Designing a Web-based Personal Health Record System for Liver Transplant Care from Healthcare Professionals’ Perspectives

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Affirmation

I hereby affirm that this Master thesis was composed by myself, that the work contained herein is my own except where explicitly stated otherwise in the text. This work has not been submitted for any other degree or professional qualification except as specified; nor has it been published.

Stockholm, June 13, 2014

Lin Zheng
Abstract

**Background:** Liver transplant care involves advanced biomedical knowledge and technologies for diagnostic, surgical and prognostic procedures and processes. A liver transplant patient often undergoes months or even years of assessment and care management in institutions overseas. The initial attempt of integrating Personal Health Record (PHR) into the health system could indicate the challenges and design solutions of ICT application to improve patient-centered care in the context of liver transplant management.

**Objective:** To explore the knowledge about developing a patient-centered PHR system based on healthcare providers’ opinions to support liver transplant care.

**Methods:** Exploratory design science research was conducted in the qualitative study. Data collection tools included participant observation, semi-structured interviews and documentary. Process modeling and GUI prototyping were also applied in the study.

**Results:** The field observation provided the understanding of existing processes and workflows of liver transplant care. The individual semi-structured interview with healthcare providers generated qualitative data on their attitudes towards PHR and desired functionality and features of the system. The GUI prototype was developed to propose the potential solution of the web-based PHRs for liver transplant care.

**Conclusion:** The healthcare providers had positive perspectives on health information technology. The PHR system could be a useful tool to support patient-centered liver transplant care by bridging the health information gaps, enhance communication between patients and physicians, facilitating clinical process and patient empowerment.

**Keywords:** Personal Heath Record, Liver Transplant Care, patient-centered care, Process modeling, graphical user interface, prototype
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List of abbreviations

Asian Centre for Liver Disease & Transplantation (ACLDT)
Business process modelling (BPM)
Cadaveric Liver Transplantation (CLT)
Clinical Decision Support System (CDSS)
Computerized Provider Order Entry (CPOE)
Electronic Health Record (EHR)
Electronic Medical Record (EMR)
End-Stage Liver Disease (ESLD)
Graphical User Interface (GUI)
Health Information System (HIS)
Hepatocellular Carcinoma (HCC)
Infectious Disease (ID)
Information and Communication technology (ICT)
Institute of Medicine (IOM)
Liver transplant (LT)
Living donor liver transplant (LDLT)
Personal Health Record (PHR)
Picture Archiving and Communications System (PACS)
Scottish Woman-Held Maternity Record (SWHMR)
Split liver transplantation (SLT)
Transplant Ethics Committee (TEC)
User Interface (UI)
Unified Modeling Language (UML)
World Health Organization (WHO)
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1. Introduction

Liver diseases have contributed markedly to the global burden of mortality and morbidity. According to a World Health Organization (WHO) study, liver cancer and liver cirrhosis rose by 50 million per year over 2 decades worldwide. (1) The number of patients who have undergone liver transplantation to save life is continuing to increase because of the epidemiology of liver disease.

While the liver transplantation treatment represents a great hope for liver disease patients, it requires long-term continuous management for overcoming various complications after liver transplantation. High patient involvement and active participation in managing their own health care can improve the care outcome. (2)

In “Crossing the Quality Chasm: A New Health System for the 21st Century”, the Institute of Medicine (IOM) issued six goals for health care system: safe, effective, patient-centered, timely, efficient, and equitable. The widespread adoption of Information and Communication technology (ICT) is regarded as a mean to hasten the health care system to achieve the IOM’s six goals. (2) The personal health informatics has become a field within health informatics that enables patient empowerment and strives to achieve higher quality care. (3)

1.1 Patient-centered care

Patient-centered care is recognized as an important aspect of health care quality. (4) There is no standard definition of patient-centeredness at present. (5) The definition of patient-centered care in the IOM’s highly influential report is stated as:

*Health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.* (4)
The concepts of patient-centeredness usually stress the opportunities of strengthening the patient’s position in healthcare and increase their involvement in medical decision making and treatment. (5)

Chronic disease management is considerably different compared to acute illness, because it requires for almost continuous decision makings and adjustments to the patients’ changing health conditions. (6) There is growing evidence that patient-centered care can optimize outcomes among most patients with chronic conditions. Its benefits include promoting greater patient responsibility and involvement, which ultimately result in patient satisfaction and improved quality of life. (7,8)

1.2 Personal Health Record

Most individuals receive care from many health care providers; consequently, their records are stored in multiple locations, recorded by multiple facilities in both paper and electronic formats. Lack of a system which can store and retrieve essential patient data from multiple sources impedes optimal care. During the booming of e-health, one emerging tool that can be used in aggregating and maintaining the patients’ medical history is the electronic Personal Health Record (PHR). (9)

PHRs are in the early-adopter phase, so the evidence to qualify its benefit is limited. However, the PHR will play a role in remodeling the physician-patient relationship by empowering the patient, as anticipated by a national consensus conference held in 2003. (10) The PHR has the potential to show a more comprehensive view of the patient. Because PHR is patient-centered driven ICT tool, through which the physician can view them directly rather than by “a screen of machines and specialists”. (11)

PHR is generating interest in the healthcare industry because it enables consumers to actively engage in their own health care and improve the way of the health care delivery. (12) One of the key findings in Deloitte 2008 Survey of Health Consumers is that more than 60 percent participants wanted online access to their medical records. (13)
1.2.1 PHR evolution

The history of personal health records could trace back to many decades ago when individuals and families kept their medical records in one place, maybe in envelopes, notebooks, loose-paper folder or boxes. Such paper-based PHR included the printed laboratory reports, copies of clinic notes, and health log created by the individual. (14) Probably the most successful paper-form PHR was the handheld pregnancy record developed in Milton Keynes in the mid-1980s and now exists as the Scottish Woman-Held Maternity Record (SWHMR) and is in use throughout the United Kingdom. (15)

The most basic electronic PHR emerged as people created health history in a word-processing program or spreadsheet applications. These records are initiated and maintained by individuals to manage lifelong personal health information and can be shared with or without health care providers. As mass storage devices such as CD ROMs, smart cards, or USB flash drive became available they were used for the storage of personal health information. (14)

The first generation web-based PHRs were promoted as a mean of providing patients and providers access to medical information from anywhere that the internet is available. One example of early web-based PHRs is the online emergency medical records that contain short medical history, medications, immunizations, allergies and care providers’ information available to emergency room clinicians. (16)

1.2.2 PHR definition

The definition of Personal Health Records is still evolving. The Markle Foundation’s personal health working group defines the PHR in the report “Connecting to Healthcare” as

“An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment.” (17)
PHRs are based on the fundamental concept of patient centricity in the health care process, since it is owned and controlled by the individual. Thus, it differs from the Electronic Health Record (EHR), which is “an electronic version of the patient medical record kept by physicians and hospitals. The data in the EHR are controlled by and intended for use by medical providers.” Another term Electronic Medical Record (EMR) in Health Informatics area refers to the legal record owned and used by the care providers to document and manage health-related information within one health care organization. (18)

![Image of Electronic Health Record Diagram](image)

**Figure 1. Electronic Health Record Diagram**

A PHR not only contains information from multiple health care providers’ paper charts and EHR/EMR but also includes health data generated by patients themselves. In short, the PHR belongs in the domain of the individual, while the EMR and EHR are within the environment of the care providers. The EMR is the basic building block which supplies the source information to feed the EHR. The EHR contains health information from several providers involved in a patient’s care; the data of EHR is probably interoperable across the regional care organization. (19) The interdependencies between EMR, EHR and PHR are clear showed in Figure 1.
1.2.3 PHR models

The simplest model of PHR is a standalone application which does not connect with any other system. Stand-alone PHRs are often PC-based and require manual data entry to generate the record. Although the free-standing nature of such PHRs provides more individual control over the data access, however, the limitation of manual data entry hinders the user’s motivation to keep the records in a stand-alone PHR up to date. In addition, care providers may not consider a PHR that only contains patient input as reliable, accurate and complete medical record data. (14,17)

Institution-specific or tethered PHRs are a limited form of the integrated model that link to a particular health care organization's electronic health record (EHR) system or to a health plan database, offering patients access to parts of their own records through a secure portal. These PHRs are an extension of a care provider’s health information system. Patients’ records are under the physical control of the healthcare provider; however, in some systems the patients have opportunities to add some health data, such as height, weight and temperature. (14,17)

