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Patient Information Sharing using a Socio-technical Approach

by

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"Wisdom is like a baobab tree, no one man can embrace it completely"

African proverb

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Abstract

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Effective healthcare relies on patient information sharing to ensure timely informed decision making by Healthcare Professionals (HCP) regarding effective treatment options and accurate diagnoses, especially during emergencies; time is also an important factor towards patient safety in Emergency Departments (ED). HCPs utilize multiples patient information sources based on the nature of the case and the most effective source present at the moment; sources include direct access to centralized systems such as Electronic Health Records (EHR), healthcare community members such as colleagues and patient community members such as patients and their representatives.

Centralized databases provide benefits to authorized HCPs such as fast and easy access to patient information; however, in some countries, privacy concerns still hinder the implementation of these systems on a nationwide level. Concerns relate to how patient information is collected, stored and utilized. If patients have no privacy concerns, then the access by physicians can be seen as a “win-win” situation. If a patient has privacy concerns, direct access by physicians can be seen as a “win-lose” situation, since the privacy concerns of patients can affect the collection of patient information during consultations. Patients can withhold information due to such concerns. Privacy concerns present a social barrier to the technical implementation of patient information sharing systems.

In order to address the social barrier of privacy concerns, this thesis contributes a community-based, socio-technical design approach using in the context of patient information sharing via patient representatives. To this end, a mobile application system has been designed based on an ethnographic understanding of the interactions between the communities in the ED setting. The design concept was then evaluated using feedback from both the patient and healthcare communities. Central to the design concept is patients’ representatives. A patient’s representative is a vital information source that has not been explored in the field of Human Computer Interaction.

A noteworthy characteristic of patient representatives is that within the *contextual* role of sharing patient information with attending ED physicians. They can be a member of both patient and healthcare communities; this finding was based on our observations in the case of unconscious patients. The observation contributed to a system design aimed at remote and proximal patient information sharing using patients' representatives. The target use case interactions between attending physicians and patient representatives during emergencies. A mobile patient information sharing application for remote and proximal sharing situations was designed and the concept was evaluated based on patient preferences and physician perceptions. Finally, to understand physicians usage of patient information using discussions, a data driven analysis and feature proposal was conducted to support effective communication via a social networking service application.

The results of each of our researches show that patient preferences and physicians information requirements can both be considered using our proposed socio-technical system using patients' representative. This thesis contributes the design of an inclusive patient information sharing system that considers both patient and healthcare communities; the patient representative is introduced as a socio-technical "bridge" between these communities in a *contextual* role. Alternative information sources utilized involve human interaction. Overall, this thesis builds upon the idea that community involvement in the process of information sharing can contribute to nationwide acceptance of proposed healthcare systems. A socio-technical information sharing approach using patient representatives that includes patients with privacy concerns can support the future implementation EHR systems. Focusing on technical solutions without input from communities risks widening the existing gap between patient and healthcare communities with regards to patients with privacy concerns.

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Although uncertain, the future belongs to those who prepare for it today. I am happy to have chosen this university and Japan in general for pursuing research. The bittersweet moments have made this journey, ‘worth it!’. I stand with the highest praise and gratitude on the shoulders of my ancestors while peering into future challenges, uncertain but confident.

Kensuke Morris, 2020

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Chapter 1

Introduction

Patient information sharing is a vital component of the healthcare domain. To obtain patient information, healthcare professionals (HCPs) utilize multiple sources using various modalities; sources include direct access to a centralized database systems and indirectly from colleagues, patients and patients' representatives. Colleagues are members of the healthcare community while patients and their representatives are members of the patient community. Both communities are important to the flow of patient information during episodes of patient care in hospitals, especially within emergency departments (ED).

To facilitate easier patient information sharing between HCPs, centralized database systems such as Electronic Health Records (EHR) systems were introduced. Centralized databases provide benefits to authorized HCPs such as fast and easy access to patient information; however, concerns for privacy arose about how the information is collected and used without the knowledge of the patient. If patients have no privacy concerns, then the access by physicians can be seen a "win-win" situation (Figure 1.1). If a patient has privacy concerns, direct access by physicians can be seen as a "win-lose" situation, since the privacy concerns of patients can affect the flow of patient information where concerned patients can withhold information due to such concerns [1–3].

Patient-centered care places patients at the center of healthcare system, with various aspects such systems design and resource allocation geared towards improving the patient, both inside and outside of hospitals. Patient community involvement, although beneficial for patients, has also introduced barriers for HCPs to perform their roles. The patient community wants control, awareness and involvement in decision making; conversely, HCPs want access to relevant patient information and require patient cooperation and trust to accomplish some important medical procedures. Efforts have made to give patients control over access to their information; however, in the event a

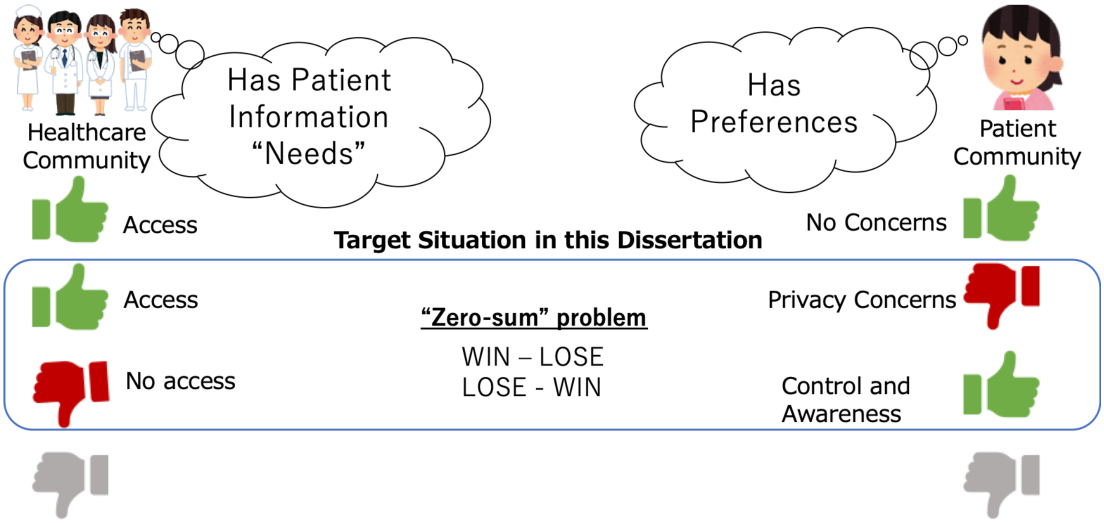

Figure 1.1: Current situations regards patient information sharing between communities

patient becomes incapable of sharing their information, such as the case of a Personal Health Record (PHR) system, physicians cannot access important information to treat patients. PHRs by definition are controlled by patients, which in turn limits patient information access to additional consulting physicians. This can be seen as a “lose-win” situation where patients have their privacy preserved, but physicians cannot access patient information.

The preferences of both communities, although justified, is subject to controversy within the healthcare domain. For example, in the patient community, privacy concerns can lead to patients withholding information along with lack of cooperation with HCPs. Alternatively, relating to the healthcare community, HCPs due to lack of patient trust can be demotivated to perform their valuable roles when they are not able to have full autonomy about how to share results with patients for various justifiable reasons. Privacy concerns about use of patient information without patients knowledge continues to be a subject of controversy. Similar to published research, recent news articles also highlight situations which can contribute to patient privacy concerns about their information usage[1,2]; these situations can contribute to a concerned patient withholding of information during a consultation [4, 5].

Ideally, a solution where both communities preferences are included can improve information flow within the healthcare domain. A “lose-lose” occurs when physicians cannot have access to patient information and patients have privacy concerns. Previous studies

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[1] https://www.computerworld.com/article/3324044/amazon-launches-patient-data-mining-service-to-assist-docs.html

[2] https://www.cbsnews.com/news/google-ascension-project-nightingale-mining-personal-health-data-privacy-concerns/

have provided control for patients while at the same time provided access to physicians [6, 7]. If the patient becomes incapable, a ”break-glass” policy can be used to access patient information; however, this policy does not preserve the active control that some concerned patients may prefer. The aforementioned problem led us our main question, how can we address the “lose-win” and “win-lose” situations where concerned patients can have someone actively involved in sharing their information with physicians emergencies?

Over the years, although efforts have been made to consider the perspectives of both the patient and healthcare communities, barriers still exist between these communities regarding patient information sharing by a fraction of members of society. Tensions can lead to a “zero-sum” problem that can adversely affect the relationship between the communities where more emphasis on patient centered systems marginalize HCPs. In the context of shared decision-making, the term “zero-sum” was also used by Grünloh et al. [8] in reference to the conflict between the patient and healthcare communities. These tensions contribute to barriers towards realizing integrated patient information sharing systems that are inclusive of both patient and healthcare communities.

Studies into various modalities of sharing patient information have been generally based on at least one of the aforementioned communities. HCPs’ can obtain indirect access to patient information from colleagues, patients and representatives. In an attempt to contribute to the reduction of tensions between the patient and healthcare community, our proposed concept assumes that to unify the two communities under one integrated system, the problem should be viewed as a design problem. Specific goals and the course of action are seen as part of the design process where the context under study needs to be understood [9]. Tensions between communities are seen as social problems that affect the technical implementation of healthcare based systems that can improve patient information sharing. Thus, viewing the problem as a design problem allows us to place more focus on the users of both the patient and healthcare community to establish a social basis for proceeding system development based on design-based findings.

Extensive socio-technical systems research has focused on centralized database systems such as EHR/PHR systems, patients and colleagues. At the point of writing this thesis, no study has been that proposes the design a technological avenue for patient representatives to be actively involved in patient information sharing on behalf of a patient that includes opinions of patients and healthcare community about the representative. The present research explained in this thesis has been undertaken to design a system that allows physicians to obtain patient information based on patient preferences via active involvement of patient representatives; this will be done by design and prototyping of a mobile application that can be used by physicians and patient representatives. Towards this purpose, the main research questions of this thesis are:

1. What are patient preferences to include representatives during remote information sharing in the event they become incapable?
2. How can we improve the patient information sharing during interaction between doctors and representatives within Emergency Departments?
3. What design features are required to share patient information within the healthcare community?

Representatives are seen as part of the patient community; however, physicians' acceptance of representatives is required to justify its feasibility during emergencies since physicians are the ones that are responsible for patient safety. A system preferred by patients but rejected by physicians will not produce an integrated patient information sharing system. In order for integration to occur, both physicians and patients need to have the same underlying consensus towards using the patient representative. The core of this study is to design a system that satisfies representative responsibilities that physicians require in emergency situations if the patient is incapable of providing that information. This thesis considers both the healthcare and patient community by using the patient representative as "bridge" to contribute to a design process and systems that are inclusive of the patient and healthcare communities; this inclusion can lead to closer cooperation between communities towards improving patient information flow within the healthcare domain.

To address the above research questions we utilized a co-led community based approach to understand the patient and healthcare community, and we propose a socio-technical mobile application design to improve patient information sharing during emergencies. The target cases are situations where there is a perceived "win-lose" or "lose-win" between the communities in the context of patient information sharing (Figure 1.1). The following is our rationale for choosing a socio-technical approach to involving both communities:

> Most of information sources are humans (social). Human involvement in the process of information sharing that can contribute to acceptance of proposed design solutions. Current social challenges of such privacy concerns affects technical implementation of systems such as EHR systems. Focusing on technical barriers without community involvement risks widening the existing social gap between patient and healthcare communities.

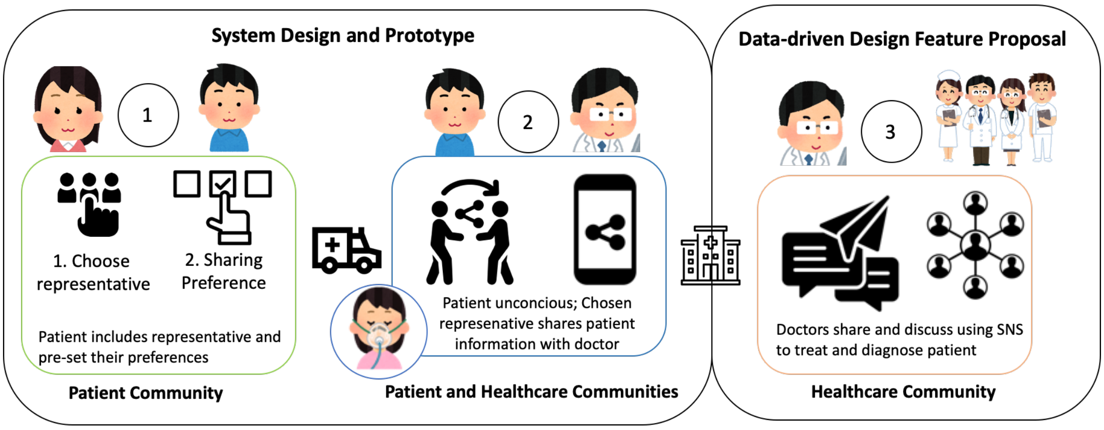


Figure 1.2: Chapters highlighting our focus in this thesis

The remaining chapters of this thesis describe our research activities in greater detail. In Chapter 2, a background of information behaviour and its relation to healthcare in the context of patient information sharing is presented; community concerns about patient information sharing are also discussed.

Chapter 3 presents related design approaches and work conducted in Japan to achieve patient information sharing. Finally, the case of the emergency department and our rationale upon which to base our research is explained. Research activities that contribute to inclusive design considering the patient and healthcare community are then discussed in subsequent chapters.

Chapter 4 explains an ethnographic approach that creates understanding of the ED setting and frame our use case scenario for the proceeding chapters. We also present categories for the patient representative that form the basis of our representative definition during the design process as shown in Figure 1.2.

Chapter 5 builds on the Chapter 4 by proposing a novel mobile remote and proximal patient information sharing system using patient representatives; prototypes for both situations are also showcased. Patients' preferences and opinions are then shown regarding using their representatives in the proposed design for remote information sharing. To evaluate proximal information sharing, opinions on the proximal system design are based on the healthcare community since remote sharing preferences are already focused on patients' opinions. This chapter focuses on the patient community to extract patient preferences before an emergency situation. A usability study based on physicians' point of view is also presented along with an additional use case scenario based on the representative categories shown in Chapter 4.

In Chapter 6, a data-driven feature proposal is shown with the aim of supporting interaction between HCPs during discussions that include patient information obtained from representatives in Chapter 5. This chapter focuses on the healthcare community and their interactions and discussions focused within the ED, although some physicians participated remotely.

Chapter 7 presents a discussion about the research presented in this thesis and additional future directions that can build upon this current research.

Finally, in Chapter 8, I conclude by presenting a summary of our contributions and closing remarks.

Chapter 2

Information Behaviour in Healthcare

2.1 Information Behaviour Overview

Many definitions about information behaviour exist due to the different interpretations in various fields of study. Information behaviour relates to the collection, management, seeking and use information [10]. This field in its broadest sense considers behaviours such as information seeking and information sharing which humans perform to achieve access to information. Various information behaviour models have been proposed throughout out the years [11–13]; one of these which is widely recognised in information behaviour research is the model proposed by T. D. Wilson [14], as shown in Figure 2.1. The concept of information seeking behaviour focuses on the search, discovery and retrieval of information from source. An individual who needs information will engage in information seeking behaviour to receive information which can be shared by another individual. Information sharing can occur when “the user may seek information from other people, rather than from systems...”[14]. In Figure 2.1, “Information Exchange” can also be referred to as “Information Sharing” [15].

Wilson’s model has been extended in an Information-seeking and Communication Model (ISCM) to include communication concepts which include the medium through which information is shared (Figure 2.2). ICSM considers that in order for an individual to share information, they must be able to communicate with another individual via a medium using a communication process.

