models for interoperability, scalability and reusability. Malaysia's telemedicine blueprint, consisting of four integrated application components, provides a comprehensive framework and a road map for the building and provision of a future healthcare information system. It is our contention that the MOHM should coordinate and enforce the existing and the future information system to adopt that framework. This is to ensure that

medical information is synchronized between the systems and that LHR can be accessed seamlessly and continuously.

5. The F2u-Lhr Architectural Framework

This section proposes a F2U-LHR framework to mitigate the problems associated with accessing patient health records during doctor-patient encounter. F2U-LHR is constructed so that it is capable of being useful in providing patient health record continuously and seamlessly using portable storage devices such as PDAs, mobile phones and smartcards in outpatient clinics [13]. The framework enables the system to be operated on a standalone basis (perhaps even off-line) and provides high availability and accessibility to LHR during disaster scenarios. This section starts with the description of the design approach and continues with the description of the components of the architectural framework. Figure 3 depicts the first draft proposed framework and its relationship between components within the framework.

5.1 Design Approach

The architectural approach for F2U-LHR is based on the unified modeling language (UML) [37,38]. The F2U-LHR architectural solution used system layer to organize the view of the framework structure [39,40]. Use case view is used to describe the functional requirements of a system and interactions between users and the system itself. Hence, the framework provides openness and flexibility for allowing the systems to evolve independently, as new technologies and healthcare system functionalities arise [41,42].

5.1.1 The F2U-LHR Use Case View

The use cases were identified to support the system implementation and to mitigate those issues described in the previous section. The crucial use cases are identified to support the critical process of consultation workflow during system disaster. In the use case approach, functional requirements are defined in terms of actors, which are users of the system, and use cases [43]. A UML use case model (Figure 2) describes the functional requirements of the F2U-LHR system in terms of the actors and use cases and, the interaction between actors/users and the system in a sequence manner [37]. Registration clerk, Healthcare Professional, Portable Storage Devices, Requestor and Provider are the actors of the use cases. The registration clerk, healthcare professional, requestor and provider are the main users interacting with the system.

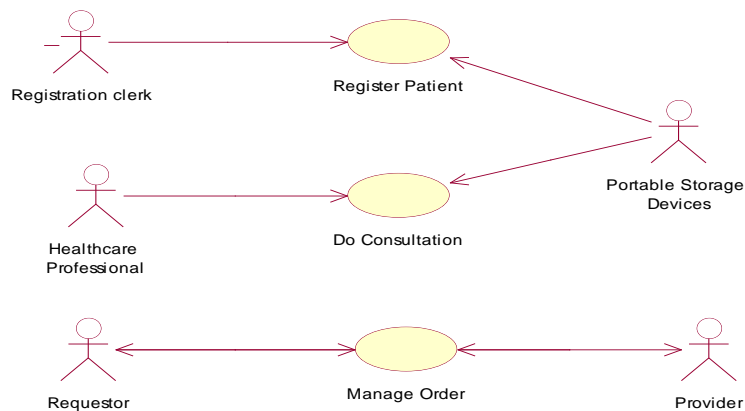


Figure 2. The F2U-LHR Use Case View

I) Use Case Register Patient

This use case is meant to register outpatient patients. Outpatient registration covers new, follow-up and referred cases. All patients who come to a healthcare facility are registered into the system before they can receive healthcare service in an episode of care. The registration process includes the process of searching the patient for verifying the patient’s identification. Besides, the registration process provides an option to maintain patient’s demographic information. A very important point is that this system can capture minimum information about the patient during a system disaster. It is not appropriate to implement the formal process of patient registration during a system disaster. The tasks for processing patient arrival and registration are relatively complex and time-sensitive involving capturing of administrative data [44]. Critical to this workflow is the ability to manage the patient. Quick registration is the process that allows healthcare professionals to enter sufficient amount of data to generate a new episode or patient identification number. This permits healthcare professionals to capture or maintain health records on the patient although formal registration and verification of administrative data have not yet occurred

ii) Use Case Do Consultation

The purpose of the use case is to enable doctors to continue capturing the consultation findings into the system during system disaster. The consultation process can be continued for gathering the medical history of the patients, recording the examination details of the patients, providing one or more diagnoses if required, prescribing treatment if required, entering clinical examination report and informing next appointment date [45]. The consultation process begins once the person gets to see the doctor. In the event of a system disaster (unavailability of network connection), the F2U-LHR framework should be able to provide a tool for the Doctors to create, display and store the patient health records seamlessly and continuously. The F2U-LHR should provide a capability for recording a minimum consultation notes such as the chief complaint, history of present illness, past medical history, social history, drug history, family history and, diagnoses and treatment. The consultation process involves viewing of patient’s health condition for better picture of the patient. The patient health records are captured and kept for future care. During a system disaster, these data can be retrieved and saved from/to portable storage devices

iii) Use Case Manage Order

This use case is meant to place the order related to health transaction (access, browse and store LHR). The order transaction can be new, cancel or response and all of them will be transacted into health order management service’s (refer section health order management services) queue list. During a system disaster, Doctors can retrieve the patient demographic and patient health condition using short messaging system (SMS) from health information management services (refer health information management services) through health order management service module.