Integrated or interconnected PHRs combine the elements of stand-alone and tether PHRs. It can be populated with patient data from multiple settings or health systems. The individual is also an important source to the integrated PHR content and is usually allowed to input data into selected parts of the record. The advantages of interconnected PHRs include eliminating manual re-entry of data, enhancing efficiency of patient-physician communication; and providing a more comprehensive view of patient health information. Some integrated PHRs have capabilities in connection with services related to a specific health condition or illness. (14,17)

1.2.4 PHR functionality

There is great variability in the functions and data elements included in different PHRs. The functions and their impact on care probably are the most crucial area of PHR research, since uptake and usage of PHR are highly dependent on the functionality of the PHR system. (20)
Based on the use of information from the patients’ perspectives, primary PHR functions are classified into four general categories:

(a) Information collection — to enter own health information and retrieve information from external sources,
(b) Information sharing — one-way sharing health information with others,
(c) Information exchange — two-way data exchange with others,
(d) Information self-management — to support own health/healthcare management, e.g., to obtain patient education and decision support. (21,22)

Fernández-Alemán JL et al. analyzed the functionality of web-based PHRs as regards to the three data categories: health information, user actions and connection with. The functions which fall into each category are listed in table 1. (23)

**Table 1. Functional categorization of web-based PHRs** (23)

<table>
<thead>
<tr>
<th>Categorization</th>
<th>Functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health information</td>
<td>Allergies, Blood pressure, Weight, Immunizations, Family history, Emergency contact. Attractions, Medication, Family history, Social history, Emergency contact.</td>
</tr>
<tr>
<td></td>
<td>Glucose level, Blood group, Height, Medication, Social history,</td>
</tr>
<tr>
<td>User actions</td>
<td>Information sharing, Export information, Modify, Grant access. Import information, Add, Remove,</td>
</tr>
<tr>
<td>Connection with</td>
<td>Healthcare providers, Other PHRs, Social networks, Health devices, Third-party applications, Laboratories.</td>
</tr>
</tbody>
</table>

The functions and features of different PHRs are significantly diverse and may have implications for PHR adoption and use, especially for patients with chronic conditions. (23,24)
1.3 Medical background

1.3.1 Liver transplantation

The liver, the largest internal organ, has a wide range of functions including processing proteins, producing bio-chemicals necessary for digestion and breaking down toxic substances such as drugs and alcohol. The liver is necessary for survival; there is currently no way to compensate for the absence of liver function in the long-term. (25) If the liver begins to fail, the patient may be eligible for a liver transplant for saving life.

Liver transplantation has become a widely accepted therapy for cirrhosis and liver failure. It has been landmarked as one of the most important advances in the medical field. Liver transplantation is usually done when other medical treatment fails. The history of liver transplantation dates back to 1963, when Starzl in Denver first performed Cadaveric Liver Transplantation (CLT) in human in the world. (26)

With the advances in surgical technique, postoperative care and improvements in immunosuppressive drugs, liver transplantation has become the gold standard treatment for the patients with acute liver failure or chronic liver disease. Liver transplantation surgically replaces a diseased or failing liver with a healthy whole liver or a segment of a liver from another person. Liver transplantation is usually done when other medical treatment fails. In such situation, transplantation is the only cure for liver failure because no device or machine can reliably perform all of the functions of the liver. There are three types of liver transplantation that are practiced in the world. They are cadaveric, live donor and split-liver/ reduced size transplant. (27)

<table>
<thead>
<tr>
<th>Types of liver transplantation</th>
<th>Brief introduction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cadaveric Liver</td>
<td>Liver transplant from a deceased donor is known as cadaveric transplant. The majority of livers that are</td>
</tr>
</tbody>
</table>
Liver transplantation has offered new treatment options for patients with End-Stage Liver Disease (ESLD) and selected patients with Hepatocellular Carcinoma (HCC). The liver transplant procedure has evolved dramatically in the management of patients with liver disease over the past decade. Long-term survival of liver transplant patient depends on the patient’s clinical status, the surgical procedure, the donated liver, and the management of surgical complications and immunosuppression. (28)

### 1.3.2 Living donor liver transplant (LDLT)

Cadaveric liver transplantation (CLT) is a preferred procedure, especially considering the risks to the donor. Unfortunately, the critical shortage of cadaveric liver organs has significantly restricted the application of Cadaveric liver transplantation. Split liver transplantation (SLT) has reduced the waiting list mortality in children, but not in adults. Living donor liver transplant (LDLT) has emerged in recent decades as a critical surgical option for patients with ESLD to overcome the scarcity of donor organs in adults. (29)

Most cases of LDLT are reported from Asia. But recently this treatment has been taken up and propagated in Europe and other countries as well. (30) The major advantages of LDLT include the better quality of graft retrieved from a healthy donor, the careful scheduling of the transplantation surgery. The shortened waiting period for a living
donor organ may reduce the risks of developing fatal complications or death before transplantation. The vital disadvantage of LDLT is the potential for complications or even death of a healthy donor. Donor safety is crucial in the application and expansion of LDLT. The surgical procedures for LDLT are technically more challenging. (31)

1.3.3 Major LDLT management process

The modeling map of major LDLT management process is combined from two sources, one is the figure ‘TRANSPLANT PROCESS MAP’ from ACLDT document (Appendix A), the other one is the figure ‘Major processes associated with the management of solid organ transplant patients’. (32) The distinction between the two sources is the pre-transplant procedures. The former model focuses on living donor liver transplant care, so there are no ‘candidates on waiting list’, and it is applied within Singapore health system and follows the law and ethical requirement in Singapore. But this model ends on the step “Transplantation Operation”. The later model is more general. However, the post-transplant procedures are quite similar.
The Major LDLT management process modeling was evaluated by a transplant coordinator in ACLDT.

1.4 Previous scientific studies

PHRs are still infant technologies and becoming popular. There are increasing number of studies reporting the benefits and the cost of PHR systems. However, the majority of these studies are performed in general health care context. (9,33,34) Little attempt has been focused on specific studies on condition oriented PHR for liver transplant care. However, there are several relevant studies on PHR for chronic disease management or particular population and condition.

University of Pittsburgh Medical Center (UPMC) implemented a web-based personal health record, HealthTrak, to support patients with diabetes self-management. Through HealthTrak, patients could view the health information in their own EMR and securely communicate with their care providers. HealthTrak had the potential to enhance patient self-management and strengthen patient-physician relationship. (35)

Mychildren's, a web-based application for pediatric and adolescent population was developed at Children’s Hospital Boston. This application combined features of personally controlled health record and tethered patient portal. Mychildren's could allow patients and their guardians more engage in managing their health. (36)

1.5 Problem description

The PHR project was held at the Asian Centre for Liver Disease & Transplantation (ACLDT) in Singapore. ACLDT is one of Asia's foremost liver centers which perform Living Donor Liver Transplantation (LDLT) Program. With its reputation, many patients around the world visit ACLDT every year. More than 90% of the patients are not Singaporean.
The procedures of LDLT generate large volumes of medical documentation from multiple sources. These medical data should be accessed by healthcare professionals to make clinical decisions. Comprehensive and longitudinal health information of one single patient is needed during the whole liver transplant care process.

On the other hand, the complex procedures of liver transplant both before and after the surgery increase the demand of new ways to communicate and monitor patients. For example, to collect patient medical history document for the evaluation process, to trace the follow-up plan for post-transplantation from several months to several years.

Moreover, most of the patients in this liver center are international, there are no EHR systems could integrate health data from different health organizations in different countries. The customized PHR comes up as a potential solution in such situation, because it not only serves as a record repository tool for the patients to access and manage their health information, but also an important tool for communication and monitoring in the long-term care.

Clinicians’ points of view on PHR are crucial in this case. Although PHRs is designed as patient-centered tool, healthcare professionals play important role in the endorsement of PHRs to patients. Having medical knowledge and working experiences in such a highly dynamic and complex care setting of liver transplant management, the clinicians can have opinions on functional requirements of the PHR to support the care process. In addition, their attitudes and perspectives towards PHR are also considerable. If they feel uncomfortable with sharing data with the patients and other providers, it could be an issue for clinicians to accept such a new tool.

Since every condition or disease has its own data elements that need to be tracked and managed, it is necessary to analyze the user needs on PHR functionality. In this study, the clinicians’ opinions are significantly important to ensure the PHR can assist in providing care for patients and help improve the effectiveness of treatment.
1.6 Research question

The research took place in the real-world setting of health care system-liver transplant care, which requires advanced biomedical knowledge and technologies, multidisciplinary team cooperation and continuous follow-up. The initial attempt of integrating electronic personal health record might indicate the challenges and design solutions for those in touch with liver transplant services.