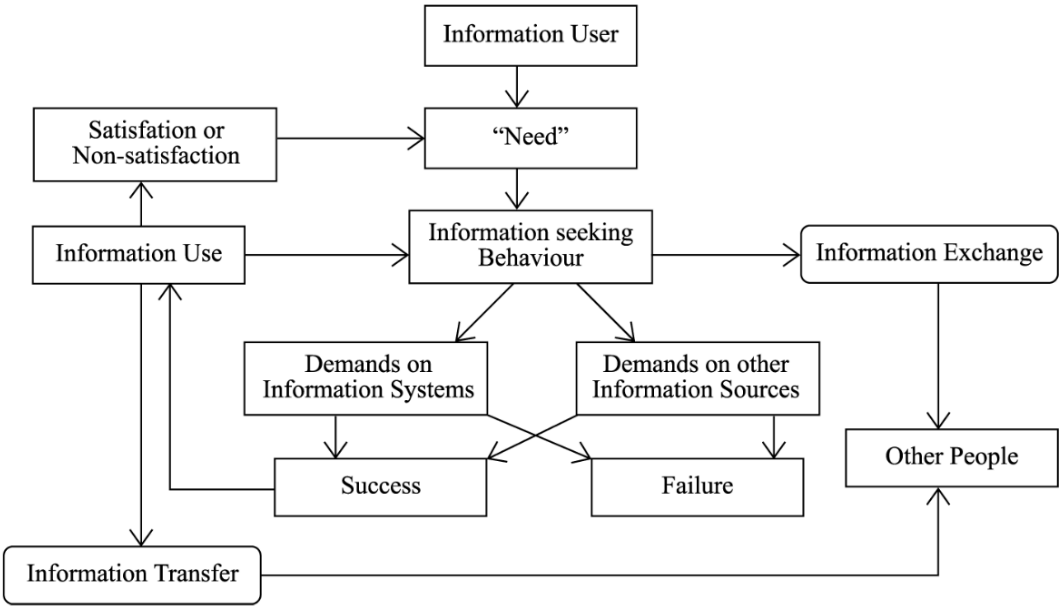


FIGURE 2.1: Information behavior model [14]

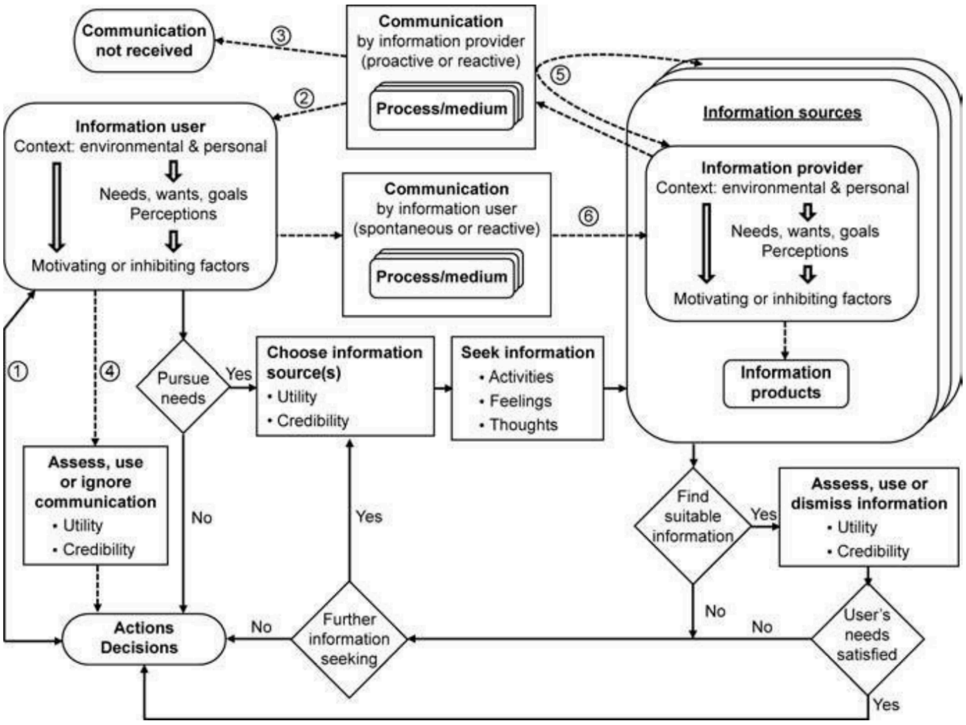


FIGURE 2.2: ISCM, partially derived from T. D. Wilson's model [10]

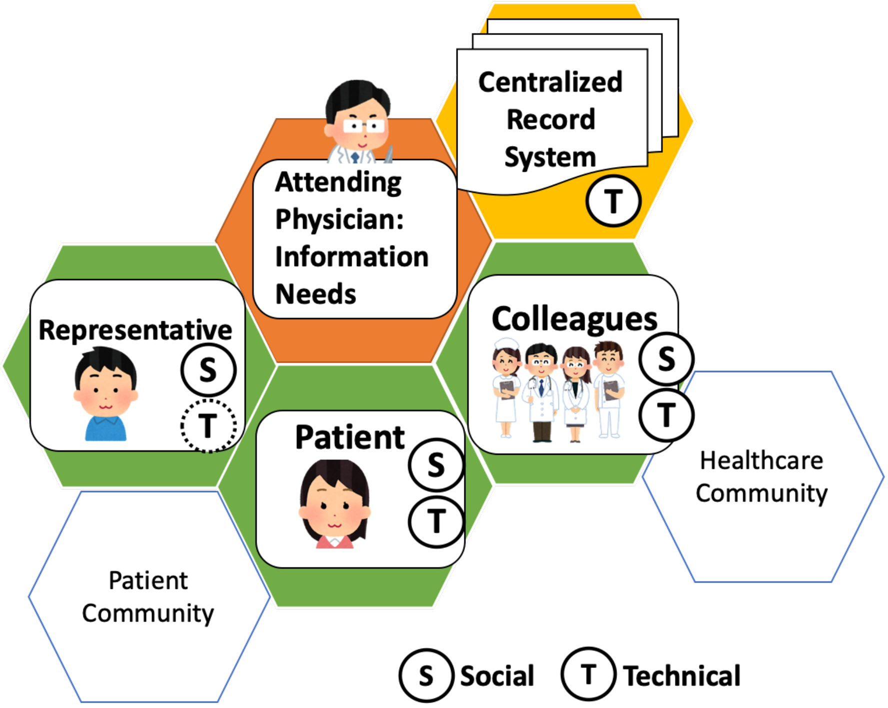


FIGURE 2.3: Patient Information Sources utilized by HCPs

2.2 Patient Information Sharing

Since sensitive patient information is utilized, information sharing in the healthcare context must include consideration of privacy and permission. On the other hand, patient information needs to be available in a timely manner to improve the likelihood of faster decision making. Healthcare Professionals (HCPs) obtain patient information from multiple information sources using various modalities (Figure 2.3); direct access to a centralized system such as EHR and EMR systems are ideal; however, indirect access to patient information via colleagues, patients and their representatives are also valuable to HCPs, depending on the situation.

Patient information can be categorized in the following categories [16]:

- *Demographic information* includes information such as patient age, sex, address, occupation, contacts for patient representatives, religion, marital status etc.
- *Clinical information* includes patients medical history including examinations, directives and medications prescribed.
- *Social information* relates to the patients activity-of-daily-living (ADL) and the events prior to the emergency.

The ways in which HCPs obtain and share patient information can be categorized into social, technical and socio-technical information sharing.

2.2.1 Social and Technical Sharing

Traditionally, physicians obtained patient information socially from patients, colleagues and patient representatives. Social communication takes many forms such as face-to-face or via telephones [17]; these communication methods are still utilized to date [18]. Social patient information sharing is a convenient and fast way for HCPs to obtain patient information; however, retention of the shared information has been a challenge for HCPs during busy shifts.

In the past decades, physicians have benefited from direct technical access to patient information shared using digitized centralized systems such as Electronic Health Record (EHR). Printed patient records are still utilized to store clinical patient information and offer physicians direct access to patient information if a patient's admission is recurring in the same hospital. However, EHRs have revolutionized the way in which HCPs can directly access patient information from any hospital connected to the internet [19, 20]. EHRs provide a number of benefits, improving upon the concept of the EMR and traditional paper based medical records. EHR systems have sparked research in both developed and developing countries [21–25]. Successful implementation of EHRs has been achieved by some countries [26]. However, barriers such as patient privacy concerns still hinder successful implementation of a nation-wide EHR system in some other countries [20, 27, 28].

2.2.2 Socio-technical Sharing

Physicians benefit additionally from obtaining patient information indirectly using socio-technical patient information sharing systems. These systems require additional human involvement in order for physicians to access patient information.

2.2.2.1 Socio-technical Systems

Socio-technical systems incorporate people and technology based on a given context [29]. General principles for what constitutes a socio-technical system have been previously described by Cherns [30]:

1. *Compatibility:* the systems design and objectives must be identical. Since the system requires use of various stakeholders, the relevant people should be included in the design process.
2. *Minimal critical specification:* this principle follows principle 1. Cherns [30] mentioned that “this principle has two aspects, negative and positive, the negative simply states that no more should be specified than is absolutely essential; the positive requires that we identify what is essential.”
3. *Sociotechnical criterion:* this principle states that unforeseen events and changes “must be controlled near their point of origin as possible.”
4. *Multifunctional principle - organism vs. mechanism:* Each stakeholder in the system has various specified functions, which in turn can be replaced without affecting the overall functioning of the system. Cherns [30] argues that instead of having a person with one specified skill, the organization “becomes more adaptive and less wasteful for each element [person] to posses more than one function. The same function can be performed in different ways by using different combinations of elements.”
5. *Boundary location:* maintaining boundaries between departments while at the same time coordinating adequately between departments and to the upper levels of management.
6. *Information flow:* having the right amount of information available to relevant persons.
7. *Support congruence:* social support should reinforce the behaviours designed by the organizational structure.
8. *Design and human values:* stakeholders should produce high quality work based on the design of the organisation structure.
9. *Incompletion:* design should always be seen as an iterative process where redesign should be considered after system implementation.

Understanding the underlying structures of social communication and where the use of technology falls into such communication in the ED is even more important, since timeliness of information is an asset to physicians in the organized chaos [29]. Badham et al. outlined five important characteristics that socio-technical system should possess [31]:

- Comprised interdependent parts.

- Adaptability in pursuit of goals in external environments.
- Interdependent technical and social subsystems should be a part of an internal environment.
- Goals that can be achieved by more than one means, i.e. there are design choices to be made during system development.
- System performance relies on the joint optimisation of the technical and social subsystems. System performance and utility can be negatively affected if focus were to be directed on one part, disregarding the other.

Physicians benefit from obtaining patient information using socio-technical patient information sharing systems. These systems require additional human involvement in order for physicians to access patient information. Healthcare systems that facilitate patient information sharing have been designed for both the healthcare and patient communities.

2.2.2.2 Socio-technical Sharing in Healthcare Community

Alternative patient information sources are accessed in the event either the patient information or the patient is not directly accessible to the HCPs. Wilson et. al [14] mentioned that to obtain information in its general capacity, “the user may seek information from other people, rather than from systems.” In the ED setting, these people can be colleagues, the patient currently being treated or patient representatives.

During patient information seeking, HCPs communicate with colleagues with the goal of not only obtaining patient information but discussing treatment options and diagnosis [32]. In many cases patient information is obtained through direct patient interviews and evaluation of the patient’s medical records through the EHRs. However, other times it is necessary for HCPs to turn to other patient information sources. Under some circumstances patient representatives become a primary patient information source; they can share patient information that is not limited to medical history but also events that lead up to the emergency situation [16]. Systems that facilitate the sharing of clinical patient information have improved communication between physicians; these features are mainly centralized around EHR systems. Recently, some HCPs prefer using SNS applications to share patient information [33, 34]. Despite various methods of interacting with colleagues, HCPs in ED still prefer face-to-face verbal discussion since a large amount of patient information can be shared in a shorter time interval [18]; however disadvantages include increased interruptions [35] that can also affect the cognitive retention of physicians [36].

2.2.2.3 Socio-technical Sharing involving Patient Community

Patients are valuable sources of patient information in cases where HCPs cannot directly access EHR systems due to various social, political and/or technical barriers [28]. In many cases patient information is obtained through direct patient interviews and evaluation of the patient' s medical records through the EHR system. However, other times it is necessary for HCPs to turn to other patient information sources. Under some circumstances patient representatives become a primary patient information source; they can share patient information that is not limited to medical history, but also events that lead up to the emergency situation [16].

If a patient is capable of sharing patient information, physicians can save a considerable amount of information seeking time and thus dedicate more time to treatment and earlier diagnosis during the episode of care. Capable patients are those who can communicate and share their patient information verbally or electronically with HCPs in ED; a patient can be conscious and still incapable of sharing their patient information such as a patient who is conscious but cannot speak. Various studies have reported efforts to improve information sharing between capable patients and HCPs [26].

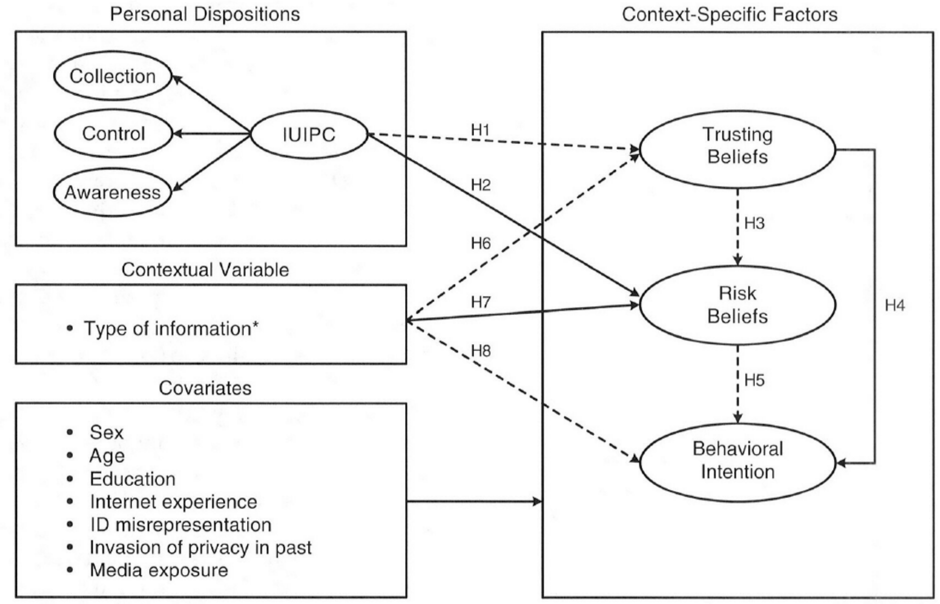
Design efforts have been undertaken to improve patients' involvement in control of sharing their information with HCPs using Patient Accessible EHR (PAEHRs) [37]. PAEHRs systems are aimed at having patients access and be aware of activities their clinical information [38, 39]. The social academic basis for future implementation of PAEHR has been reported [40]. Drawing from the reported guidelines, various countries have implemented PAEHRs. Some PAEHRs allow patients to actively/passively share their clinical information with HCPs [26, 41–44].

Patient representatives have been referred as 'family member' , 'proxy' , or 'representative' where they make decisions on behalf of an incapable patient [45–49]. In this thesis, we define the patient' s representative as any entity which occupies a *contextual* role of sharing patient information with HCPs on behalf of a patient.

2.2.3 Concerns about Patient Information Sharing

2.2.3.1 Patient Community Concerns

Privacy concerns can affect preferences of patients with regard to sharing their clinical information. In most cases, concerns are related to who is accessing one' s individual record, why, when and where the access is occurring, and what part of the medical record is being accessed. Mistrust of third party use of confidential information exists



Notes. *Less sensitive information (0), more sensitive information (1), positive effect ⟶, negative effect – – →.