All orders which are already placed either by the placer or filler will be distributed/routed to the destination by the health order management service manager and the destination address is looked up from the service directory address. health order management service manager is a software program that also responsible to validate the order information in order to ensure that the order information is meeting the standard orders specification. Upon completion of placing or distributing of the order processes for a particular order’s transaction, the acknowledgement message is prepared and then placed to the order queue. An acknowledgement is then sent to the placer or filler to acknowledge the status (success, failure, received, rejected) of the orders. The order transaction can be tracked and monitored by identifying the status of the order. The order status would be: success, failure, just received, in progress or rejected.

5.1.2 The F2U-LHR System Component

i) Overview

The framework is divided into three components, namely clinical care support (CCS), health order management service (HOMS) and health information management services (HIMS). It should be stressed that the three components provide a set of services needed to attain particular visions and goals of the research project. As such, F2U-LHR framework provides a common solution to cover the whole range of needs for accessing, creating and storing patient LHR continuously and seamlessly.

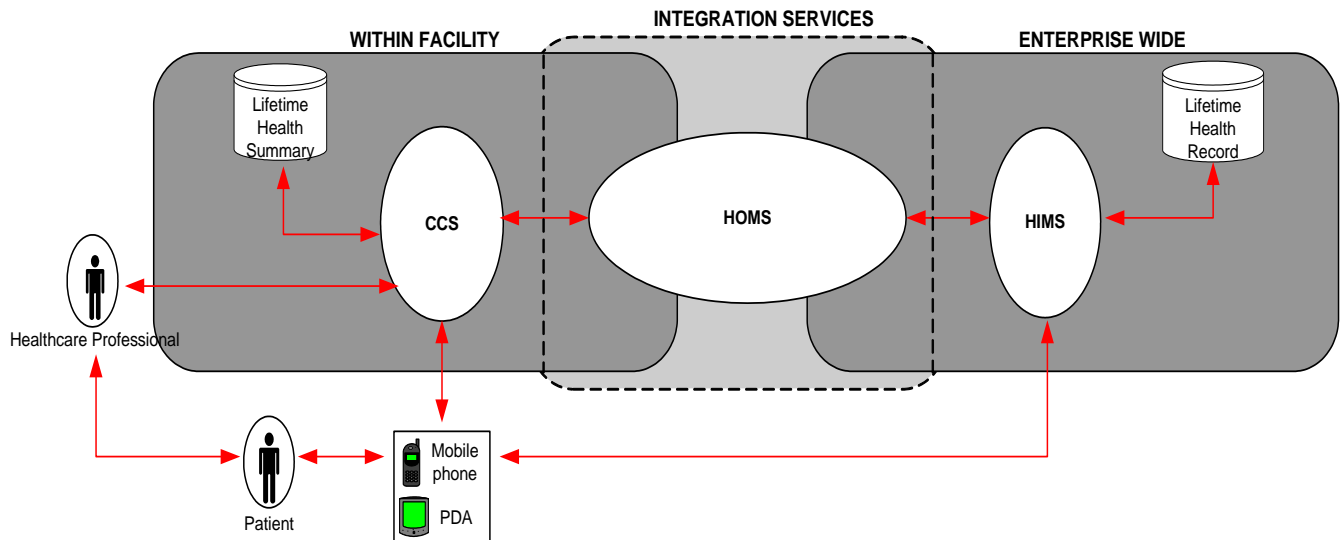


Figure 3. First Draft of Proposed Framework (F2U-LHR)

ii) Clinical Care Support

The left part of the diagram shows the position of a clinical care support (CCS) component which focuses on providing support for clinical and administrative service at healthcare facility centers. The essential goals of the CCS are to:

- To provide support for clinical and administrative functions at healthcare centres
- To create health records that directly contribute towards the creation of LHRs.
- To make sure the lifetime health summary can be accessed, created and stored continuously and seamlessly.