How can a PHR system be designed to improve patient-centered care in liver transplant center from the healthcare professionals’ perspectives?

1.7 Aim and objectives

The purpose of this thesis was to explore the challenges and potential solutions of designing a PHR system to support liver transplant care from the clinicians’ perspectives. This study would form the base of the PHR system development project held at Asian Centre for Liver Disease & Transplantation (ACLDT). The whole project was called “Towards Sustainable Health Information Systems: A Personal Health Record system for International Liver Transplant Care”. However, this study only focused on design part at the initial stage of the whole PHR project.

To achieve the aim this study had the following objectives:

- To understand the clinical processes and workflows in the liver transplant center.

- To investigate the liver transplant professional’s attitude and opinions about PHR

- To elicit the major functionalities of the PHRs to support the process of liver transplant care.

- To propose potential solutions in the form of a small prototype.
2. Method

The research methodology in this study was considered as a combination of research methods or techniques in such a way that they make a coherent entirety that can fulfill the objective. (37)

2.1 Research design

Research design serves as the blueprint to implement research project in practice and should ensure the research agenda containing design, data collection and analysis to systematically answer the research questions. (38) Depending on the purpose of research, social science research can be generally classified into three types: exploratory, descriptive and explanatory. Exploratory research is conducted when problems are in in a preliminary stage of investigation. Descriptive research seeks to provide an accurate description of observations of phenomena. Explanatory studies look for explanations of the nature of certain relationships. (39,40)

Exploratory research is used when the topic or issue is new and often begins with secondary data/literature reviews. This method helps researchers to gain familiarity with and acquire insight into a phenomenon to formulate relevant hypothesis for further investigation. It is preliminary research and is characterized by its flexibility. (40) The exploratory study design could assist in gaining insights into the liver transplant process and healthcare practitioners’ perspective on PHR and its functionality to support the transplant continuous care. Taking these into consideration, exploratory research was chosen in this study.

Design science research (DSR) has emerged in the research of Information System (IS) discipline with the aim to create novel IT artifacts to address practical problems and generate knowledge about the artifacts, their use, and their environment. (41,42)
science is an important part of socio-technical IS research since the field should not only endeavor to understand how the world is, but also how to improve it. (43)

The design science is fundamentally a problem solving paradigm and has its roots in engineering. The field of IS research involves the confluence of people, organizations, and technology. IT artifacts are broadly defined as constructs (vocabulary and symbols), models (user requirements), methods (effective development practices), and instantiations (a type of system solution). (44,45) The main activities in design science method comprise of problem investigation, requirements definition, artefact development, demonstration and evaluation. (42)

As the research project was more applied in nature and the objectives of this study involved process modelling of the liver transplant care, understanding end-users’ attitudes and needs towards the PHR system, and creating a prototype, design science research could provide an appropriate framework to conduct the overall research process with logical coherence. This study focused on the first three stages of design science and applied several research methods depending on the project’s characteristics and goals. The research framework is illustrated in Figure 3.

![Figure 3. Research design framework](image-url)
The design science conducted in this study emphasized the process of exploration through design (46) and desired to explore the practical problems and to explore potential solutions for the problems.

### 2.2 Research approach

Qualitative research is studying matters in their natural settings in order to interpret the phenomena in terms of meanings from the people’s views. Qualitative research involves the collection of a variety of materials, e.g. case study, personal experience, life story, interview, observation, which describe routine and problematic moments and meanings in the real world. Qualitative research approach is concerned with subjective assessment of people’s beliefs, values, attitudes, and actions. (47,48)

The division between qualitative and quantitative approaches is not only the kind of data produced or the methods used to produce them, but also the overall aims of the study. Qualitative studies mostly seek answers to questions about ‘what’, ‘how’ or ‘why’ of a phenomenon, rather than questions about ‘how many’ or ‘how much’. (49)

This study employed qualitative approach which could generate a rich understanding of the clinical process and workflow of liver transplant and analyze healthcare professionals’ opinions on PHR and their needs to facilitate transplant care.

### 2.3 Data collection

The choice of data collection tools should be tailored to the defined research focus and driven by practical consideration, such as time and resource limitation. (50)

#### 2.3.1 Participant observation

Participant observation is a vital element for most of the qualitative studies and demands firsthand involvement in the social context chosen for study. Specific clinical, technological, organizational contexts will shape uptake of new ICT systems. In order
to obtain intimate knowledge of the work structure of the liver transplant care and to ensure that Health Information System (HIS) could assist the costumer well, the researcher performed field observation in the clinic. A total of three days was spent doing participatory observations using a master-apprentice method. According to Beyer and Holtzblatt, through face-to-face interaction in the master-apprentice observation, customers and designers could define together what the proposed system should address and what patterns of work it must account for. (51) The expected outcome of the field observation was to understand the liver transplant clinical process carried out in the LT center. The field observation was also the way to explore the current ICT usage in the liver transplant department. During the observation, there were conversations between researcher and the healthcare professionals, including questions and classification. Data of the field observation was documented by field notes and transcription of audio recording.

2.3.2 Semi-structured Interviews

Interview is a popular data collection tool of exploring and capturing an individual’s opinion and experience of a specific topic. (52) For investigating care providers attitude towards HIS and eliciting the user needs on PHRs for liver transplant care, identifying and analyzing the information needs, interview is a useful mean in this study.

Semi-structure interview is a useful data collection tool when the researcher has defined the topics and questions, but is willing to change the order of questions depending on the conversation flow and ask additional questions if interviewee brings up issues which are related to the topics. Exploration of such unexpected thoughts from interviewees is important to obtain a better understanding of the topic. (53) In this study, snowball sampling technique was applied for selecting participants. The interviewees were 4 nurses, 1 clinic assistant, and 1 doctor at the liver transplant center. The interviews were held at the offices and the meeting rooms of the liver transplant center. The contents of the interviews were documented both by transcriptions of audio recording and taking notes. Each interview was conducted for approximate 20 to 45 minutes.

Table 2. Characteristics of the study participants
<table>
<thead>
<tr>
<th>Participants</th>
<th>Specialists</th>
<th>Experience at liver transplant care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse 1</td>
<td>Transplant Coordinator</td>
<td>Senior</td>
</tr>
<tr>
<td>Nurse 2</td>
<td>Transplant Coordinator</td>
<td>Senior</td>
</tr>
<tr>
<td>Nurse 3</td>
<td>Transplantation nursing</td>
<td>Senior</td>
</tr>
<tr>
<td>Nurse 4</td>
<td>Transplantation nursing</td>
<td>Junior</td>
</tr>
<tr>
<td>Management</td>
<td>Clinic assistant</td>
<td>Senior</td>
</tr>
<tr>
<td>Doctor</td>
<td>Respiratory physician</td>
<td>Senior</td>
</tr>
</tbody>
</table>

**2.3.3 Documentation**

Documents can be treated as an efficient method of generating data for social science research. (53) Like the primary data produced by the researcher, documentary data can be used in qualitative studies. (49)

Document analysis in this study was specifically referred to found documents at the organization: paper-form medical record sheets and health information brochures. The medical record sheets included blood test chart, consultation sheet, follow-up chart, etc. All the sheets obtained were blank and no personal data was involved. The health information brochures provide liver transplant related information. The documents are necessary supplement data collection tools to observation and interview in this study. It mainly aimed to identify the essential medical information elements, data format and templates used in liver transplants domain.

**2.4 Data analysis**

This study applied qualitative content analysis technique. Bryman states that qualitative content analysis comprises a searching of underlying themes in the materials being analyzed and emphasis on allowing categories to emerge out of data and on recognizing the significance for understanding the meaning of the context in which an item being analyzed. (54) The data processing for the study was done manually and the procedure of the content analysis includes three phases: preparation, organizing and reporting. (55)
Preparation phase is making decisions on what to analysis with what details and selecting the meaning units. A meaning unit is the constellation of words or statements that relate to the central meaning. (56)

Organizing phase implies generating code, creating categories and formulating themes. Generating coding refers to the label of the meaning unit. Creating categories is the core feature of qualitative content analysis. Krippendorff defines a category is a group of content that shares a commonality. (57) Formulating themes is a way to link the underlying meanings together in categories. A theme is described as a recurring regularity developed within categories or cutting across categories. (58)

2.5 Process modeling

A business process is a series of activities within an organization with a structure describing their logical order and dependence aimed to produce a desired result. Business process modelling (BPM) is deployed to facilitate the software development and enable the analysis and re-engineering or improvement of them. (59)

In this study, flow chart technique was mainly applied in the BPM. A flow chart is a graphical representation of the logic sequence, work process or other similar operations in a program (59). The diagram of BPR was created by online Unified Modeling Language (UML) modeling tool-“Creately”.