FIGURE 2.4: Causal model proposed and validated [52]

among individuals [50]. This mistrust is one component that needs to be removed to have an effective patient information sharing.

In an effort to quantify privacy concerns, previous research has developed metrics to with varying dimensions [51, 52]. We chose to use the Internet Users’ Privacy Concerns (IUIPC) scale proposed by Malhotra et. al [52] as our basis of understanding the qualitative dimensions of patient privacy concerns. IUIPC was developed and validated with three dimensions; these were collection, control and awareness. Malhotra et al. [52] was of the view that “when applied to information privacy, social theory suggests that a firm’ s collection of personally identifiable data is perceived to be fair only when the consumer is granted control over the information and the consumer is informed about the firm’ s intended use of the information.” A causal model was developed to illustrate the notion of IUIPC as shown in Figure 2.4. The collection factor is considered a central theme of information exchange based on the social contract theory. The control factor represented individuals’ freedom to voice their opinions and opt-out. The individual can be able to control the collected information about them. The awareness factor indicates the understanding about existing conditions and organizational practices. Apart from *collection* which remains the same, Malhotra et al. [52] argued that *control* and *awareness* summarizes unauthorized secondary use, improper access, and error. More in-depth explanations about studies relating to the concepts “privacy” and “privacy concerns” are located in Appendix A.

Australia’ s government approved the implementation of Personally Controlled EHR (PCEHR) which was later changed to ‘My Health Record’ ; this EHR system not

https://www[redacted]issue.html

健康総合病院
千葉 太郎

病院の患者番号 9998989

患者番号を入力してボタンを押すと、バーコードが表示されます。
登録するスマホで「リンク付き承認設定」を押すことで、アプリの登録が完了します。

For each participating facility, the user ID Issued by the workers on the basis of the (such as a patient number) QR the code

病院	外した時刻	承認
千葉大学医学部附属病院		☑
健康総合病院		☑
健康調剤薬局		☑
健康訪問介護ステーション		☑
健康介護センター		☑
健康内科		☑
健康アイクリニック		☑

リンク付承認を外すことにより、外された医療機関はSHACHIで共有している医療情報を閲

Access control

Input and viewing of information by the users themselves.

FIGURE 2.5: Access control feature in SHACHI PHR [translated] [6]

only allows the patient to access their clinical data from the comfort of their home, but it also controls who can access their data. The privacy preserving nature of the 'My Health Record' aims to maintain privacy with the inclusion access control via patients [7]. The introduction of systems that include access control like 'My Health Record' and Social Health Assist Chiba (SHACHI) system have attempted to overcome patient concerns and create patient control over releasing medical information [6]. However, one shortcoming of these solutions is that patients with concern for control and awareness of their medical record cannot assign control to other trusted representatives who can then be able to continue access control in the event the patient is unconscious. Previous studies have reported patients access control preferences and decisions [53–55]. Some PHR systems have an option for representatives to grant access to HCPs [49]; however the levels of access and patients perceptions about how to utilize representatives to grant remote access to HCPs have not been reported to date.

2.2.3.2 Healthcare Community Concerns

Tensions arising from HCPs who feel restricted to perform their roles because the lack of trust affecting the quality of consultation between patients; this can affect the motivation levels for some HCPs. Core to physicians' role is the treatment and diagnosis of patients. Searching for patient information is a non-clinical task, but it sometimes uses a considerable amount of physicians time.

There are also concerns about which limited guidelines support the sharing of patient information using modernized modalities for patient information sharing, e.g. social network services (SNS) applications. These applications have recently been used to discuss topics relating to a patient; however, the lack of guidelines hinder extensive meaningful use of SNS platforms.

The next chapter shows design approaches and their applicability to patient information sharing along with some implemented examples.

Chapter 3

Healthcare System Design: Context of Patient Information Sharing

3.1 Approaches to Understand Users

User-centered design (UCD) since its inception, has influenced design of socio-technical technologies in various disciplines [29, 56]. Central to UCD is the notion that user (or stakeholder) input in a system's design process is paramount to the successful prototyping and implementation [56]. UCD takes into account that technology should center around and follow the natural tasks of users. The design process of UCD involves understanding users, developing ideas, prototyping, and validating and improving ideas as an iterative approach. A designed system, even after implementation, is never completed; constant iterative improvements and updates to ideas based on understanding of users and system experience shape the iterative design of systems [57]. Three principles of UCD have been posited [58]:

- **Early focus on user and task needs** to be supported by structured planning of how data will be collected from users since direct contact with users "can be hazardous if it is not structured" [58].
- **Empirical measurement of artefact usage** relates to the use of prototypes to test obtained behavioural measurements such *ease of use.*
- **Iterative design of artefact under evaluation** is required to improve the artefact development based on user feedback.

Design ethnography has been utilized in various fields to allow researchers to understand users in their cultural context [59]; it also give researchers an understanding of the cultural context which can affect users' professional environment without changing the environment under investigation [60]. Design ethnography has been used to understand the emergency setting towards improving technological solutions proposed by designers [61] since it provides culturally specific suggestions for a user centered design for culturally specific features [62].

Co-led redesign has been defined as "the development and implementation of health care services based on both a clinical and patient perspective and experience or experience-based design" [45]; clinical perspectives relate to the healthcare community while patient perspectives represent the patient community. Co-led design can contribute to improved information flow through community involvement. Involvement of the patient community with consideration for the healthcare community has been identified [48]; these are direct care, organizational design & governance, and policy making [48]. Co-led redesign, in the context of patient information sharing, can occur in "all three levels of engagement in differing capacities" [45]. Direct engagement includes patients or their representative (patient community) sharing using a technological modality to share patient information with HCPs (healthcare community).

3.2 Patient Information Sharing in Japan

Patient information sharing has improved through many countries with private and public sector solutions [26, 63, 64]. The following section highlights previous work in Japan to improve patient information sharing and the research position of this thesis.

3.2.1 Direct Technical Patient Information Sharing

Dolphin Project, started in 2001, is a scheme created to improve patient service, improve the quality of medical care, and achieve efficient medical care of within Japan [65]. The project has three stages of development, two of which are in Japan and the third involves potential international cooperation of participating countries, as shown in Figure 3.2. Stage 1 is iDolphin and corresponds to the regional level. Stage 2, named Super Dolphin, corresponds to a national health information network [66]. The Super Dolphin stage involves development of the basic structure using Medical Markup Language (MML) upon which a nationwide EHR can be created. The Dolphin project ensures the collection and sharing of patient information on a nationwide level.

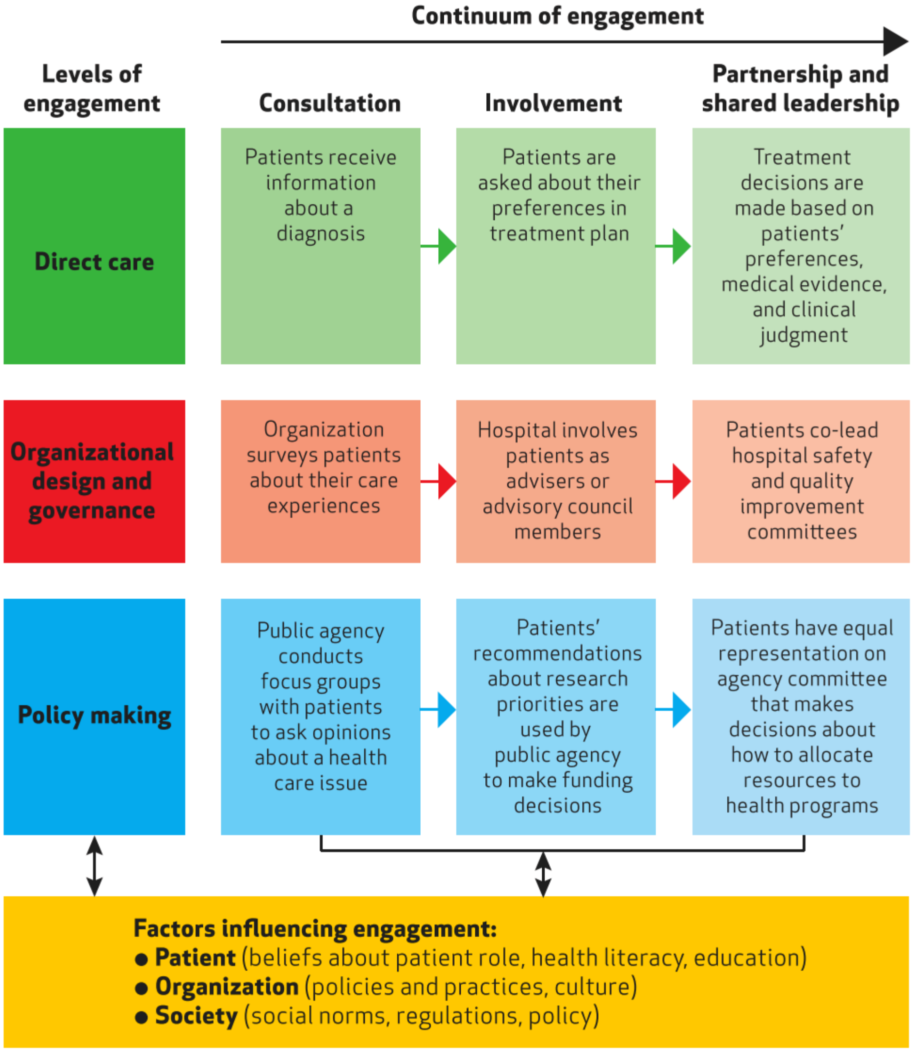


FIGURE 3.1: Framework for Patient Community Engagement [48]

Millennial EHR started in 2015, this project (千年カルテプロジェクト) builds upon the foundation laid by the Dolphin project. Along with increasing the amount of connected hospitals to allow HCPs to access patient information directly, this project also aims to support the secondary use of patient information [67]. Figure 3.3 illustrates the technologies utilized to achieve patient information sharing using the Millennial EHR Project (MEHR).

3.2.2 Socio-technical Patient Information Sharing

Social Health Assist Chiba (SHACHI) is a mobile application that enables patients to access, manage, control and share their medical information with their physicians, relatives and trusted friends. Within the scope of EHRs, remote access control by the patient is a recently emerging phenomenon. However, with Personal Health Record

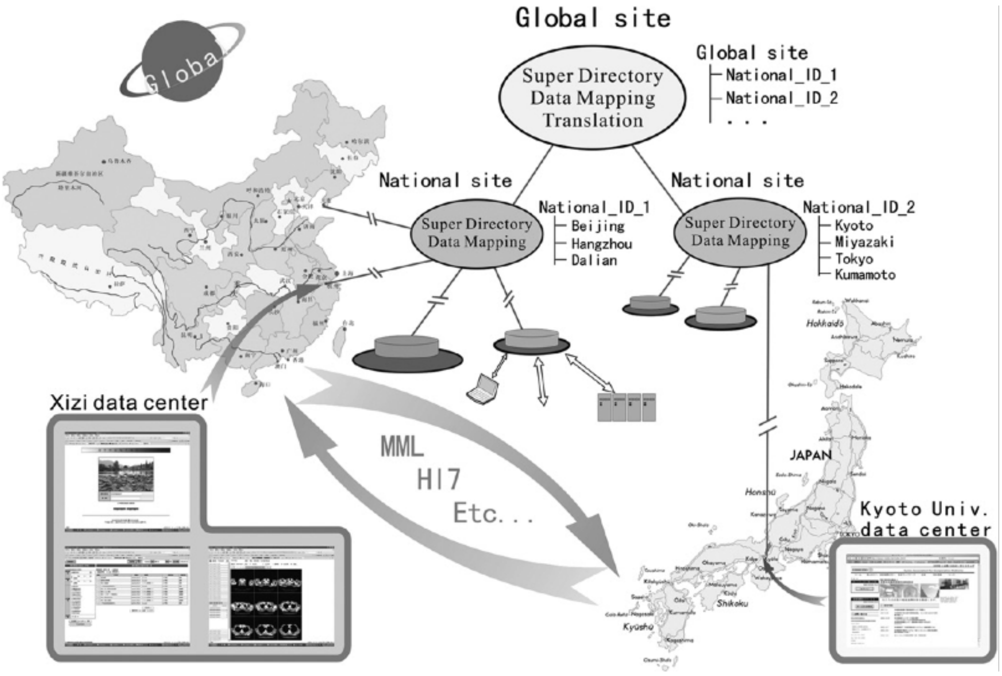


FIGURE 3.2: Dolphin Project's Overall Structure [66]

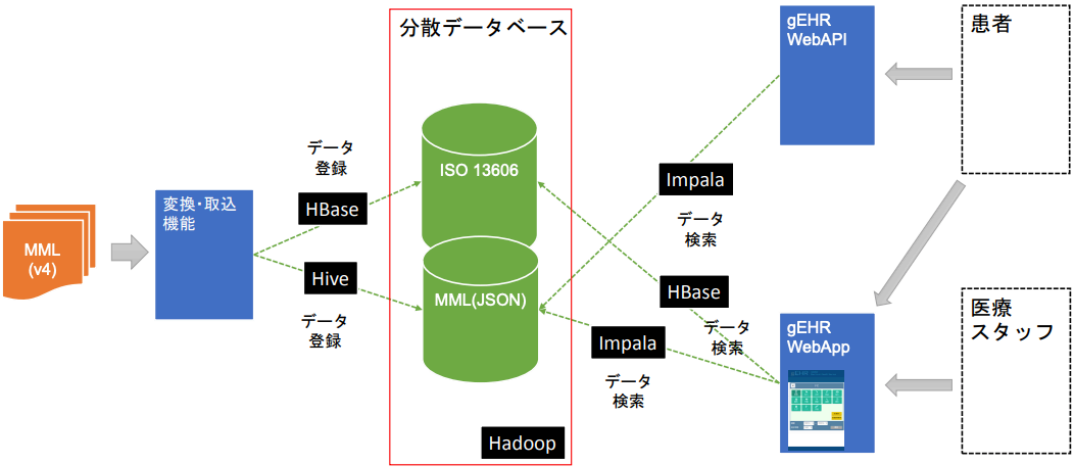


FIGURE 3.3: Flow of Millennial EHR Project (In Japanese) [67]

(PHR) systems like SHACHI, where the patients manage their medical data as opposed to EHRs, work has been done to have better access control for patients managing their data. In the case of EHRs, patients do not own their data; the data belongs to the entitie(s) that is/are responsible for housing the data. SHACHI aims to also combine PHR and EHR to realize patient centered care, with the belief that HCPs and patients can read and use the same system and information. Using SHACHI, physicians write information that is readable to patients.

3.3 Case of Emergency Departments in Japan

Emergency situations, including disasters, usually occur outside the walls of healthcare institutions. In the case of day-to-day emergencies, emergency departments, located within healthcare institutions, are vital to patient care. Emergency departments have unique characteristics in that emergency physicians need timely access to patient information to make faster informed decisions about patients' treatment and diagnoses [16]. Patients are evaluated simultaneously, some are diagnosed and managed at a faster rate. Physicians must be knowledgeable about illnesses and injuries as well as have access to knowledge about medical history for each episode of care [16] and specific context of care [68]. Additional information such as past treatment is beneficial to physicians and other HCPs. Patient information sharing relating to emergency departments was chosen as a case study for this thesis based on the unique characteristics of the ED. Healthcare facilities in Japan are divided into primary, secondary and tertiary levels [69, 70]. We chose to base our study on a tertiary level ED within the aim of addressing overarching research questions.