The principal target for the CCS is to provide support for the clinician during a consultation and diagnosis process at the point of system disaster (unavailability of telecommunication network or downtime of computer system). Support is required by the clinician in order to provide a high level of care, and more accurate diagnosis and treatment [3,45]. To ensure seamless and continuous care, the clinician would require past health records of his patient, such as past treatments, drug prescriptions and past chronic problems provided earlier by himself or by other clinicians [46]. These also can be retrieved from the lifetime health summary. The lifetime health summary file stores crucial summary of LHR decentralized at every healthcare facility centre and even within doctors' PCs and patient's portable storage devices. During system disaster, the lifetime health summaries can be retrieved and stored from/to local hard drive of a doctor's PC or portable storage devices in patient's possession. Thus, the major requirement of the CCS is the ability to retrieve past health records seamlessly from the same healthcare centre as well as from other providers.

In addition, the CCS is crucial because it is a source for generating EMRs and forming the LHR repository and group data services [47]. A meaningful LHR repository cannot be expected before sufficient LHRs are collected which, in turn, are dependent on the usage of the CCS applications. As such, a flexible system should be provided for healthcare professionals to retrieve, capture and store the health records of patients continuously. This will ensure that sufficient EMRs are collected to form the LHR repository.

iii) Health Order Management Service

The central part of the diagram is HOMS components that act as integration services between CCS component in healthcare centers

and the HIMS component at the enterprise level. The HOMS provides a common contact link in managing the health order request (retrieve and maintain health records and patient master index information) flow within the healthcare facility base, and between the healthcare facility base and the enterprise level. The essential goals of HOMS are:

- To make all systems within and between the healthcare facility work together to share relevant information (patient health records and demographics) electronically.
- To establish a common framework for integration between systems (in particular between CCS and HIMS) that enables a participating healthcare facility to send and receive orderable requests (patient health records and demographics) electronically.

The HOMS provides a common 'gateway' for CCS application and other application systems to retrieve/send patient LHR from/to the HIMS. The HOMS architecture will be a common framework for integrating all EMRs from other participating sources that may come from other types of CCS applications, such as tele primary care and other HIS. HOMS acts as a central agent to delegate and acknowledge an order for LHR from the requestor to the service provider regardless of application or location of a healthcare facility. The HOMS features enable all participating healthcare centers to send and receive LHR request electronically, where the contents of the data should be standardized. When a system disaster occurs (e.g. unavailability of telecommunication network) and to achieve fault tolerance without affecting the scalability of integrating applications, the solution is to communicate asynchronously through portable storage device interface. This is where the HOMS plays its rescuer role. The HOMS will grow in term of services to be provided and its architecture should be flexible to incorporate enhancements of future functionalities as well as non-functionalities (such as load balance, for getting a reasonable performance). For this proposed framework, only three order services are offered namely: maintain and retrieve patient lifetime health records (LHR), maintain and retrieve patient master index and maintain patient identification number.

iv) Health Information Management Service

The right hand side of the diagram is the HIMS component which is hosted centrally (enterprise-wide) for accessing its services anywhere and anytime nationwide. The HIMS component is responsible for managing the request services of LHR and patient information continuously and seamlessly (such as collecting and distributing patient's master information and LHRs). The essential roles of the HIMS are:

- To manage the collection, creation, retrieval and distribution of LHRs.
- To collate and manage patient master index information.
- To manage the generation of patients' unique identification number.

The LHR repository and patient information database requires an information system for ensuring the completeness of individual demographics and medical history from birth to death. The HIMS puts together all EMRs to form a single integrated LHR for each individual, where the integration transcends time as well as location (as the person may have visited the same healthcare centre at different times or may have visited different health centres). But what if the system is down or the participating healthcare centers do not have the capability to provide a landline network connection to HIMS for accessing the LHR? If this is the case, the 'client storage manager module' is invaluable. The LHRs located in the HIMS will be accessible from CCS using portable storage devices through Global System Mobile (GSM) digital network and Short Messaging Service (SMS).

The final LHR will contain all EMR summaries for that person in chronological order from birth to the current date as well as some form of summary (Lifetime health summary) is required for easy reference. Obviously the HOMS and the HIMS need to be active at all times because the LHR contents need to be updated with every new encounter at various healthcare centres.

6. Conclusion

This proposed flexible framework (F2U-LHR) for Malaysian telemedicine system is derived from the literature, case study and close collaboration with the MOHM. Lessons learnt from the previous health ICT project implemented in the public healthcare facilities of MOHM such as Telehealth, TPC and THIS, contribute crucial element into the framework. The use of the F2U-LHR framework can provide flexibility in maintaining patient health records and can greatly increase the accessibility to LHR. In addition, F2U-LHR can also be used to overcome any telecommunication network inadequacy and unpredictable system downtime. F2U-LHR easily integrates with other existing application system (such as TPC and HIS) through the HOMS components. The research work will proceed to the process of validating the proposed framework with the MOHM. Future work includes testing of the framework in close collaboration with the MOHM. It will be evaluated by three major health ICT projects involved in the MOHM and the comments and suggestions will be analyzed and, if required, the framework subsequently refined.

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