2.6 GUI Prototyping

Prototyping is a system development methodology with purposes of clarifying vague requirements by developing a small scale version of a complex system. (60) User Interface (UI) prototype can be built with various tools, ranging from paper and pencil mockups of displays to interface construction software toolkits. (61)

There are several prototyping methods in software design, such as card sorting, wireframe prototyping, storyboard prototyping, paper prototyping, digital prototyping,
blank model prototyping, video prototyping and coded prototyping. A wireframe is a narrative prototyping and used in the beginning of the design process. Wireframe prototyping display sketches visualizing conceptual assumptions about the product structure and general interaction. A digital prototype is almost a digital version of the paper prototype; however, a digital prototype can range from more narrative low-fidelity style, such as PowerPoint-based prototype to a fully interactive high-fidelity coded prototype. The digital prototyping method has the ability of preceding and informing the first detailed screen designs, so it is best used during the initial conceptual design phase.\(^{(62)}\)

In this study, both wireframe prototyping and low-fidelity digital prototyping were used as the means to visualize the design concept of the customized PHR system in the early stage. First, the structure of web-based PHR system was defined in the site-map. Then, website’s content including interface elements and navigational systems was arranged. Wireframe was made to present skeletal framework of a web page. Last, mockups including some details (e.g. color, style and images) were added onto the wireframe.

Paper and pencil were used to draw the wireframe and the content in the initial prototyping, because they are easy to express the idea of the design. Then, the paper-form prototype was refined and transformed into electronic version with an online diagramming software—“Creately”. This UI mockups application not only provides some common web design elements but also allows users to insert customized objects.

### 2.7 Ethical considerations

By applying scientific methods, researchers can gain the findings that may advance scientific knowledge. However, it is necessary to consider potential risks and ethical conflicts when conducting the studies with human participants.\(^{(63)}\)

The participants in the study were informed of the purpose of the research. The assurance of confidentiality will be confirmed to the study participants before the participant observation and semi-structured interviews start. The observation conducted in the clinic was overt research, which got the participants’ consent. Audio recordings
of the field observation and interviews were done only if the interviewees permitted. The identities of the participants were excluded during the data transcription and processing.
3. Result

The results in the study are presented in three sections. First, the data of the liver transplant process which mainly acquired from field observation are analyzed and rendered as process modeling. Then, main findings gathered by the semi-structured interviews are categorized into four themes. Lastly, the design of PHRs is demonstrated in the form of small prototype.

3.1 Liver transplant process analysis

Problem explication is the first step in the design science research. Having a rich problem understanding is important in this study, and that the process analysis and description is part of this. Identifying the clinical process and workflow in the liver transplant center is prerequisite to analyze how PHR system can improve patient care in the particular care context. Designer should work with health care practitioners to ensure that PHRs would fit into the existing heath care system and improve effectiveness of treatment. The ultimate purpose of understanding the clinical care processes was for requirements elicitation and creating a prototype of the PHRs.

There are some process descriptions available, but none of them are detailed enough about the whole liver transplant process for the purpose of explicating problem. The major LDLT management process is described in the introduction section. Pre- and post-liver transplant processes are mainly obtained by participatory observation in the clinic, including discussions with the transplant coordinator as described in the method. The focus of process analysis is on the most common processes and those that are specific to certain health condition care.
3.1.1 Pre-transplantation

<table>
<thead>
<tr>
<th>Recipient</th>
<th>Liver Transplant Team</th>
<th>Donor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical data collection</td>
<td>Arranging first appointment</td>
<td>Initial test at home country</td>
</tr>
<tr>
<td>Initial investigation</td>
<td>Identifying candidate donor</td>
<td>Medical data collection</td>
</tr>
<tr>
<td>Patient education</td>
<td>Further pre-transplant medical assessment</td>
<td>Patient education</td>
</tr>
<tr>
<td>• Blood test</td>
<td></td>
<td>• Blood test</td>
</tr>
<tr>
<td>• Radiology: X-ray, scan</td>
<td></td>
<td>• Radiology: X-ray, scan</td>
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<tr>
<td>• Vaccine</td>
<td></td>
<td>• Vaccine</td>
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<tr>
<td>• Hepatologist</td>
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<tr>
<td>• Respiratory assessment</td>
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<td>• Cardiac assessment</td>
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<td>• Surgeon</td>
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<td>• Infectious Disease</td>
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<td>• Infectious Disease</td>
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<td>• Psychiatric assessment</td>
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<td>• Psychiatric assessment</td>
</tr>
<tr>
<td>• Dentist</td>
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</tr>
</tbody>
</table>

Figure 4. Pre-transplant process model

First appointment at LT center

Patients may be referred as candidates for liver transplantation either through self-referral or by their physician. New patients should bring their medical records and scans, and all medications to the first visit. At the first appointment, the patient will meet the transplant coordinator (TC), who has extensive experience in management of liver transplant care, both before and after transplantation. Patients need to undergo initial investigation including blood test, urine test, CT scan and chest and abdomen, or bone scan/PET scan for patients with cancer. The purpose of the initial investigation is to
determine the severity of patients’ liver disease and whether liver transplant is the best treatment option.

Meanwhile, the TC explains to patients and their family the whole process of liver transplant, as well as its benefits and risks. TC usually emphasizes to the patient to find a compatible liver donor. The donor can either be next of kin or someone emotionally related. It will take some time for patients to return home and identify a donor.

**Identifying potential living donor**

The potential donor may have some initial test done at his/her home country in order to check the chance of being a suitable donor before coming with the recipient for further pre-transplant evaluation at the transplant center. The patients will normally email the test results of donor candidate to the transplant center. The TC needs to check the tests they have done are sufficient. The tests that the donor candidate performed only indicate if he/she has significant medical problems. The TC also has to know whether or not the recipient’s blood group is compatible with the recipient. Once all test results are completed, the TC can inform the recipient and donor to come to the liver transplant center to do the pre-transplant assessment.

When donor candidate visits the transplant center, the TC will explain the whole procedure, and gather basic medical data, such as bio-data and medical history, etc. If there is any issue, the TC will alert the doctors before further tests for donor candidate. Otherwise, TC will proceed to pre-transplant assessment.

**Further medical assessments for recipients and donors**

If it is confirmed that the patient needs a liver transplant, further evaluation will be scheduled depending on the urgency of the case. Both the recipient and donor candidate will be examined by a multi-disciplinary group of specialists. The groups of doctors who assess the donor and recipient medically include Transplant Surgeon, Hepatologist, Respiratory Physician (ICU intensivist), Cardiologist, Pulmonologist, Nephrologist, Psychiatrist, Infectious Disease (ID) Physician, and Dentist. Each specialist assesses the
patients and gives advice regarding pre-transplant concerns or post-transplant management issues that may affect the outcome of the liver transplant. Such evaluations from various specialists give a clear picture of the recipient’s and the donor’s overall health status and to determine if transplant is the best option for the patient.

To minimize the risks of complications, all the major organs need to be assessed before operation. Cardiologist, Pulmonologist and Nephrologist will respectively ascertain the patient’s heart, lung and kidney are in good status. For example, if a patient has heart block and takes some medication to thin the blood. The patient cannot do the operation until the heart status is good and the medication is stop, since the medication will cause excessive bleeding. That is why they do all the steps of pre-transplant assessment before sending the patient to operation.

Any infection will be high risk for the post-transplant recipient, who is taken anti-rejection medication and in lower immune system. Infectious Disease (ID) physician needs to look after the patient even before the transplant itself. If the patients have any kind of infection, they need antibiotics before the transplant surgery. Infections will be checked before and after the operation. Similarly, if there is any existing infection in the teeth (e.g. tooth decay), it may cause major problems. A dentist therefore needs to pull out those decay teeth before the operation.

The liver transplant is a major operation to both the recipient and the donor. Psychiatrist need to assess the transplant candidates to ensure that they are mentally prepared for the operation and understand the consequences of the medical procedures.

Once all the medical assessments are done, the transplant team will review all the pre-transplant evaluation reports and get ready for the ethical meeting. The transplant surgeon will explain to the donor and recipient the detailed transplant procedures and the technique for their surgery.

**Ethics assessments**
In Singapore, there are stringent rules for human organ transplant. The hospitals’ Transplant Ethics Committee (TEC) has to be satisfied that transplantation is the viable treatment option and there is not any form of coercion or financial incentives to donate the organ. TEC is completely independent of ACLDT. Only with the approval of TEC, can ACLDT plan for transplant.