Table 3.1: Our research position compared to similar projects in Japan based on stakeholder focus; T means a direct technical source; ST means an indirect socio-technical source

Criteria		Dolphin	MEHR	SHACHI	Our Concept
Target Source	EHR/PHR (T)	√	√	√	
	HCPs (ST)	√	√	√	
	Patient (ST)		√	√	√
	Representative (ST)				√
Target Users	HCP	√	√	√	√
	Patient	√	√	√	√
	Representative				√
Mobile Sharing	Remote	√	√		√
	Proximal			√	√

Understanding communities using ethnography and other approaches has provided better insights as opposed to addressing problems on an individual level [71]. Utilizing a community based design, we consider patient and healthcare communities while designing a patient information sharing system centered around patient community members, i.e. representatives. In this research, we use a patient community member to improve patient information sharing with the members of the healthcare community in line with patient preferences, thus preserving the patient-centered design. This community based approach considers both patient and healthcare community perspectives. Considering

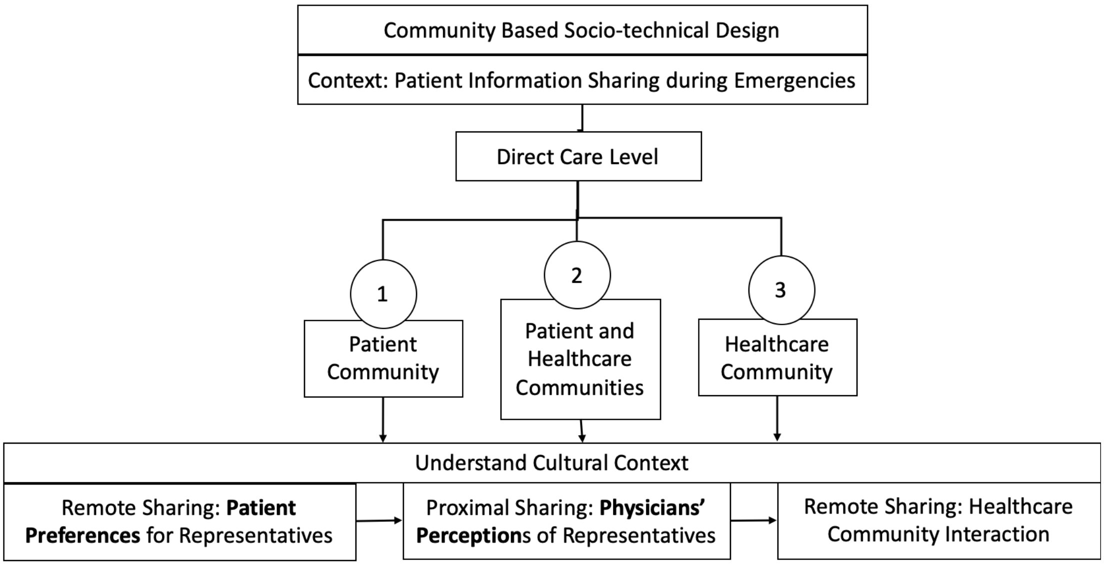


FIGURE 3.4: Our steps using a community-based design approach to achieve a socio-technical sharing using patient representatives

the Patient Engagement Framework proposed by Carman et al. [48], we focus on direct patient community and healthcare community at the highest level of the continuum of engagement, i.e. partnership and shared leadership (Figure 3.1). Building upon work related to patient information sharing in Japan [6, 67, 72], our target stakeholder focus and use cases are shown in Table 3.1.

Patient and family engagement has been defined as “a relationship between health care providers working together to promote and support active patient and public involvement in health care and to strengthen their influence on health care decisions at an individual and collective level” [48]; to this end, we expand this definition to include patient and healthcare communities in the design process towards an integrated patient information sharing system that is inclusive of both communities in the initial stages of design.

In a community based design approach, we must first start understand the cultural context of patient information sharing in Japan (Figure 3.4); this understanding evolves throughout the proceeding design activities focused on the patient and healthcare community. We then determined patients' preferences for their community members (representatives). Our focus then shifted to the interaction between both patient and healthcare community. Finally, we focus on the healthcare community after interaction with patient community.

Chapter 4

Understanding Cultural Context for Patient Information Sharing between Communities

The previous chapter showed the topics of this thesis (Figure 3.4) This chapter commences our ethnographic understanding of the ED setting in Japan, a process that can only occur through immersion in a cultural context.

4.1 Overview

Information-seeking behaviour of HCPs in Emergency Departments involves the non-clinical task of seeking patient information [73]. Insights about the information needs and behaviour of HCPs [18] have been reported. Studies have also discussed sources HCPs utilize during patient information seeking. An important responsibility of HCP is the clinical care of patients; however, during some episodes of care, information seeking for patient information as a non-clinical task occupies a considerable amount of their time [74–76], a challenge further compounded by the ED setting [77, 78].

HCPs turn to alternative information sources to obtain patients' clinical patient information if they cannot access patients' medical history within a healthcare facility. If a patient is capable of sharing patient information, physicians use minimal patient information-seeking time, thus dedicating more time to treatment and earlier diagnosis during the episode of care. In this thesis, capable patients are considered to be those who can communicate and share their patient information verbally or electronically with HCPs in ED.

In this study we focus on the patient’ s representative, an information source that can contain various people who are assumed to have a close relationship with patients before an emergency situation. The objective of this study is to deepen our understanding of physicians information seeking behavior and interaction with patient representatives.

The above objectives were achieved through conducting observations mainly within the scope of emergency department physicians and their interactions with patient representatives.

4.2 Understanding through Observation

4.2.1 Study Design

A 31-hour observation was performed at an outpatient ED of a tertiary level hospital in Japan to gain more understanding about the patient information needs and information-seeking behavior of physicians and their interactions with patient representatives [79]. Observations were necessary because of our limited knowledge about information seeking behaviour of physicians in Japan as opposed to other cultural contexts [18, 32]. On a weekly basis, the observed ED receives an average of 97 ambulance visits and treats an average of 229 patients; in the case of the observed ED, physicians’ contact with paramedics was first done via telephone to confirm that the ED was available for certain patient conditions. As a tertiary ED, physicians decide whether or not a patient can be accepted based on the resources available, including beds (Figure 4.1). Observations are beneficial in collecting data during fieldwork about the ED setting in which physicians operate, which provided a substantive observation context for subsequent inquiries and proposals [59]. Permission was obtained from the ED management prior to observation. One observer was involved in the observation stage.

4.2.2 Data Collection and Analysis

Five attending physicians were present during the observation along with additional medical students, resident physicians and nurses. Informal interviews were done with physicians during the observation. Information behavior of physician and representative in the ED were recorded by hand-written notes. Although the activities of various HCPs were observed, our main scenario of focus was the situation where physicians could not access patient information in the ED during the admission and treatment stages of patients’ journey in the ED.

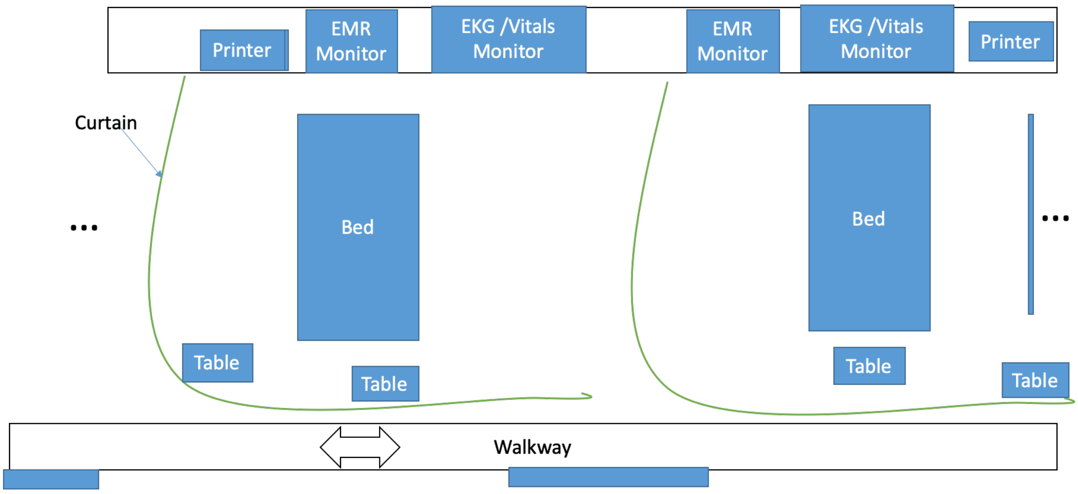


FIGURE 4.1: Layout of Emergency Department where observation was conducted

The observation notes were then read multiple times for familiarization. Notes were then checked to verify that no patient or physician identifiable notes were present in the data. The notes were then imported into QDA Miner [1], a software tool used to code the observation notes. The focus of the analysis were scenarios where physicians interacted with representatives to obtain patient information. Data from the observation formed the basis for brainstorming ideas to improve the interaction between representatives and physicians in the ED.

4.3 Results

4.3.1 General Findings

Half of admitted patients did not have their clinical patient information available within the hospital (48.7%). Twenty-six patients arrived by ambulance (66.7%) and six were walk-in patients (15.4%). The arrival status of seven patients was undetermined by the observer (17.9 %). Physicians also tried to contact a remote colleague through repeated telephone calls, a similar practice reported in a previous study [35].

Physicians usage of available patient information sources varied depending on the emergency situation. For example, a physician may use information from a patient' s family member to identify and contact the primary care facility. Additionally, physicians were observed trying to obtain patient information from patient representatives via telephone calls; the representative is advised to come to the hospital if they can. At least two physicians commented about the long time taken to obtain clinical patient information from primary care facilities; one physician commented: "*It sometimes takes about twenty*

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[1] https://provalisresearch.com/products/qualitative-data-analysis-software/

minutes to see the first set of requested clinical patient information from another facility which is sent by fax. It can take as long as a day to send the documents by post."

Representatives shared information and spoke to physicians upon arrival with patients in the ambulance. In some cases, patients who were capable of sharing their information were uncooperative with physicians; this led physicians to seek information from the representative if available. Uncooperative patients without representatives led to longer treatment during the episode of care, especially during busy time intervals. Representative involvement to share patient information was mainly during the admission and treatment stages of patients' journey (Table 4.1).

TABLE 4.1: Active persons and their roles during a patient's journey based on our observations and discussions with physicians; Roles can be HCP, Administration (Admin) and *contextual* representative (Rep).

Role	Examples	Patient Journey			
		Admission	Treatment	Diagnosis	Transfer & Discharge
HCPs	Physicians	✓	✓	✓	✓
	ED Nurse	✓	✓	✓	✓
Admin.	Support staff	✓			✓
	Care manager				✓
Rep.	Nurse	✓	✓		
	Caregiver	✓	✓		
	Family member	✓	✓		
	Relative	✓	✓		
	Spouse	✓	✓		
	Close friend	✓	✓		

4.3.2 Representative Categories

Apart from family members, some patients were accompanied by members of the healthcare community (nurses and caregivers). This finding led us to consider patient representatives as not just members of patients' community but also the healthcare community since they interact with some patients on a day-to-day basis. The observer noticed that some HCPs also occupied a *contextual* representative role similar to patient family members, e.g. a nurse sharing patient information with and ED nurse and physicians; this led us to further categorize patient representatives into the following groups:

- Chosen Representative (CR) : CR members are people appointed by patients to make important decisions. CR are considered to be adults and capable of making a responsible decision when choosing a representative. Since the choice depends

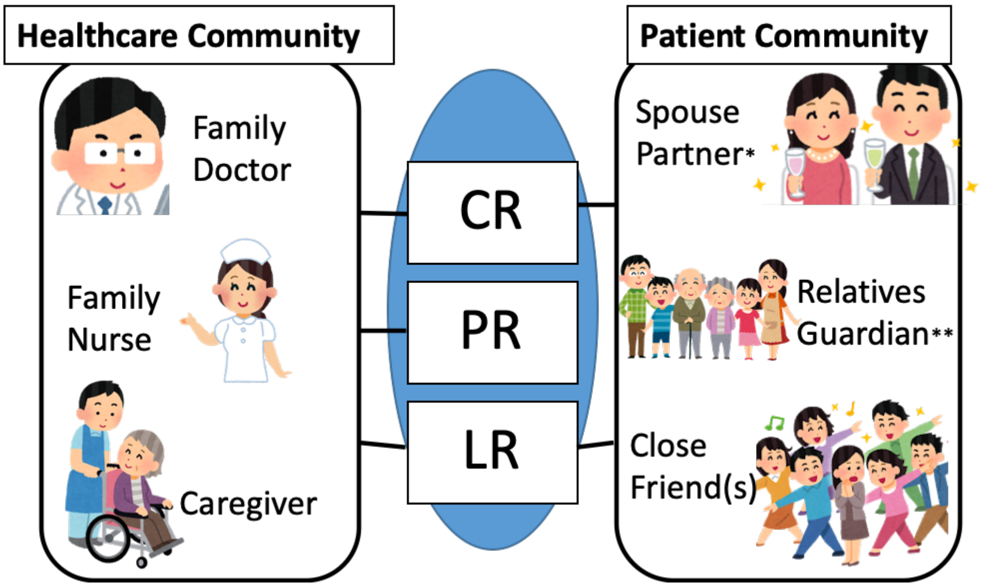

FIGURE 4.2: Possible representative groups derived from our observation; we assume that the chosen representative (CR) and legal representative (LR) can belong to the patient and healthcare Community while professional representatives (PR) can only belong to the healthcare community

on the patient and their relationships, CR can be members of the patient and healthcare communities. Close friends are also considered as members in this group.

- Professionally Allowed Representative (PR) : PR group members are people professionally allowed to provide physicians with patient information and decision making on behalf of patients for patient treatment. This group comprises only HCPs who, based on their professions, have varying levels of responsibility for the health and well-being of patients. We assume that prior to emergencies, family doctors, nurses and caregivers are assumed to have various points of contact with the patient which makes them more knowledgeable and familiar with the patient.
- Legally Allowed Representative (LR) : LR group members are people legally assigned to a patient to provide HCPs with patient information and also shared decision making for patient treatment. This group also includes the legal guardian and parents of children who are not yet the legal age to choose a guardian.

4.4 Discussion

In this study, we aimed to get a deeper ethnographic understanding of physicians' interactions with patient representatives. Insights from the observations suggested that limited patient information shared by patient representatives contributed to additional patient information-seeking behaviour of physicians.

4.4.1 Representative Groups

The representative categories were described based on our observation findings and discussions with physicians. Our focus was mainly on adult patients. However, regarding children, CR can be applicable, but the parents will have to choose on behalf of the child. There is a possibility for one person to occupy more than one of the above-mentioned groups. To establish a social basis for this exploratory research about the patient representative, we focus on group CR. PR and LR will be included in future improvements and updates to the system design. CR was chosen as the focus of this study because of the following:

1. CR is assumed to be already trusted to make decisions on behalf of the patient,
2. CR can provide patient information to physicians that is not present in the EHR system, e.g. patient's condition earlier before patient arrives at the hospital (social information).
3. A gap exists in the literature about using patient representatives in design sciences for patient information sharing. Henceforth, group CR will be referred to as representatives. We assume a representative is a member of at least one of the groups (Figure 4.2).

We consider physician's colleagues as part of the healthcare community and the patient and their representative belonging to the patient's community; both communities are regarded as part of society with important roles. Designing healthcare systems that consider both communities is necessary towards alleviating the social barriers to various technology-based healthcare initiatives that are patient-centered.