3.1.2 Post-transplantation

![Post-transplantation process model](image)

**Figure 5. Post-transplantation process model**

**Hospital recovery and discharge**

After the surgery, the recipient and the donor are transferred directly to Transplant Intensive Care Unit where the patients are closely monitored and supported by different equipment and medication to ensure body functions after operation. When body
condition is stable, the patients will be transferred to the liver ward. During the hospital recovery phase, the patients will be seen by the transplant team.

Towards the end of the stay, the nurse will teach the recipient and the main caregiver (the person will look after the patient) how to take care of transplant patient and what each medication is for, along with its side effects. Before the patient leaves the hospital, the nursing officer normally will go through the form and give the patient a small test on post-transplant self-management.

**Follow-up visits to LT center**

After discharge, the recipients will return to the liver transplant (LT) center for follow-up care. They will be required to do blood tests and scans, according to the transplant team’s instruction. Outpatient Laboratory work is reviewed by the TC, abnormal values are then reviewed by the liver transplantation physician.

Recipients are supposed to stay in Singapore for intensive monitoring at least two months after leaving the hospital, since the first 60 to 90 days after transplant are the time of highest risk for rejection and infection. In the first month, they need to come back twice a week, whereas in the second month approximately once a week, if the condition improves. If everything goes well, they can go back to their country. They are required to come back to LT center for a follow-up every 3-4 month in the first year. As time passes and their condition improves, the frequency of LT center visits decrease, from every 3 months, 6 months, till once a year. Follow-up plan goes on regularly, unless there are an issue, for instance, the patient is not feeling well, and has to return to LT center urgently. Eventually, they only need to perform annual screening at LT center.

The donors have to stay in Singapore at least two weeks after discharge. They need to come back to the LT center once a week to do blood test and ultrasound in the two weeks. If their conditions are good, they can go back to their countries. They are advised to do the lab test in their country every one month, three month and six month, if their conditions are stable and good. They do not need follow-up visits to the transplant clinic, but are suggested to send their medical reports.
Local clinic visits and medication update

After a liver transplant, the recipients will take medications for the rest of their lives. It is important to determine the amount of anti-rejection medication in the bloodstream so that dosage can be adjusted to patients’ individual needs. The blood should be drawn in their local laboratory every 3-4 weeks. Frequency of lab test will depend on their individual progress and condition. They have to send the reports (including medication list) to the LT center, where transplant teams will adjust the medication. If there are abnormal values in the lab result, the patients will be informed to go to LT sooner. The feedback from the transplant team will be given based on the reports from patients. The patients and the healthcare providers use multiple channels to communicate, such as email, phone call, fax, text message.

3.1.3 Example of one follow-up appointment after discharge

The clinic organizes the entire schedule the patient, fastest and available time. Before each visit, the nurses will go through the record and see which tests are required for this visit. So the nurses will prearrange laboratory and radiology facilities at other departments, such as the blood test, radiology test, ultra sound and CT scan. The nurses prepare the request forms first. When the patients arrive, they will first go through blood test, then ultra sound, radiology. The nurses will plan the consultation time after all the test, normally in the afternoon of the same day.

Before the patient returns, the nurse calls the lab to trace the result, and physically chart it down. The nurse also needs to call the radiology to collect all the result. Usually the nurse needs to check the patient on medication adherence again, before actually seeing the doctor. Because the medication is really important, it will affect the results. Then they will have a consultation with a physician. Based on the test results, the physician will give advice and modify medication dosage. At the end of the visit, they may set up a date for the next appointment.

TC and other nurses will physically record the medication list and medical procedures on consultant sheet. All these are manually updated. TC will update the patient’s
follow-up chart include liver diseases related data, metabolic screening and cancer screening.

### 3.2 Healthcare professional's perspectives on PHRs

The results of interviews are categorized in four themes: Attitudes towards health information technology; healthcare professional’s opinions about PHRs; functional requirements of PHR from providers’ perspective; problem envision of PHR implementation.

#### Table 3. Findings from the interviews

<table>
<thead>
<tr>
<th>Themes</th>
<th>Main findings</th>
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| Attitudes towards health information technology | • Low degree of ICT usage currently  
|                                       | • Positive expectation of ICT                                                  |
| Opinions about PHRs                  | • Transplant patients are in need of PHR                                    |
|                                       | • Enable more patient engagement                                             |
|                                       | • PHR could enhance practices in transplant care                             |
|                                       | • Sharing health information                                                 |
|                                       | • Potential benefit for research                                              |
| Functional requirements               | • Basic health information                                                   |
|                                       | • Medication list                                                            |
|                                       | • Lab test                                                                   |
|                                       | • Follow up reminder                                                         |
|                                       | • Scheduling appointment                                                     |
|                                       | • Communication                                                             |
|                                       | • Home monitoring                                                           |
|                                       | • Sharing                                                                   |
### Problem envision of PHR implementation

- Reliability
- Computer competency and Internet access
- Security and privacy

#### 3.2.1 Attitudes toward health information technology

In general, there are three categories of ICT applications in healthcare: administrative and financial systems; clinical systems; and infrastructure that support both the administrative and clinical applications. Examples for administrative/financial applications are billing, cost accounting systems, and patient registration. The following health information technology are often implemented in hospital for clinical purpose: Electronic health record (EHR), Computerized Provider Order Entry (CPOE), Clinical Decision Support System (CDSS), Picture Archiving and Communications System (PACS), etc. (64)

**Low degree of ICT usage currently**

Most of participants acknowledged using technology for a wide variety of reasons in their practice. Nurses and clinic assistants reported frequent use of phone call, e-mail and text messaging to communicate with patients. However, the usage of clinic systems is low within the liver transplant center. In other words, there is no electronic record system currently. A few of the participants in the study have experience of electronic patient records and most of them have heard about EMR and/or EHR. In the clinic, most of the patient records are documented in paper-form. Computer software used here is Outlook for appointment scheduling, and Excel for medication list, consultation sheet and follow-up chart.

**Positive expectation of ICT**

The semi-structured interview with the health care providers in liver transplant care revealed a generally positive attitude toward ICT applications. Most participants felt
that technology can improve communication, minimize medical errors and enhance efficiency in the clinical practice.

Currently a lot paper work. If we have a system, it would be helpful. Less paper will be more helpful, so that we are more systemized, like recording documentation... Prefer more IT for documentation, for recording purpose. (Interview 2)

Obviously when technology is involved, it reminds me. Especially when it comes to documentation, it makes sense. When you actually miss out certain things, like doctors order, you do something and you don’t record. Then somebody else has to do it. All these things need to be documented when the paper is concern. I believe if technologies involved, the mistakes can be minimized. And make work more efficient for all of us. Otherwise we end up with a lot of workload and space to keep them. Of course, it is better with technology, make things systematic anyway. (Interview 4)

3.2.2 Opinions about PHRs

The purpose of this section was to ascertain participants’ interest in, need for, and preference regarding a possible PHR that would support liver transplant care. Some of the participants were not familiar with the concept of PHR. Before asked questions about opinions on PHR, the interviewer explained the definition of a PHR system, and gave some examples of its usage.

**Transplant patients are in need of PHR**

Most of the participants thought that maintaining personal health records is necessary for individuals whose health conditions are not good and need to visit clinic often. Liver transplantation is an applicable treatment for the patient who has acute or chronic condition resulting in irreversible liver dysfunction. A liver transplant patient often has to go through months or even years of assessment and care management in institutions
overseas. During the long-term liver transplant treatment, one single patient could have volumes of health record from different sources.

The reasons why transplant patients need PHR are they are very sick, they have many encounters. So the care is more complicated than well patients, some patient only see doctor once every 10 years. Transplant care is more complicated. More elements of information, e.g. what medication you are taking, more surgery, more lab test, more Xrays... (Interview 5)

Some of the respondents emphasized the need of a system or tool for continuously monitoring various health parameters for transplant patients. These records are critical data for their diagnosis and medical decision-making.

Compared to the normal clinic patients, the transplant patients really need a good record system, in fact there are more things to keep track of, I see; like blood test, radiology, medication, for both patients and clinicians to get access to them. (Interview 1)

One participant felt that personal records could avoid duplicated tests, since transplant patients might seek care from various healthcare organizations. So keeping a PHR could reduce waste and inefficiency. Another participant mentioned that a PHR could be very important in emergence situation.