4.4.2 Defining Target Scenario

The information seeking behaviour of physicians confirmed previous studies account about knowledge access. Physicians' interaction with colleagues and representatives can be categorized as remote or proximal (near) to the information seeking physician. Drawing from the observations, the following scenario served as a basis for our concept design in the following section (Figure 4.3):

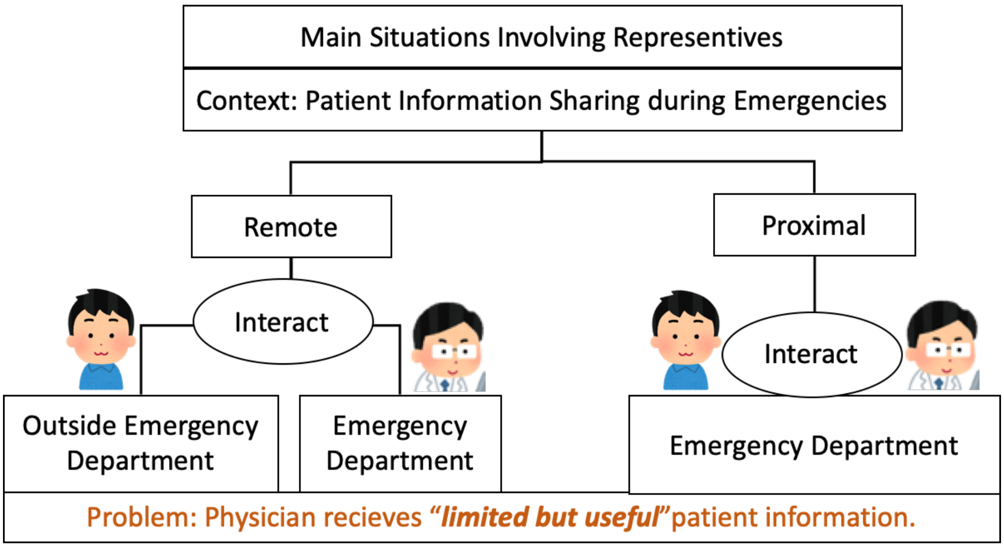

FIGURE 4.3: Scenarios involving representatives; the basis for the following chapters

> An emergency situation where a patient is incapable sharing patient information with physicians in the ED. **The patient's representative is in a remote location but can be contacted.** Physician requires patient information and cannot find the information on the current information system of the ED.

> An emergency situation where a patient is incapable sharing patient information with physicians in the ED. **The patient's representative is present in the ED.** Physician requires patient information and cannot find the information on the current information system of the ED.

The chosen scenarios above formed the basis for the problem definition for the following Chapters 5 to 7; they were derived from our observational study. Physicians interacted with representatives via mobile phone but were limited to voice conversations. At least two physicians confirmed our assumption that patient information shared by proximal representatives is "*useful but very limited*".

4.4.3 Limitations

This observation focused mainly on the information seeking behaviour of physicians and their use of various patient information sources. Nurses and administrative are also vital members of the healthcare community who require patient information to fulfill their roles in the ED. The results of the observation are not conclusive and cannot be generalized with other members of ED.

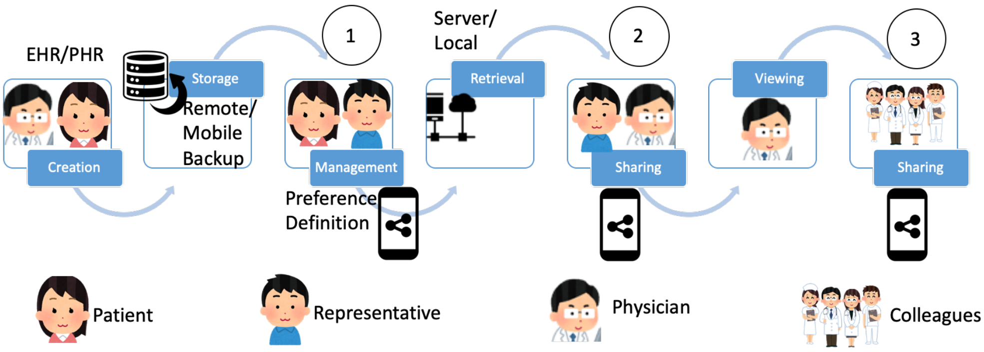

Figure 4.4: Our focus in relation to situations involving patient information; Chapter 5 will focus on numbers 1 and 2; Chapter 6 will focus on number 3.

4.5 Conclusion

This chapter provided an ethnographic understanding of the information behaviour of the patient and healthcare community inside the the ED, in particular, physicians' interaction with patient representatives. Two scenarios regarding remote and proximal information sharing were defined based on the observation. Involving patient representatives in community-based socio-technical design preserves the patient-centered characteristics that currently exist within healthcare systems. We focus on the flow of patient information from patient to representative and finally to physicians who then share with their colleagues. The key steps for patient information sharing and our socio-technical foci are outlined in Figure 4.4.

In the following chapter, we will present the design of a patient information sharing system using the representative in the remote and proximal scenarios.

Chapter 5

Remote & Proximal Sharing via Representative Involvement

The previous chapter presented two observed scenarios in which physicians utilized a valuable patient information source, the patient representative; one of these was remote patient information sharing. This chapter presents a system design based on the remote and proximal information sharing scenarios inclusive of the patient and healthcare communities. The design of a patient information sharing application is presented along with patients' preferences for remote sharing using their representatives; a usefulness evaluation via interviews is also presented based on physicians' point-of-view. We attempt to answer the first two overarching questions:

- *What are patient preferences to include representatives during remote information sharing in the event they become incapable?*
- *How can we improve the patient information sharing during interaction between physicians and representatives within EDs?*

5.1 Overview

Healthcare facilities in Japan are divided into primary, secondary and tertiary levels [69, 70]. We chose to base our study on a tertiary level ED within the aim of addressing the second overarching research question highlighted above. Studies have reported efforts to improve information sharing between capable patients and HCPs [26]. In Japan, mhealth solutions such as the SHACHI system allow patients to share their clinical patient information with third-party healthcare facilities [6].

Patient privacy concerns are important issues to address when at the design stage of patient information sharing systems such as EHR and PHR systems. Meaningful use of patient-centered information sharing systems can be jeopardized in the presence of mistrust of patients. A key component in creating trust in accessing records is individual control over who can gain access to described personal information [52]. More in-depth explanations about studies relating to the concepts “privacy” and “privacy concerns” are located in Appendix A.

For concerned patients, EHR systems linked to PHR systems have allowed physicians to access patient information that patients chose to share prior to emergencies. “Break-glass” access provides HCPs with access to EHRs and PHRs in situations when patients are in a life-threatening situation. [49, 80].

Physicians have benefited from improved information sharing during interaction with capable patients. However to the best of our knowledge, in the context of patient information sharing, no study has focused on improving the information shared by patient representatives within the ED setting. A gap exists in the research regarding the use of socio-technical systems for patient information sharing from the patient representative in incapable patients. Some studies have discussed the patient representative in the domain of shared decision making [45, 81]. To date, no research has introduced active socio-technical role of the patient representative in the context of patient information sharing. Additionally, no study has reported about physicians’ perceptions of the patient representative during information sharing.

5.2 Objectives

Previous systems addressed patients’ privacy concerns relating to their medical record; however, their focus was patient involvement and does not consider options for active sharing of patient information using patient representatives. Socio-technical systems require social involvement to be effective. Drawing upon the principles of patient-centered care outlined by Gerteis et al. [82], our research questions are as follows: How can we allow patients to have their preferences for control and awareness be preserved in the event they become unconscious? What are patients opinions about using their representatives to control access to their clinical information? How do we improve the interaction between physicians and representatives based on patient preferences? In an attempt to answer these questions, our objectives are as follows:

1. Propose a socio-technical system design for concerned patients control and awareness

2. Introduce patients' trusted representative within system design for incapable patients
3. Evaluate patients' acceptance of using their representative
4. Propose a conceptual design to improve interaction between physicians and patient representatives based on observation findings in Chapter 4.2.
5. Gather emergency physicians' perspectives about their experiences and opinions about the patient representatives.
6. Obtain feedback from physicians about the proposed conceptual design outlined in objective 5.

The above objectives were achieved through patient-based surveys, along with physician-based semi-structured interviews and a usability evaluation of the design concept for remote and proximal patient information sharing. In this study we focus on using the patient' s representative, an information source that can contain various people who are assumed to have a close relationship with patients before an emergency situation occurs.

5.3 System Design

We designed a system that includes the representative as an alternative person who can grant access to the requesting physician if the patient is unconscious. This is a patient centered access control approach for patients concerned about control and awareness of their medical data to opt-into if desired. The difference between our approach and previous systems designed to share patient information is the introduction of patients' representatives in the system design to actively share patient information with HCPs[1] several features in the event a concerned patient becomes unconscious.

The system we propose entails each patient having access control that enables physicians' access to a patients' medical record when authorized by the patient or by the patient' s designated representative when the patient is incapable of sharing their information. Access cannot be granted without awareness of the request and activities regarding use of the patients' medical data. This socio-technical design is based on increasing access control and awareness for concerned patients which in turn can reduce privacy concerns that can affect the trusting beliefs of patients in EHR systems.

The designed mobile application system is focused on the first two stages (admission and treatment) of the patient's journey (Table 4.1); this design was made based on our

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[1] In this case, we focus on physicians throughout this thesis

observations and discussions with physicians, discussed in Chapter 4. In the context of patient information sharing, we focused on admission and treatment stages where physicians interacted initially with patient representatives to obtain patient information. During these stages, physicians engaged in extensive patient information seeking behaviour before a more informed diagnosis could be made during the diagnosis. The following design hypotheses (DH) formed the basis of our design concept:

- *Concerned patients will want control and awareness options for information sharing between representatives and physicians* (DH1).
- *Physicians will accept using the system while interacting with representatives if it is easy to use* (DH2). A busy physician requires simple but effective interactions that can yield the desired patient information. We assume that during interaction with representatives physicians will want to use our proposed system if it is easy to learn and use.
- *Physicians will accept the proposed system if it seamlessly supplements the current interaction process that occurs between physician and patients' representatives* (DH3). Since the ED setting has many stressful situations, introducing a new system should not add additional troublesome non-clinical tasks to physician's workload [83].

The remainder of section presents an explanation of the elements that contributed to the designed mobile application for proximal information sharing.

5.3.1 Target Community Stakeholders

The process of including stakeholders in the design of our system was taken from the end user point-of-view as outlined in the Dolphin system [65]. Within the scope of our design process, we will focus only on the end-users and disregard other stakeholders. Including patients' representative gives a concerned patient flexibility of choice. To establish more focus to the design process, instead of all HCPs, physicians will be the only medical professional included at this point of our design. Therefore, the three stakeholders determined to be involved within the scope of this research are the physician, patient, and representative.

Patient The system design is patient-centred since a patient determines who will be added as a representative. The patient will also choose what the representative can do with their information. In our research, after discussions with emergency physicians, the following states deem a patient to be incapable [84] in the context of patient information sharing:(1) unconsciousness based on Glasgow Coma Scale or Japan Coma Scale, (2) inability to speak, (3) inability to speak and move, (4) psychological disorders and (5) mental state where conscious judgement is impaired, e.g. alcohol intoxication. The following statement summarizes the current target incapable patient during this design process:

“An adult who has a representative and has added them using our system. During emergency, is currently in admission or treatment stage; conditions are *unconscious* or *cannot speak/move*”.

We chose to use the capable-incapable classification instead of the conscious-unconscious classification because a patient can be conscious and not capable of transferring data to physicians due to different factors. The incapable classification includes more scenarios where the patient is unable to share their information verbally or physically. Another assumption is that if patient is capable of consent, they will be capable of sharing their information verbally [85];

Attending Physicians HCPs require an efficient and secure way to obtain patient information that has the least possible effort since searching for patient information is not the core of the treatment and diagnosis process [68]. As the capacity of an ED increases, the problem of continuous searching for patient information that cannot be accessed through the system in the hospital will increase. Hospitals provide facilities for physicians to treat patients. Hospitals house various technological tools [86] to support physicians and other HCPs. Since the patient information has to be viewed on a device that is managed by the hospital, hospitals must be included at the system design stage. The following statement summarizes our current target of HCP during this design process:

“A physician who is interacting with representative; this physician requires demographic and medical information about current incapable patient in the ED”.

Representative Within an *contextual* role, representatives will share patient information if the patient is incapable of doing so themselves. The representative is seen as someone the patient trusts (family member, friend caregiver, close friend), and this role of acting on behalf of the patient is seen as an extension of the patient. The representative is considered a vital subset of the patient community. Based on the *contextual* role of sharing patient information, the healthcare community and patient community are joined into one role, the patient representative. The following statement presents our description the current target representative during this design process:

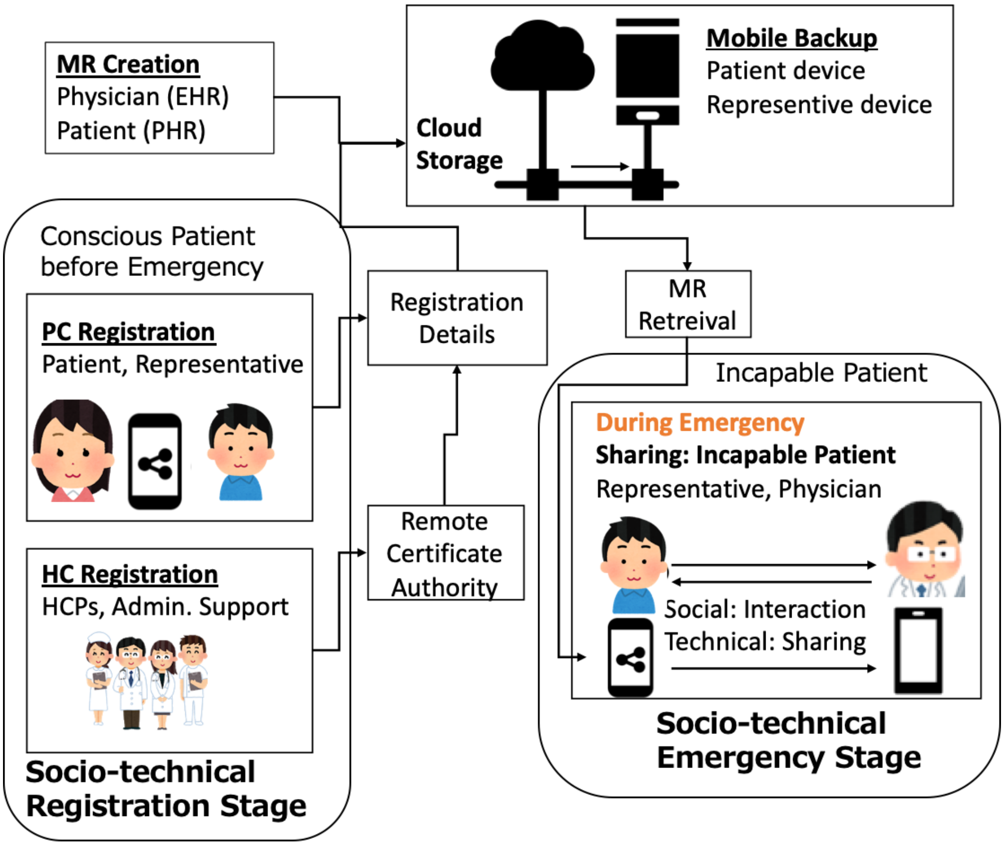


Figure 5.1: Overview of proposed system allow representatives to share patient information (MR) with physicians; the emergency stage is assumed the be the first point of contact between representative and physician

"A chosen entity in patient or healthcare community who is located inside or outside the ED; in the emergency situation, they can be identified and contact (interact with) HCPs in the ED."

5.3.2 System Stages

An overview of the system designed for proximal sharing is illustrated in Figure 5.1. This design for proximal information sharing extends the requirements outlined in Section 5.3.6 in the previous chapter. Central to realizing this system are social and technical requirements. Socially, trust and community support are vital components while technically, security, privacy, efficiency and cost-effectiveness are also important. Additional regulatory requirements are also required to ensure that the role-based preferences of healthcare and patient communities are considered. Policies are necessary before the system is fully realized. The aforementioned requirements will be explained in subsequent sections.

Registration Stage In this system design, the patient’ s active role is during the registration stage before the emergency. We assume the patient is anyone who possess a basic reading literacy level; patient registration options are named based on the actions of the representatives during interaction with physicians. The necessity of this stage was considered from recent changes in focus of healthcare systems to being patient-centred, with the patient having more control over their clinical patient information [4, 87], and with the support of relevant authorities [88]. A patient is assumed to want granular control over some parts of their shared information, even during emergencies [89]. At this stage, a patient adds a chosen representative. This representative can be a trusted family member, spouse, relative or close friend. The mobile application used by physicians is assumed to be used on a smartphone which is owned by the hospital. Using a remote certificate authority described by Ming et al. [80], physicians are registered to reduce the risk of unauthorized physician registrations. The design of the representative registration was created as part of the layout of our system as shown in Figure 5.2. In our design, we assume that the patient initiates the representative registration process from their device. A contact detail of the potential representative (PR) is entered by the patient. Upon submitting the PR’ s contact detail, the system sends a notification to PR with the two options. The PR can either accept or deny the role of representative for the patient. At the end of both options, the patient is notified about the result of PR’ s decision. In our design, the PR signs into our system if they are already registered as a representative for another patient instead of registering as new representative.

Emergency Stage During the emergency stage, i.e., interaction between physician and representative, the patient is assumed to be incapable of sharing patient information with physicians. If a patient is capable of sharing their patient information, there is no need for the representative in our system. Based on patient’s preferences, representatives share patient information with physicians. After patient information is shared with physicians, the representative can revoke access rights based on patient preferences defined during the registration phase. In this system, the representative role does not allow them to see patient information, but they are able to share the information with physicians and revoke access to information depending on the design features chosen by the patients.

5.3.3 Design Scenarios

Within the scope of this thesis, the remote sharing and proximal-based scenarios with appropriate alternatives were designed to test our design concept (Figure 5.3). The stakeholders are assumed to be registered and logged into the system using a username

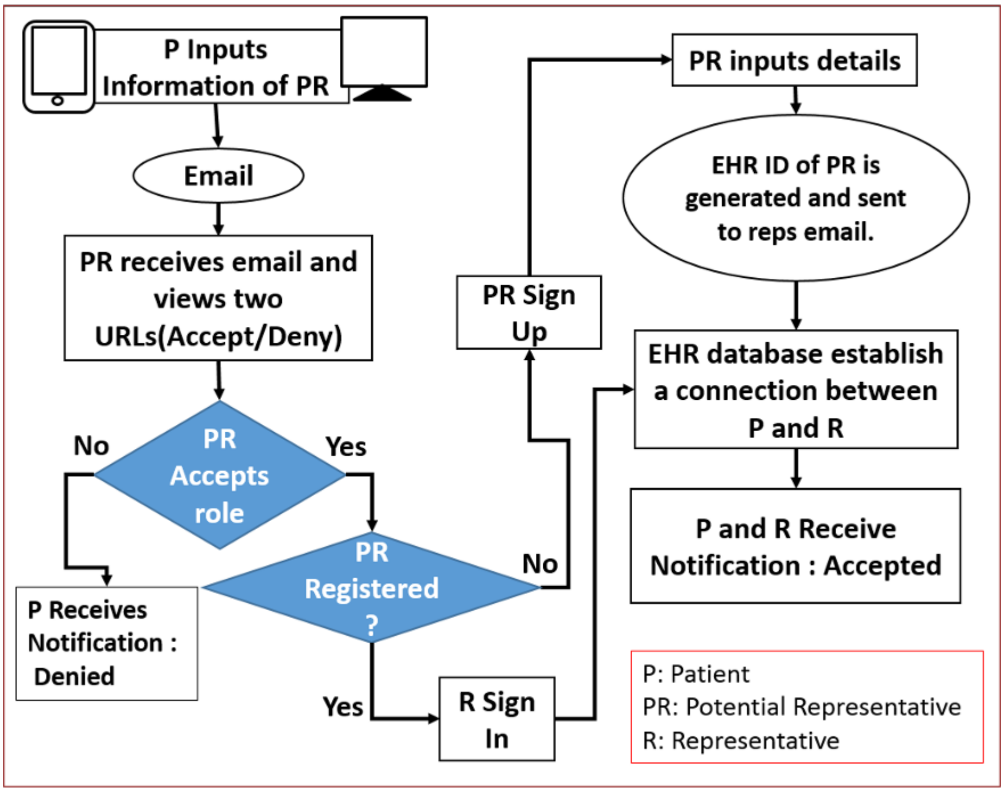


FIGURE 5.2: Illustration of representative registration process in our system.

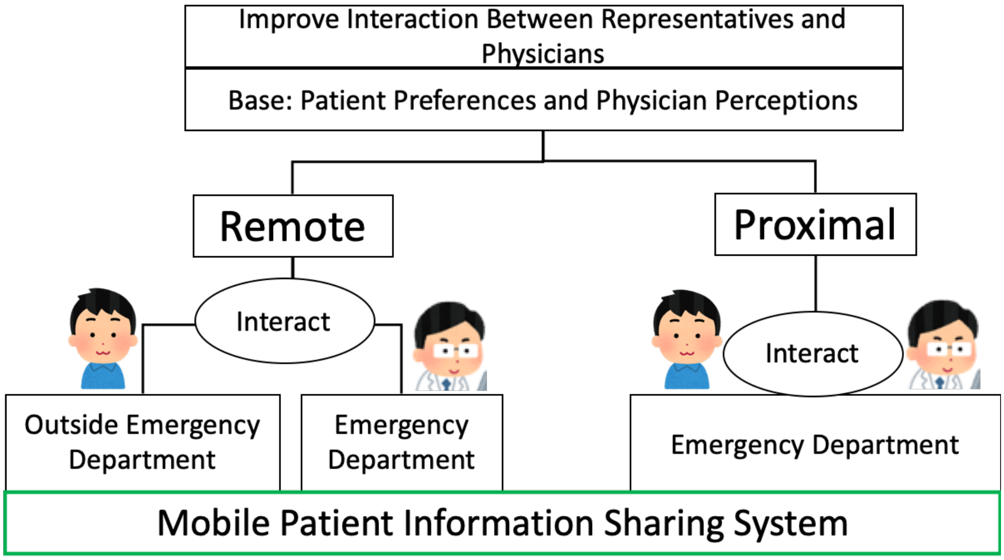


FIGURE 5.3: Two main scenarios of focus based on findings in Chapter 4

and password before the beginning of each scenario. Figure 5.4 shows an overview of the scenarios for patient information sharing and is primarily focused on the remote and proximal representative in the event a patient is unconscious.

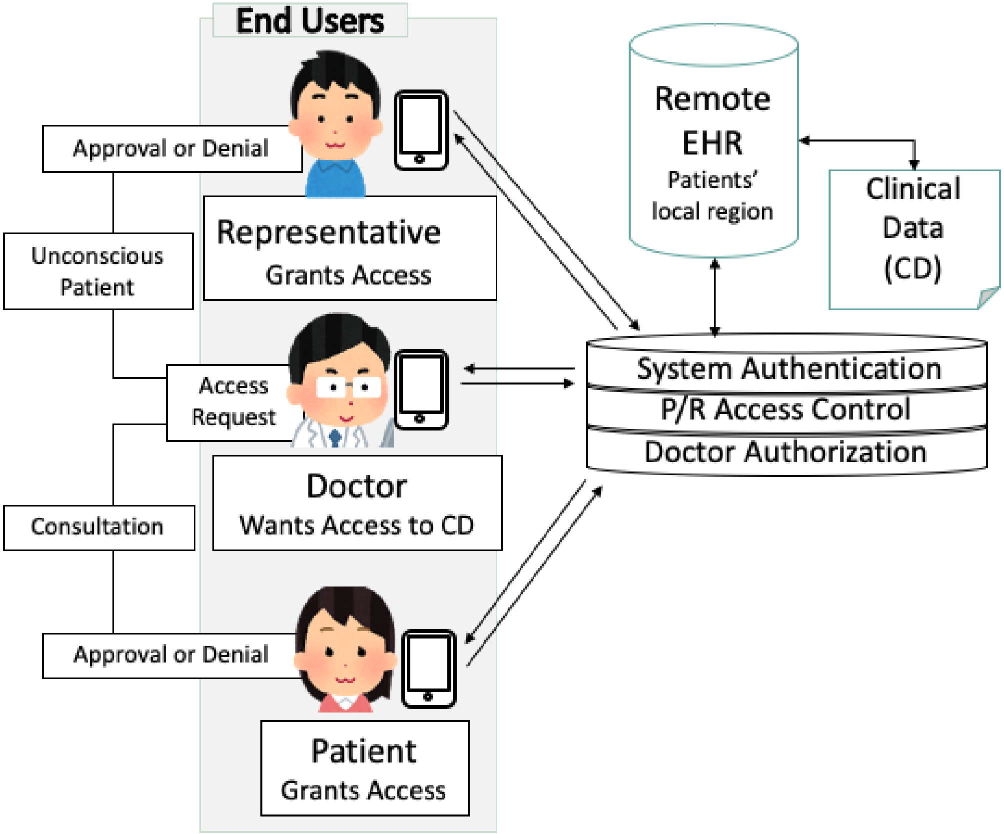


FIGURE 5.4: Overview of scenarios for patient information sharing; representatives can be in a remote location or proximal to physicians

5.3.3.1 Scenarios for Remote Information Sharing

Design of this system is based on whether the patient is capable or incapable of controlling access to their medical record. Most of the scenarios which are based in Japan focused on incapable patients, as mentioned in Section 5.3.1; one scenario focused on capable patients who are concerned about control and access to their medical information. The following scenarios for remote information sharing (RS) are shown as follows:

Conscious Patient Scenario (RS1) The patient and physician are the main stakeholders with the patient initiating the process. There is no need for the representative since the patient is conscious and can make their access decisions about their medical information. This scenario was included based on DH1. Based on the previous studies, we assume that concerned patients will also want control when they are conscious and interacting with physicians. This scenario assumes that concerned patients will want to use our system for remote or proximal information sharing. The patient is physically close to the physician during the consultation. A random code (RC) can be used by patients who do not want to use their ID information. They can use this code to assist the physician in identifying their basic information (name, age etc.). Alternatively (RS1A), the patient and the intruder (impersonator of physician) are the stakeholders involved. The representative is not required in this scenario since the patient is conscious and can make their access decisions. The patient, who is does not require medical treatment, denies the request received.

Unconscious Patient Scenario (RS2) The representative and physician are the main stakeholders with the physician being the first stakeholder to initiate the process because patient is unconscious). The number of representatives the patient can have is not defined because it is outside the scope of our approach; however, a minimum of one representative is needed for situation two to be realized. Alternatively (RS2A), the representative and intruder (impersonator of physician) are the main stakeholders. The patient is not directly involved in this access attempt. The representative, who is aware that there is not any situation which requires use of the patient's information denies the request received.

Unconscious Patient Scenario: Life Threatening (RS3) Similar to RS2 the representative is in a remote area but the condition of the patient can be potentially fatal if not addressed with the first two hours after the emergency situation.

5.3.3.2 Scenarios for Proximal Information Sharing

Personas and scenarios (PS) were created because the emergency setting is unpredictable and has many situations (Appendix E); this strategy also allowed us to have a deeper discussion with physicians about their patient information requirements of physicians using specific cases. Figure 5.5 illustrates the three main scenarios used.

Patient is unconscious based on the GCS/JCS (PS1) Originally from Chiba, Mayuko (39 years) came to Kyoto after accepting a job offer at a famous university in Kyoto. There, she met and married Fela, her current husband. After having her first child, Mayuko has been exercising regularly since the pregnancy weakened her abdominal region. One day during an exercise routine at the gym, Mayuko had a headache and collapsed at about 18:00. The staff immediately called the emergency services and put Mayuko in the ambulance at about 18:30, then took her to the nearest available hospital. During that time, Fela was contacted by the paramedics; he immediately left his job on route to the hospital. Fela arrived at the emergency department at 18:55. Since his Japanese was good, he was able to converse with the attending physician. During the conversation, the physician wanted Mayuko's information. Fela shared a contact card

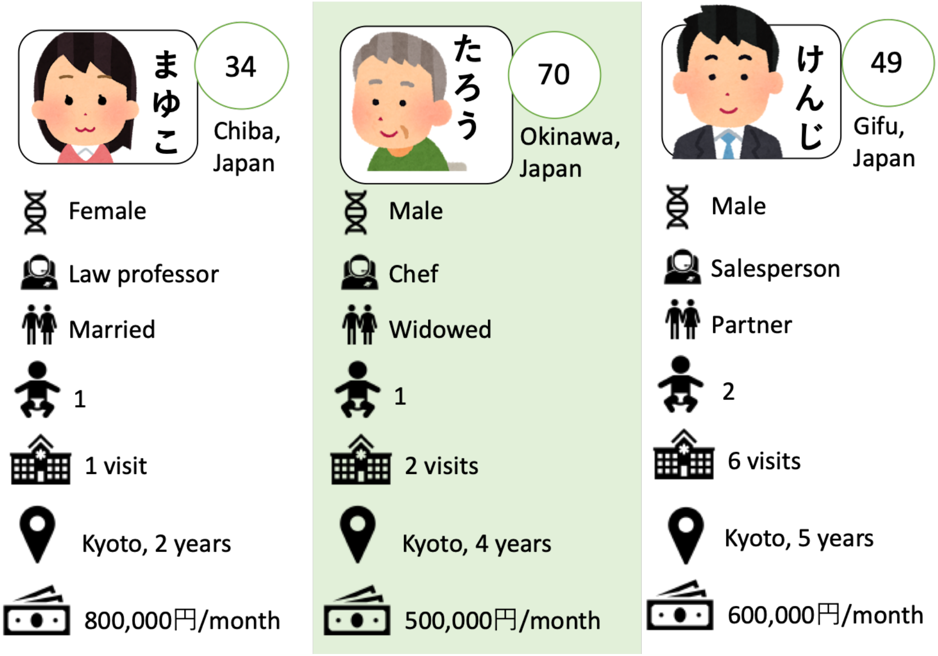


FIGURE 5.5: Personas created for use case scenarios shown in Appendix E

for Mayuko's hospital in Chiba along with her medication history book (known as "お薬手帳" in Japan).

Patient is conscious but has a psychological disorder (PS2) Taro is an elderly patient (70 years) who is attend to by two caregivers("介護士") per week. As usual, Taro was put to bed by the caregiver at about 20:00, after which Taro drifted off to sleep. Around 23:00 during an unpleasant dream, Taro fell of the bed. Erika, the caregiver on shift, who was sleeping in the adjacent room was awakened. She called the emergency services and accompanied Taro to the nearest available hospital at about 23:20. During admission at 23:55, Erika spoke with the attending physician who wanted Taro's information. Erika shared the contact information for Taro's primary care hospital; that was the only information she had at the time.

Patient is conscious but can speak or move (PS3) Kenji (49 years) is a salesperson from Gifu who has been living in Kyoto for five years. Recently, Kenji has been having above average stressful experiences at his place of employee since his target sales has been falling below expectations. Combined with his personal problems, Kenji has been contemplating suicide. One day Kenji overdosed on prescription drugs and was found unresponsive by a close co-worker at his office. His coworker, Megumi, called the emergency services at about 17:21 and accompanied Kenji to the nearest hospital. At 18:05, during admission, Megumi spoke with the attending physician. She did not have any information to share with the physician. Although Kenji and Megumi are close friends, he would not want her to know his medical information.