Enable more patient engagement

Most of the respondents expressed that they promote greater patient participation in the management of their own health. The success of liver transplant treatment is directly affected by patients’ compliance with the medications, follow-up plan, and adherence to suggestions of the transplant team. Especially for post-transplant stage, they and their family need to take responsibility for maintain their long-term health condition. PHRs is an ideal tool to help patients to understands their health condition better and participate more in their treatment decision making.
Keeping their own health information is good to our patients. By doing so, input their data or collect reports from different providers, they can know their condition better and be active in managing complications following the transplant operation. (Interview 2)

The participant indicated that if the system were easy to use, it might result in more active patients in their care.

**PHR could enhance practices in transplant care**

The participants were very interested in the concept of the PHR and how it might help their patients to improve the transplant care management. They noted a number of positive factors of PHRs that could benefit their practices, primarily focused on information that could be tracked by the PHR to enhance the healthcare providers’ understanding of their patients.

*The main purpose (of PHR) is to have a record, it is more record keeping. Whenever we need it, we can get it as soon as possible. By the time the patient reaches our clinic, we have all the record into our system. Rather than go through all the physical piece of the form to understand “what is this, what is that”, if the picture is already store in the system. (Interview 2)*

*Currently we just manually track patients. We need to see and compare all the reports. We physically have a chart. We have to do manual chatting. If there is a system, of course we will be efficient in terms of man power. (Interview 6)*

**Sharing health information**

Most of the patients will visit different health care providers. Thus, when a patient comes to a new provider, the information from previous providers is being shared with the new one through the PHR. Liver transplant care is typical in such condition which require to seek different provider frequent and in a long term.
Part of the information in a PHR could be posted by health care providers, such as medication list, lab test, follow-up plans and so on. It makes sense to understand provider’s attitude towards sharing health information with both patients and other providers.

Generally, participants in the interviews were willing to share health information in a PHR with other providers. They believed that such sharing could lead to better care for patients by gathering a more complete picture of the patient’s health information. Sharing the health information also could support the care cooperation for the individuals.

No worries about lost customers (because of sharing medical record). This is just a record system, like a database system. You still need medical experts. When a patient requires a treatment, this system will not provide any treatment. So the patients still need to come here to understand/consult us, if they have health issues or any important issues. (Interview 3)

Nevertheless, some of the participant indicated that information should be shared with limitation, not every piece of medical records should be included in a PHR. For example, one participant was reserved about sharing doctor’s note about a patient.

Patient can access certain things they need to know. Doctor notes, we don’t give to patients. If patient need to know more details, we provide medical reports. Because the doctor notes are not for the patient, is for the medical center. (Interview 4)

Some of them mentioned that sharing patient records could reduce medication conflicts, therefore improving patient safety. Moreover, it could reduce duplicated care procedure; consequently lessen the cost of health care.
**Potential benefit for research**

The use of IT systems for storing health records makes it easier to leverage data to improve health research, quality, and outcomes.

> When we do any research or write any paper, we need to physically get out all the notes and read one by one. If we have a system having all the track, e.g. this patient have liver cancer, have hepatitis B, have done CLC, ... So we can pull out the data from the system directly. Rather than we go through every file. (Interview 2)

### 3.2.3 Functional requirements

Each condition oriented PHR will have its specific features, as every condition or disease has its own elements that need to be tracked and managed. In the study, the functionality and features were grouped by their characters and then prioritizing them according to the need of the users and how important they are supposed to assist liver transplant care.

Clinical information in the PHR should at least consist of basic health information, medication, lab test as well as home-monitoring data. From administrative aspect, the PHR should contain functionality of scheduling, events reminder, message and sharing.

**Basic health information**

All the participants request medical history in the PHRs. They express that medical history is the fundamental information should be included in a PHR.

> History report is very very important. Why was the liver damage, because hepatitis B, cancer or ... helps the doctor to treat the patient according to. (Interview 1)
Medication list

Information about medication is the highest demanded piece of information across the participants in the interviews. Most post-transplant patients are prescribed a combination of immunosuppressant drugs, which can protect the new organ and preserve its function. Meanwhile, these drugs are powerful and have some side effects. Frequent checkups are necessary when taking immunosuppressant drugs. So that physician could make sure the drug is working as it should and to watch for unwanted side effects. The patients may be also seen by local physician for routine or acute care. The medication is vital medical data for both transplant team and local care providers

Every time patients send us report from their side, we want to know what medication they are taking exactly, just to make sure certain medication are in our record. Suppose they are taking hepatitis medicine, maybe they haven’t seen doctors here, some other doctor’s prescription medication may or may not be good for kidney, the result came out protein is too high, and then we want to know why. It is good to update us what changes in the medication. (Interview 1)

Lab test

Many participants felt that laboratory results are especially important data used for assessments of donor and recipient before transplantation and managing patients after transplantation. Especially, for patients on immunosuppression therapy requiring ongoing monitoring, laboratory testing provides key information for clinical decision making.

Without lab result we cannot tell patients what is happening to them. (Interview 4)

Follow up reminders

Some of the participants, especially the nurses, were concerned about how to perform the follow-up. Transplant patients need periodic testing for monitor and manage
immunosuppression. The clinicians need a system for tracking lab results to identify recent critical or overdue lab test.

*Reminder/alarm system for next appointment or blood test due date order. From the healthcare professionals’ keen data, this will be send to the patient, to remind them, your next appointment is due, or you are due for your blood test, or you are due to your checkup. That will be good. (Interview 1)*

*I really want the system is to prompt them when do what tests. That is the main thing, because we cannot physically take up more than 200 patient profiles. For Hepatitis B patient, they have to come monthly, for cancer patient how many months until they have to do a CT scan. If these things have alarms or reminders one or two weeks before, then we can start to contact patient and inform due to the treatment, or test or what so ever. It would be helpful to the practices in the center as well as the patient. (Interview 6)*

**Scheduling appointment**

Giving consumers the ability to schedule and cancel appointments at their convenience can benefit patients and providers by increasing administrative efficiency.

*Scheduling is important especially for the patient immediately after transplant when they come back here twice a week. So long as they are here, it is easy to confirm the appointment. But if they go overseas and come back after 3 months, 6 months, they have to confirm appointment beforehand. Sometimes patients might have difficulties coming at the scheduled time. Normally they call us one week earlier to inform us, and then we manually put it in the calendar for all the subsequence. Which time, which doctors? Task is written on the file. (Interview 4)*

**Home monitoring**

After discharge from the hospital, patients need to perform self-monitoring to manage immunosuppression therapy and to prevent organ rejection, infections, and medication
toxicity. Complications after liver transplant may show up as changes in lab tests or vital signs. Thus, checking vital signs (blood pressure, pulse, temperature, and weight) and doing lab tests regularly are an important part of post-transplant management. The Transplant Team needs to keep eyes on such changes so they can take action before complications become worse.

...e.g blood monitoring, sugar monitoring. Our patients are prone to do so. Patient should be allowed to upload their health data. The majority of our patients are foreigners, so most of the time they do tests at their home country. When they get the report, at the moment, they have to scan the result and email to our center. And then we have to chat it out, to get doctor to review and give some advices and comments. We do need a system that patients can access and upload their results. So when they call us and say I just upload the result, then we can take a look from that. (Interview 3)

Home-monitoring will generate patients input data, which are a supplement to clinical information. One respondent in the interview also mentioned that exercise and nutrition would be important for liver transplant patient. However, the home-monitoring will initiate with recording vital signs parameters.

**Communication**

Many participants requested the feature of providing a communication platform for patient and providers. Besides phone calls, secure massages were considered the efficient communication method. More communication could help they keep track of what is going on with their patient. Messaging is also valuable for patients on asking LT related questions and getting feedback, facilitating documentation updates and scheduling. However, massaging can only be used with non-urgent situation.

*How often do we get access to the system? How urgent is the problem? How efficient is it in emergency matters. They have to call and consult with doctors.*

*(Interview 1)*
Sharing

In general, the participants agreed with the PHR’s central idea that the consumers own their own health data. A key feature of the PHR should be that the patients decide upon who can access their data, and to what extent they would like to involve the healthcare providers or main caregivers.

Most patients are foreigners. If they can have a system that other doctors can also connect to the system, they can have all their records there. So they can get appointment to the patients over here. (Interview 3)

Patients decide who can access and when. Instead of bringing paper form medical report, patients can just share PHR to their local doctors. (Interview 5)

Education

Some of the participants indicated that a PHR would provide authority medical knowledge of liver transplant care and motivate patients to be more active in their health management, especially for the post-transplant phases. On the contrary, others thought that it is better to offer education to patients face by face, because of the complexity of long-term outpatient care after transplant, in particular on immunosuppressive management.