5.3.4 System Features

5.3.4.1 Mobile Application: Healthcare Community

HCP Account Creation To create accounts for HCPs, a website will be used with a UI dedicated to system administrators of a remote certificate authority. The system administrator will perform a background check on each HCP and collaborate with hospital administration to create hospital based HCP and administrative support accounts. Identification information of the new account is inputted, and the server generates a new userID and temporary password.

User Login This is done by healthcare community users (physicians, nurses, and administrative staff) the first time they open the application or if the previous authentication information has expired. If the initial temporary pass has not been changed, the user must change their password. An existing user indicates their username and password and submits the information to the server. After a 'successful' response from the server, the authentication information is saved for future sessions.

Refresh Session A refresh is done when the user opens the mobile application. If a valid token is present, the application client will contact the server to refresh the session. When the server receives the refresh request, it updates the last access timestamp of the user. If the token is expired, then an error is returned.

Request Patient Information The HCP user scans a QR code that identifies the patient and/or the representative. Alternatively, the user receives a token via near field communication (NFC). The server sends a notification to the representative and patient's version of the application. On their smartphone, the representative or the patient can either accept or reject the request, and this response is sent to the server. If the request is accepted, the HCP user receives requested data which is limited to their permission based on their professional role. If the request is rejected, an explanatory message is shown to the HCP user. If the request times out, an error message is displayed.

Additional Users can change their password or request a password reset. During reset, the HCP user submits their personal and professional information to the server which generates a temporary password after checking the registered information.

5.3.4.2 Mobile Application: Patient Community

Account Creation This is done by patients and representatives. The user inputs their basic information, non-existing username and password, and submits the information to the server. If there is no error on the input, the server creates a new account. After a ‘successful’ response from the server, the authentication information is saved for future sessions.

Login This is done by existing users (patients) the first time they open the app or if the previous authentication information has expired. If the password is temporary, the user must change their password. An existing user indicates their username and password and submits to the server. After a ’successful’ response from the server, the authentication information is saved for future sessions.

Request Password Reset The user submits their personal information to the server which generates a temporary password after checking the registered data.

Patient Request to Add Representative The user (patient) locates another user (potential representative) by (1) their ID, (2) telephone number, (3) scanning a QR code that identifies another normal user or (4) a token received via NFC. The user submits the request to the server, and at this point the potential representative is added to the requested list. The server notifies the potential representative via a push notification who can accept or reject the request, after which the server sends a response to the initiator (patient). If the request is accepted, the new representative is added to the patient’s list of authorized representatives.

View Relationships The patient must be able to see their requested representatives and their authorized representatives. The representative must be able to see a list of their representee(s) (patients).

Revoke Relationship The patient must be able to select a specific representative from either list (requested representatives and authorized representatives) and revoke their permission. After the server deletes the relationship, the representative is removed from the list. A notification is sent to all involved users the deleted representative and patient via push notification.

Identifying Physician The representative selects the patient from a list of patients. A screen showing QR code which contains patient and representative identifiable information is shown to physician, who scans the QR code.

Authorization to Patient Information This is done by a user who is a representative. When the user receives a notification of request to access patient information from a physician, they can confirm the representee (patient) profile, the physician profile and the requested information.The user can then accept or reject the request.

File Transfer After seeing a patient data request from a physician, the representative can (1) grant access to physician using internet (the token and password must be correct before the file is accessed), (2) transfer patient data directly to the physician's mobile phone.

Additional Users can change password or request password reset. During reset, the HCP user submits their personal and professional information to the server which generates a temporary password after checking the registered information.

5.3.5 System Tasks: Representative and Physician Interaction

The steps included in the system were based on our observation findings in Chapter 4.2. Steps for remote sharing differ to proximal sharing although the same goal exists.

5.3.5.1 Tasks for Remote Sharing

The tasks for remote patient information sharing scenarios (RS1-RS3) are illustrated in Figures 5.6 and 5.7.

5.3.5.2 Tasks for Proximal Sharing

We considered the following steps aimed at proximal physician and representative interaction towards sharing patient information in the ED; the steps are explained using mockups:

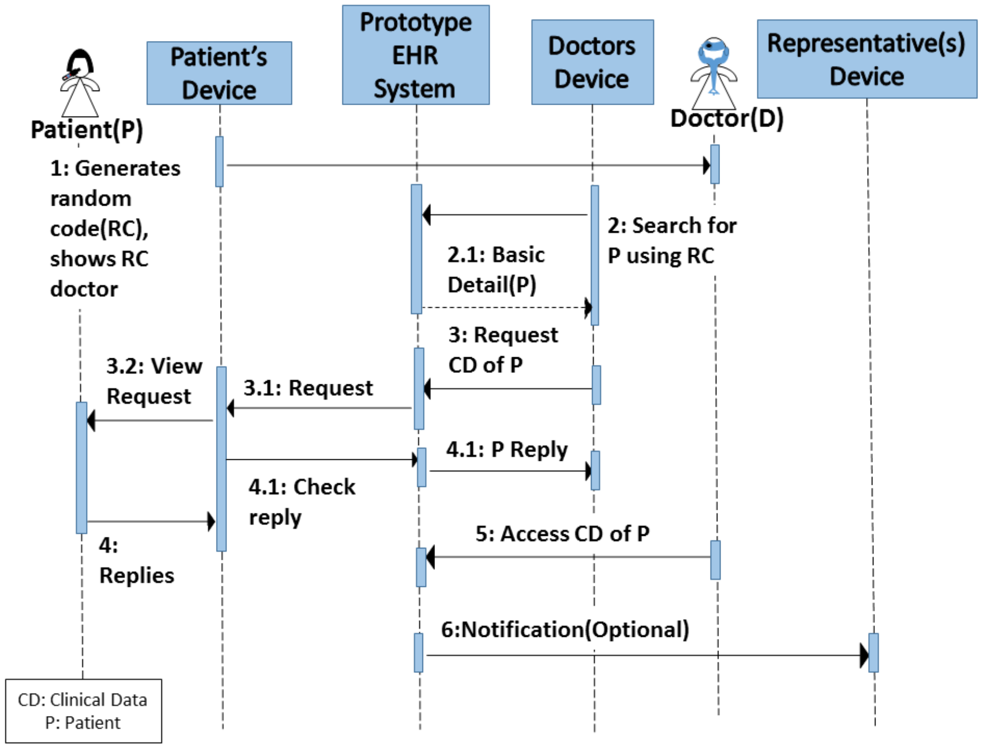


Figure 5.6: Process flow between physician and patient when patient is conscious, RS1

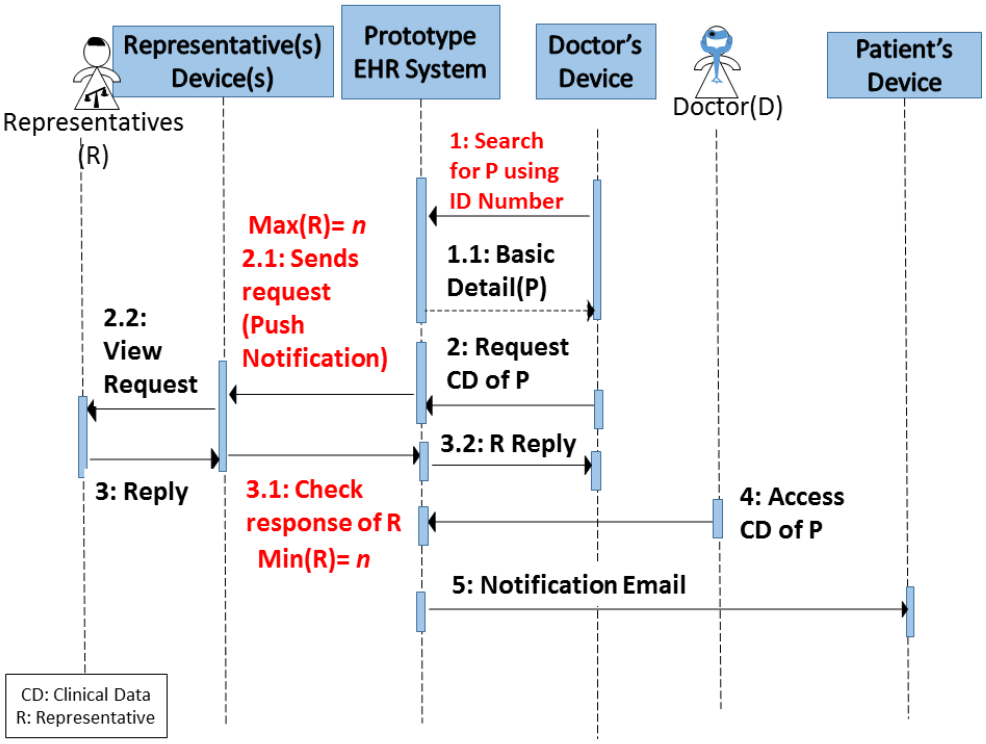


Figure 5.7: Process flow between physician and representative in RS2 and RS3

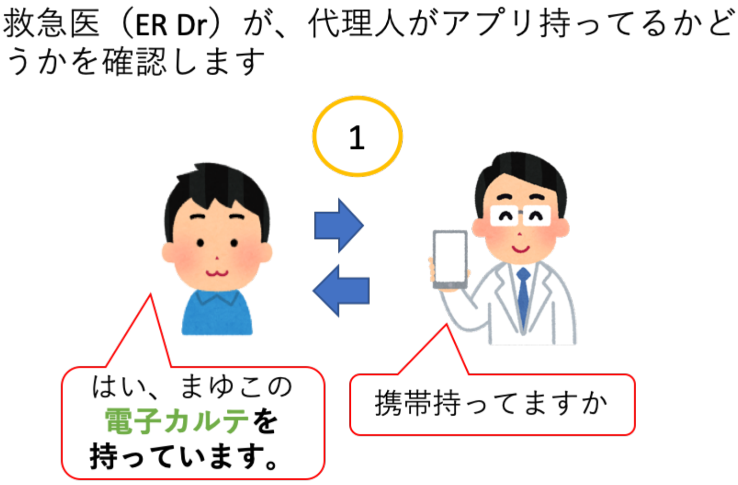


FIGURE 5.8: First step within Physician and Representative interaction process in our proposed system

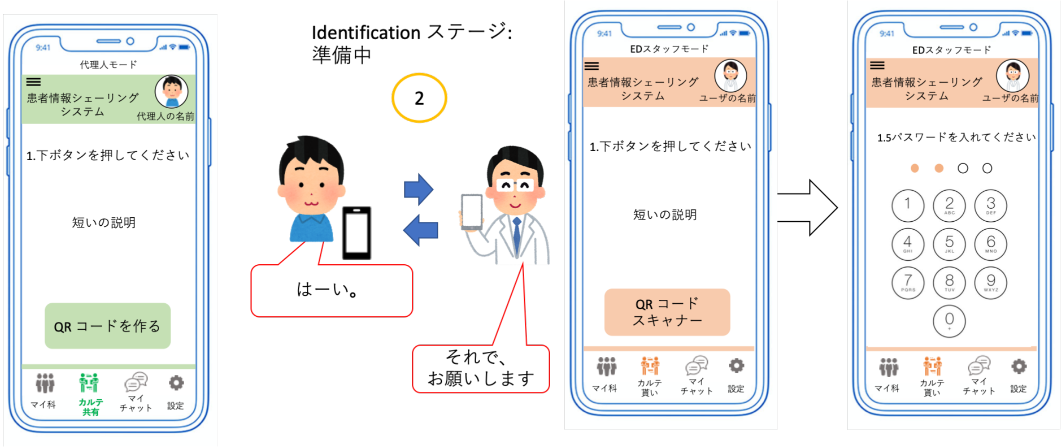


FIGURE 5.9: Second step within Physician and Representative interaction process in our proposed system

Step 1 The physician confirms that representative has the application installed on their mobile device (Figure 5.8).

Step 2 Both users navigate to the menu button to begin the technical interaction. Representatives will select the button that allows them to share patient information while physicians select the button to begin receiving patient information; physicians are now subject to two factor authentication. In this case, physicians will use a four-digit PIN number which is separate from the username and password used to sign into the application during their shift in the ED (Figure 5.9).

Step 3 Representative selects the patient whose information they will share and the QR code containing the system IDs of the patient and their representative is generated.

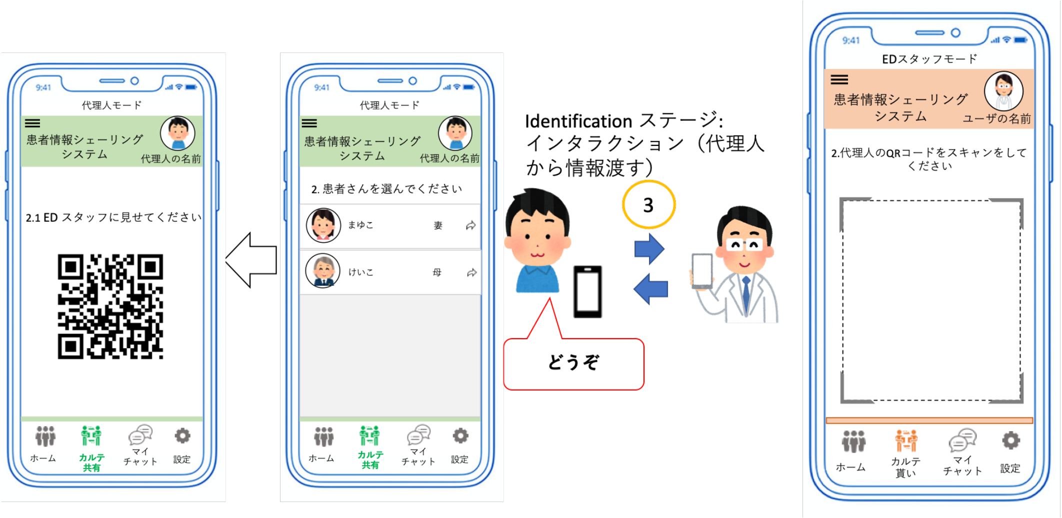


FIGURE 5.10: Third step within Physician and Representative interaction process in our proposed system

FIGURE 5.11: Fourth step within Physician and Representative interaction process in our proposed system

Since it is assumed that the representative is interacting with the physician for the first time, the QR code will be used by the physician's application to search for the basic information of both the patient and their representative. At the same time, the physician's QR code scanner will be shown on their mobile device (Figure 5.10).

Step 4 Physician can view the basic information of the patient and confirm that the person who they are interacting with is the representative for the assumed incapable patient. The representative can view the information about the physician that includes their medical license. Representative can share patient information after being authenticated using a four-digit number (Figure 5.11).

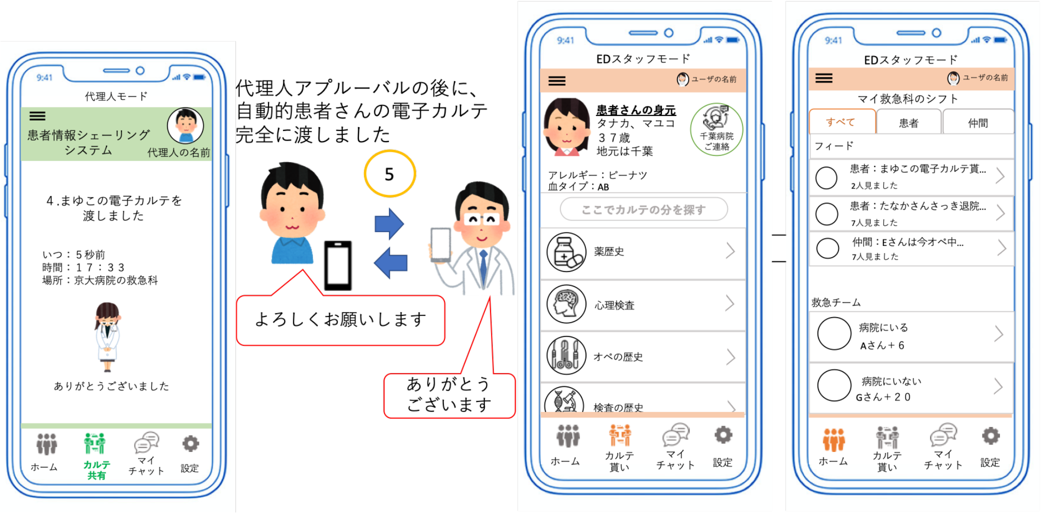


FIGURE 5.12: Fifth step within Physician and Representative interaction process in our proposed system

Step 5 Representative can view a notification screen about the interaction that occurred. Physicians can view the clinical information of the incapable patient. Although outside of our scope, for demonstration purposes a mock-up showing the status of other colleagues is also included (Figure 5.12).