If they are transplant, we will have a lot of sections, to teach them, even before transplant. After transplant, they are still here. We provide education before they discharge. Education is to be done here physically, face by face. It will be better for them. If they want to know more information, they can google themselves. (Interview 4)
3.2.4 Problem envision of PHR implementation

Reliability

Some participants pointed out the matter of losing records if the IT system fails. The system design should have back-up solution and data recovering plan.

Reliability of the system. Sometime if the server is down, everybody will all be in trouble. Now we at least have physical record. But if new system is down, then no record at all. (Interview 2)

Computer competency and Internet access

The interviews also indicated that consumers’ computer competency and Internet accessibility may become an issue of adoption of PHRs.

In some developing countries, infrastructure is not as balanced as Singapore. We do have a lot foreign patients, they come from Indonesia, and may have problems accessing or using it. (Interview 3)

Some people may not be used to the internet. How can they upload the test into the system? Will they be able to see? Will they be able to manually do it? Even though the old patients can get help from children with internet access, but you will never know the real percentage, until we get that. (Interview 1)

Security and privacy

The most common concern was the safety and security of health information. All the users will not be able to use a PHR unless they feel security measures are adequate. Some participant indicated that consumers should be in charge of controlling who can access PHR and what information allowed to be seen.

Patients want to keep their health record confidential. (Interview 6)
3.3 GUI prototype

The thesis proposes a Graphical User Interface (GUI) prototype as the initial attempt design of the customized PHR system for the liver transplant center. The functionality embedded in the design was more focus on post-transplant process. The site map below (Figure 5) presents the structure of web-based PHRs.

Figure 6. Structure of web-based PHRs

The outline depicts the conceptual design to meet users’ needs. Each roman number represents an individual web page. Graphical user interface prototypes have been designed for some of the most important pages. These will be presented below.

I. Home Page

Secure login by Username and password.

Main page presents the structure of clinical information, overview of the health condition and medical events in the form of calendar. A GUI proposal of the home page can be seen in figure 6.
II. Personal Profile

Personal profile include demographic information and contact information, such as Name, Date of Birth, Gender, Ethnicity, Personal Contact Information, Emergency Contacts, Healthcare Providers, etc.

III. Health information

Health information pages provide the basic health record and customized health information for transplant care. It organizes patient medical records in an easy-to-read format. Some pages have borrowed the paper-form records used in the liver transplant center.

Health Profile page comprises of Medical history, Infection diseases, Immunizations, Allergies, Family history

Other clinical components are Medications, Lab test, Follow-up, Home monitor.
Figure 8. PHR GUI Health Information/ Medication

Figure 9. PHR GUI Health Information/ Lab test
IV. Calendar

Calendar is a clinic administrative functionality in the PHR to support scheduling of medical events. The feature of the calendar offers a timeline view — a visualization of time-based medical events involved in the standardized care process view of medical events, such as lab tests, follow-up visits or other relevant occurrences. In the timeline graph, any changes made or individualizations could be highlighted. For example, a timeline will show the upcoming lab tests the patient need to take. It is also possible to use the flexible scheduling function to record reminders, for instance, a reminder to book a follow-up visit.

V. Message

Customers can message healthcare professionals with questions or health issues. However, this site must state that patient should not report emergent or urgent issues through secure message. Additionally, the messages are expected to be responded within 2 work days.
VI. Sharing

Sharing feature permits patients the ability of controlling who can access selected area of information in personal health record.
4. Discussion

In this section, the author will discuss about the methods and the results separately, and suggest on the future work.

4.1 Discussion of methods

4.1.1 Alternative methods consideration

A case study research focuses on depth rather than breadth of the instance or case in its natural setting. With case study, researcher uses multiple data sources and methods to conduct holistic study on the cases, concentrating on the complexity of relationships and processes and how they are interconnected and inter-related. (53) However, this method requires advance observational and integrative ability of the researcher. (39) It can be risky for a research beginner to apply this method.

Focus group is one alternative collection methods used in qualitative healthcare research. Focus group discussion use interaction and group dynamics to generate information on different participants’ views, and the meanings that lie behind those views. They are also useful in getting firsthand insights into participants' experiences and beliefs. (65,66) This method was abandoned in this study since it was difficult to organize a number of clinicians meeting at the same time within this highly busy healthcare setting.

4.1.2 Study limitation

The data collection sample only involved the healthcare providers. It is very important that the needs of all potential users are addressed when deciding on system features. It is worthwhile to hear patients’ opinions about PHRs and their needs on its functions and features. However, the ethic approval regarding patient involved research in Singapore is very strict and needs a long time. The data collection on patients’ attitudes and opinions was not practicable in this short period study.
The knowledge about PHR among the participants in this study was varying. A few of them knew about PHR and mentioned about accessing to some patients’ personal medical records previously. However, the others had no experience with PHR and had no idea about it. Even though, the author attempted to explain the definition of PHR. It was difficult for the respondents to understand PHR clearly in a short period. Additionally, their points’ of view might be affected by the description from the author. This could lead to bias in the findings about the clinicians’ perspectives on PHR.

### 4.2 Discussion of results

Despite widespread of electronic health record systems in health care organizations, there are still obstacles to their adoptions. The main obstacles include the cost constraints, the inherent complexity of medical field, technical and standardization limits. (67,68) In this study, the liver transplant clinic is not equipped with advantage ICT system, even so, the healthcare professionals expressed a genuine interest and high expectation on information technology could attribute to their clinical practice, thus improve care quality.

Not all of the participants were familiar with the concept of PHRs; however, all of them expressed positive perception of having an electronic tool for patients to store their own health data. They thought that PHRs could help with managing and monitoring patient health information and communicating between patients and physicians. Furthermore, some of the participants commented that PHRs could empower patients by helping them to understand their conditions and promoting engagement in their own health care.

From the providers’ points of view, the PHRs for transplant care should be basically served as record purpose system. This finding is alike with a summary that most PHRs share a basic goal of enabling patients to access and stewards their own healthcare data, although there are much differences in functionality across systems. (69) The customized PHRs should at least consist of information of medical history, medication, lab test and follow-up plan. These predominant data elements are most keen information in liver transplant care. Regarding literature about clinicians’ perspectives on PHR,
medication and medical history are almost universally requested information modules (70). Corroborating with previous studies, laboratory test result is essential data in transplant care, especially in the post-transplant management (32). One particular health data component highly demanded among the participants was follow-up chart. This could be the specific functionality of PHRs in the context of liver transplant care setting.

Communication is a crucial user need of the PHR system in the study. Most of the respondents expressed strong need of systematic communication tool to facilitate the long-term LT care. Previous study findings about healthcare professionals’ perspective showed that efficient communication lead to improved relationships between patients and clinicians. Secure messaging is the tool to support information sharing and bidirectional communication. (71)

Most of the participants thought that sharing the patients’ medical information was beneficial, since more involvement of providers’ data input could improve PHR’s data quality. This finding is similar to the finding from previous study; however, having larger study samples the summary of the benefits of sharing in the literature is richer (70). In the study finding, some participants were not willing to share doctor notes or some other similar medical records, because they thought they are not so useful for the patient. Other concerns about sharing were not mentioned much in the interviews. In the literature, it was described more detailed about the concerns of sharing patient data which included causing unnecessary anxiety for patients and risk of legal ramifications (70).

Almost all respondents pointed out the security and privacy issue in PHR system. This finding was coincident with other healthcare professional’s opinions in the literatures that security and privacy have always been serious concern with electronic health information system (72,73). From consumers’ perspectives, most of them want to maintain privacy of their health data, nevertheless, they also felt this goal was very difficult to achieve, considering the current situation of information security (74).

For the healthcare professionals, the tool which they are more familiar with is the EHR system, even though they currently used paper-based system. In the interviews, some
participants commented that the system could automatic download labs and test results from the facilities in other departments. However, this user requirement should be incorporated into the features and functions of EHRs instead of PHRs.

The model of the customized PHR is neither standalone nor tether PHR. The clinicians in the liver transplant center is supposed to post electronic medical data to the PHR, thus, there is some connection between the ICT tool and the healthcare provider. The data population is not only by the patients themselves. On the other hand, the PHR currently does not link to any electronic health system. Probably if the LT center implement the EHR or EMR, the PHR could be the tether model in the future.

One major reason for the failure of many information system projects in healthcare domain is poor understanding of the underlying clinical and business/administrative processes that the system are intended to support. It is important to recognize that health information application is less about technology and more about its effect. In order to design a PHR system that can actually support liver transplant care, it is primary to understand the workflow and information process in the liver transplant organization.

In result section, process analysis focus on major LT process with different care professions involved and obvious problems in clinical practice. Firstly, in the introduction part, the picture of major steps of LDLT management provides the whole map for transplant patient journey. Then, the analysis zoom in pre-transplant and post-transplant processes respectively. Again, focus on the post-transplant mangement and zoom in one follow-up appointment in LT center. The process analysis basically scoped with outpatient based, where patients and physicians can benefit from PHR. The process analysis was reflected in the prototype design.

In pre-transplant process, the transplant team could access their “Personal Profile” and “Health Profile” in PHR system instead of physically collecting such data in the first appointment. Similarly, the transplant team could obtain donor canditates’ personal and health information from their PHR prior to the first appointment, which consists of medical history, bio-data. Moreover, the result of donor canditate’s initiate test result
taken in local lab can be upload in “Lab test”. The transplant team can efficiently have pre-evauluation of donor canditate, so that the chance of being a suitable donor is higher when they come to LT center for further pre-transplant accessment. Thereby, it could expedite the pre-transplant evelation both for the recipients and the donors, and save patients’ time and money.

After the liver transplant surgery, the patients need to assume a lot of responsibility for building and maintaining their strength. In the post-transplant process modelling, there are two important monitoring activities that patients need perform, one is monthly local lab/clinic visits, the other is follow-up visits to LT center with decreasing frequency of every 3, 6, 12 month. The functions of “Calendar” and “Message” are useful to assist with the long-term monitoring and communication.

“Calendar” could remind the patients the due for monthly laboratory work. Patients will visit local lab to have blood work done. The lab result can be scanned and uploaded to “Lab tests”. Based on the data in “Lab test”, transplant team will make treatment decisions, e.g. adjusting medication. Medication is essential in immunosuppression management. The PHR could assist each individual to maintain an active medication list. Transplant team will modify patients’ transplantation-related drug and dosage in “Medication” module.

Follow-up visits are usually flexible depending upon the clinical status of the recipients. The “Calendar” can remind the patients for follow-up visits in advance. The appointments need to be planned and prepared by both patients and care providers. Most of the patients in LT center need to travel abroad for their continuous liver transplant treatment. If the appointment time is confirmed, TC will book time for doctor’s consultation and order laboratory and image facilities in other departments to perform tests. After the appointment is done, care providers will modify “Medication” and update the “Follow-up chart” of post-transplantation management.

The care professionals needs and preferred functionality about PHR was also considered in the prototyping process. The main functional requirements were visualized in the prototype. The function which may be useful in PHRs but less preferred or with
uncertainty was excluded in the design. For example, their opinions were very different regarding the function of patient education. In the literature, some PHR system could storage or link to patient education materials (14,76). This interesting finding might need further exploration on how the PHR can be used as a tool for patient education (as a complement to the face-to-face education or as a replacement). However, in this prototyping version, patient education was not included.

Generally, the participants wanted the health data be organized in clear manner. Some of them wished to see summary of resent health condition. Templates used in the clinic were recommended to be used in the system. In their views, template is more suitable for track and analysis compare to plain text. Besides, they were used to the template; they prefer the system could mimic the paper-form record somehow.

The PHR can also facilitate patients’ local (own country) healthcare providers. Long-term complications are frequently occurred in liver transplant recipients. They are at risk for developing various medical diseases like hypertension, diabetes, cardiovascular, renal dysfunction. (30) The chance of seeking other medical care is high for the transplant patients. The information about medical history, immunosuppression medication, could be important for local clinicians. From this point of view, the PHR could serve as the information platform for patients and different care providers.

### 4.3 Transferability

Design science may appear similar to system development, since both of them focus on artefact development. The main difference is on the purpose that design science should contribute knowledge that is relevant for a global practice. (42) It is difficult for such a qualitative research to have generalizability to large population; however, it is possible to transfer the result of this study to other similar contexts or settings.

The transplant care process analysis and description, the functional requirements of the PHR system as well as the GUI prototype in this project could be useful for information system development in other transplant program.
The PHR could be a useful tool for international health setting, where patient is traveling and the health data is difficult to access. For example, a patient prepares surgery in other country. The ideal of using PHR is relevant to such setting; even it is not transplant care. The PHR can be a convenient way to exchange the medical data between different care providers in different countries.

4.4 Future work

This study only undertook in depth the first three steps of design science research. In order to complete the whole design science research process, the future work could be demonstration and evaluation, and focus on evaluation. Demonstration is to show the prototype can solve an specific case in the problem addressed (42), for instance, through the PHR system, the LT team can regularly monitor the patient’s immunosuppression status based on the lab test result and give feedback to the patient. Evaluation is to determine how well the prototype fulfils the user requirements and to what extent it can solve the practical problem (42). The static prototype would be evaluated to improve the design of the system. The intention of the evaluation will focus on the functionality and usability. Based on the feedback from the participants, health informatics specialist can work on functional (dynamic) prototype. Second round evaluation could focus on the users’ interaction with interface.

From development aspect, an open-source platform could be adopted for developing the customized PHR system. The advantages of building health information system on the open-source platform are cost-effective, interoperable and sustainable. The study would start with comparison and evaluation the popular open-source platforms for health records system, e.g. Indivo, (77) OpenMRS, (78) and Tolven (79). The purpose of learning their architectures, entire features, and each component/module, is to choose the open-source platform and component/module that are suitable to liver transplant condition oriented PHR and robust capability of changing functionality flexibly in the future.
5. Conclusion

This study aimed at generating knowledge about designing a patient-centered PHR system based on healthcare professionals’ perspective to support the liver transplant management. To achieve that, the study was conducted under the framework of exploratory design science research with four objectives.

The participant observation provided the understanding of the major clinical process in liver transplant care. For the initial stage of the whole PHR project, the study focused on the post-transplant process, which needs to communicate with and monitor the health condition of the patients who are living in foreign countries over a long period of time. In order to develop a PHR that is useful and acceptable to the users it is crucial to understand their attitudes, needs and opinions. The semi-structure interview is an efficient method to generate such expected qualitative data. Generally, the participants had positive perceive of technology intervention to support the care process and workflows in liver transplant care. They wished the customized PHRs could storage the medical history, medication list, lab test, follow-up plan, since these components are essential data for liver transplant care. Additional to banking of the records, healthcare providers preferred the features of scheduling, communicating and sharing. Based on the users requested functionalities, and combined with found documents in the LT center, the proposed prototype was made in the form of static GUI.

With chronic conditions, patients will receive care from several care providers, which means the health services will become fragmented. Long-term liver transplantation care is one of such conditions. The role of patients in the care process has taken on much greater importance. The customized PHR is a potential ICT solution to support patient-centered care liver transplant management by bridging the health information islands, promoting communication between patients and physicians, and enabling their participant in their own care.
References


15. Readers’ perspective. Personal health records will be widely used within five years, supplanting the need for regional health information


55


34. Framework C, Networked FOR, Health P. Connecting Americans to their healthcare: a common framework for networked personal health information.


42. Johannesson P, Perjons E. A Design Science Primer. Creative Commons Attribution-NonCommercial-ShareAlike 3.0;


77. Mandl KD, Simons WW, Crawford WCR, Abbett JM. Indivo: a personally controlled health record for health information exchange and


Appendix A. Transplant Process Map

Asian Centre For Liver Diseases & Transplantation

TRANSPLANT PROCESS MAP

Recipient Assessment

Donor Assessment

Ethics Assessment

Financial Status

Recipient's Condition

Payment Received

Suitable

Final Arrangement

Transplant Confirmed!
Appendix B. Interview Guide

- Your attitudes towards technology applied in health care.

- Your experience of health information technology.
  - Do you use ICT tool in your practice?
  - Do you use any electronic health record system in the clinic?

- Do you know about PHR system?
  Interviewer briefly presents the concept of Personal Health Record system.

- Your opinion about PHR
  - What do you think of PHR could be useful to your clinical practice?
  - How do you as a healthcare provider want to involve with the PHR?
  - How could PHR integrate into the liver transplant process?
  - How can PHR system help your patients?
  - How might a PHR to enhance patients’ role in their health?
  - What do you think about sharing health information with other providers?
  - What are the issues should consider in the design of the PHR?
  - What kinds of problems can you envision with PHR?
    - Implementation?
    - Adoption?

- PHR functions and features
  - Which health information components are most important for transplant care?
  - How do you prefer the information to be present in this system?
    - Generally or Give some examples.
  - Which features should be included in PHRs?
    - Potential options: PHR functionality list.