5.3.6 System Requirements

The control and awareness of the patient is the core of this research to reduce privacy concerns since these factors ensure the privacy of concerned patients [90]. When applied to healthcare, our approach is based on the authorization of a physician accessing a patient’s clinical data with permission from the patient or their trusted representative. The design of our socio-technical approach including patient representatives can supplement conventional EHR/PHR systems and is not aimed to be a replacement.

5.3.6.1 Social Requirements

Trust: patients must trust their representative to act on their behalf. The representative needs to trust physicians to maintain a professional access to patient information for the purpose of treating the patient. In some countries, lack of trust can hinder the implementation of a patient information sharing systems [4, 91].; the perceived barriers are more social than technical, i.e. technically, the implementation of a patient information sharing systems is possible but socially, opposing views of various stakeholders and privacy concerns by a fraction of citizens hinder successful implementation of nationwide EHR.

Community: our design concept assumes that a patient has at least one person they can trust to represent them during emergencies. Our current scope does not include patients who do not have a representative. The patient representative is seen as an extension of the patient in the system design; the representative must be assigned to a patient. Each stakeholder needs to be aware of their roles in the system before registration can be complete. Additionally, inter-community understanding is necessary to ensure the long term support and future implementation of our proposed concept. Trust between the patient community and healthcare community is necessary to make information available to physicians while considering confidentiality of patient information [92]. To support the technical part of the system, it is necessary that HCPs, patients and patient representatives have an understanding of the system at the registration stage to obtain meaningful use whole maintaining patient privacy [37].

5.3.6.2 Technical Requirements

Security and Privacy: although technical security mechanisms are needed to realize our system, they can only go as far as the awareness of the system stakeholders [37]. We consider patient privacy as not only a technical responsibility but also a social responsibility. This is the reason we used a socio-technical approach to designing a patient information sharing system using stakeholders' input from the design stage.

Efficiency: mobile patient information backup system is necessary to automatically update the patient and representatives' mobile device. This update will take place after a physician or patient updates patient information after a visit to a medical facility or online consultation.

Cost-effectiveness: developing countries need cost-effective systems while at the same time implementing citizen-centred healthcare systems. Implementation of complex patient sharing systems may also be a barrier for countries with less infrastructure to support these systems [32]. Our socio-technical technical system is proposed to be integrated in the current hospital information systems; the cost effectiveness of the design is a paramount consideration [29].

Additional regulatory requirements are also required to ensure that the role-based preferences of healthcare and patient communities are considered. Policies are necessary before the system is fully realized. To realize the proposed system design, the use of hardware and software components are required. The following are the factors for realizing our system design and achieving implementation.

5.3.6.3 Implementation Requirements

Software Requirements

1. Centralized database: with the centralized database system such as EHR/PHR system, a database is needed that is linked to the citizens' national database.
2. Email service: the patient should be notified whenever their medical record has been accessed.
3. Push notification capability: in emergency situations highlighted in the design of situation two, push notification is needed to alert the representative since they will not be expecting a request from the physician. The use of this feature presents two challenges that must be considered in our approach. One is certainty of representative that the request is a physician; the other is management of replies from more than one representative.
4. Mobile application: The mobile application needs the push notification capability in order to access the representative' s mobile device
5. Web portal: this is used for the EHR system to connect to the stakeholders'devices.

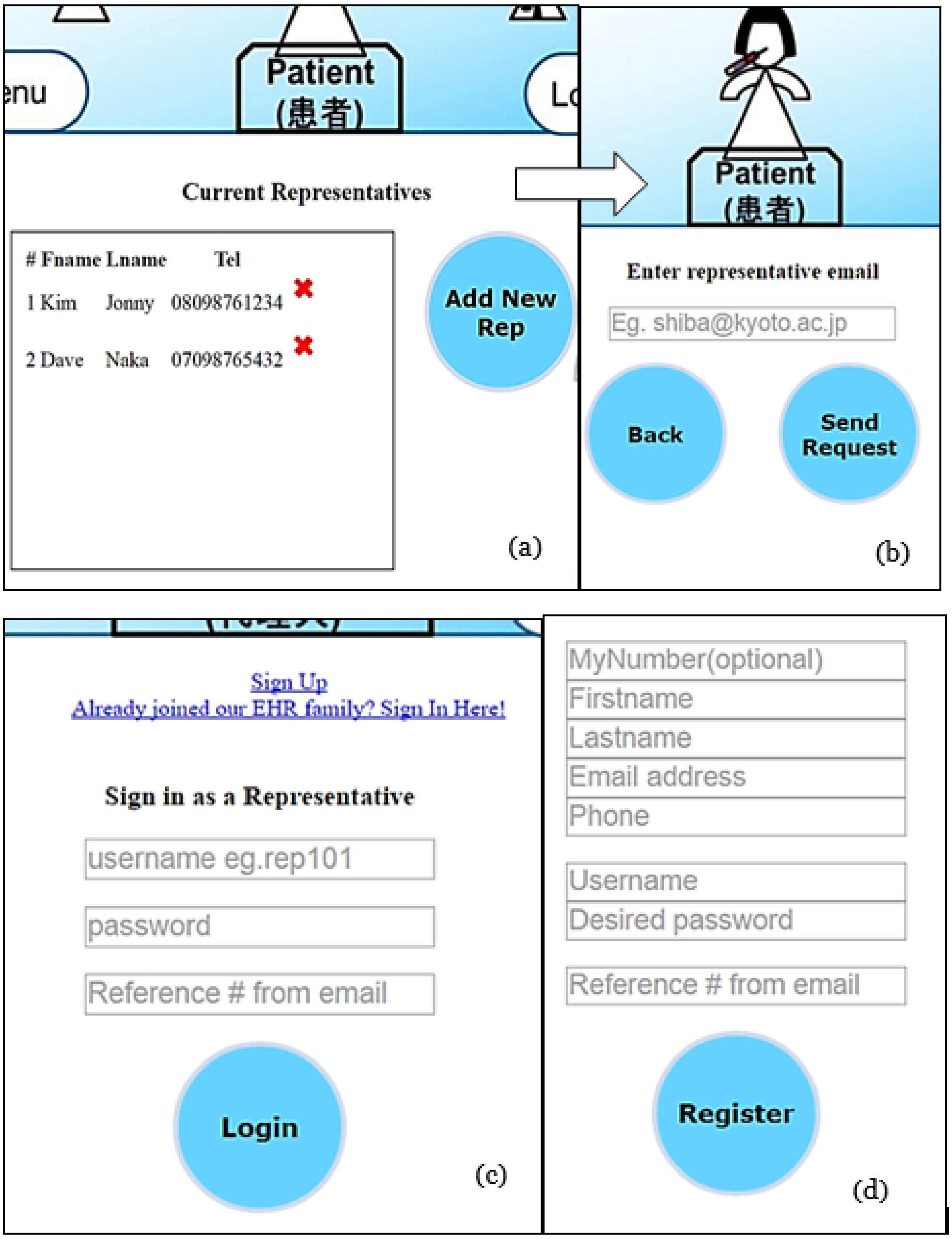
Hardware Requirements All stakeholders can use a mobile device. The representative needs a mobile device while the physician can have either a mobile or desktop computer device.

5.3.7 Prototyping

5.3.7.1 Remote Sharing

A prototype demonstration was created based on the above design specifications. This section contains the main views for representative registration, situation one and situation two. This demonstration was developed to illustrate our proposed approach. Additional explanation of the prototype is available in Appendix B.

Representative Registration In Figure 5.13, the patient can view their current representatives and can add a new representative (a). Patient enters the contact information for PR which in this demonstration is the email address of the potential representative (b). If the person is already a representative for other patient(s), they need to sign in with the random number sent to their email; then the patient will be added (c). If the



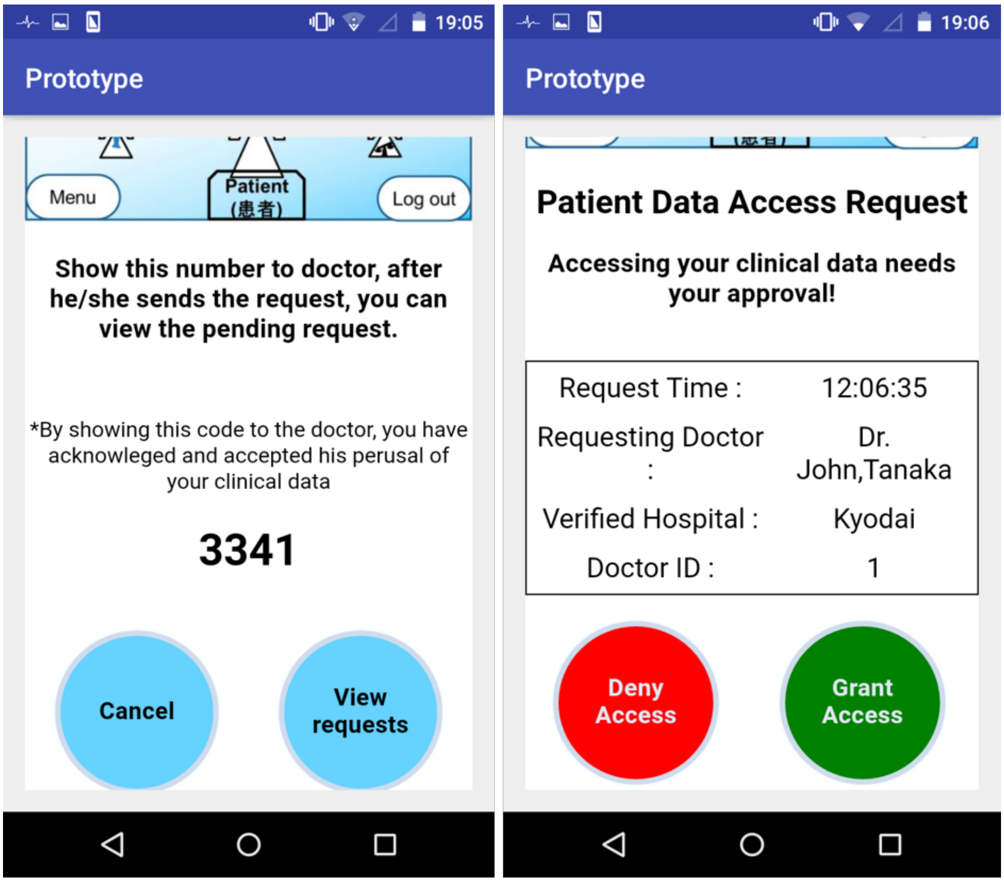
Current Representatives

#	Fname	Lname	Tel
1	Kim	Jonny	08098761234
2	Dave	Naka	07098765432

FIGURE 5.13: Representative Registration Main Views

person is not a registered representative, they can sign up with the option of not using their national IDs (d).

Remote Sharing Scenarios In Figure 5.14 the patient generates a random unique code and then shows it to the physician who, by using the random code (RC), requests the patients' medical record. Then the patient receives a request for the physician to access their clinical information. Figure 5.15 shows the physician using the patients ID



Show this number to doctor, after he/she sends the request, you can view the pending request.

*By showing this code to the doctor, you have acknowleged and accepted his perusal of your clinical data

3341

Patient Data Access Request

Accessing your clinical data needs your approval!

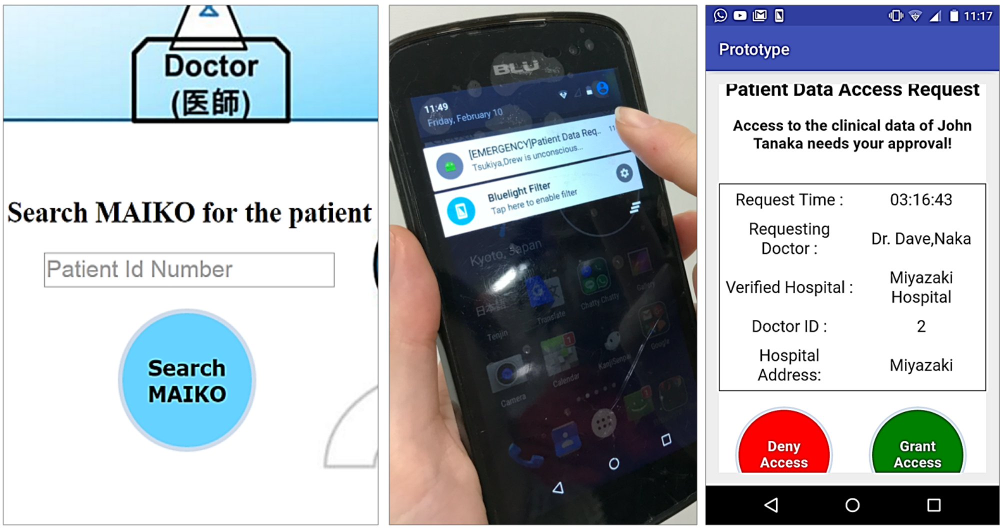
Request Time :	12:06:35
Requesting Doctor :	Dr. John,Tanaka
Verified Hospital :	Kyodai
Doctor ID :	1

FIGURE 5.14: Main patient views of RS1

number to perform a basic search of the patient. A push notification is sent to the device of the representative. Finally, the representative views the request from the physician.

5.3.7.2 Proximal Sharing

A low level prototype was developed with functionality focused on the interaction between physicians and representatives. The application developed for physicians differed from the one made for target representatives (Figure 5.16) in that the former contained a functionality to allow physicians to view patients' medical information. Patient information needs mentioned by physicians in the were used to categories of patient information. As shown in Figure 5.16, the physician selects button to activate QR scanner (top-left). The representative also selects the relevant patient from their list of patients (top-centre). The representative then shows a QR code to the physician who in turn scans the code (top-right). While awaiting the representative's approval, the physician confirms the identities of the incapable patient and their representative (bottom-left). After confirming the basic information of the patient and representative, physician can see patient information upon representative approval (bottom-right).



[EMERGENCY]Patient Data Req...
Tsukiya,Drew is unconscious...

Patient Data Access Request

Access to the clinical data of John Tanaka needs your approval!

Request Time :	03:16:43
Requesting Doctor :	Dr. Dave,Naka
Verified Hospital :	Miyazaki Hospital
Doctor ID :	2
Hospital Address:	Miyazaki

FIGURE 5.15: Attending physician sends a request to representative in RS2

5.4 Experiment (EX1): Assessing Patient Preferences

5.4.1 Overview

The patient-centred approach to our design gives rise to the need to address patient concerns and design a feasible system that is realistic for the healthcare domain. In this research, we will determine the feasibility of the use of the representative by the designing a system with the representative as a stakeholder. The patient centred nature of our research requires us to get feedback from members of the Japanese society to further justify and make changes to our system design if required.

5.4.1.1 Dimensions of Privacy Concerns to Assess

Since patient concern is subjective, a quantitative measurement scale was needed to evaluate patients’ privacy concerns [51, 93]. We chose to use the dimensions proposed by Malhotra et al. [52] which are concerns for collection, control and awareness. The focus of our system is to provide access control and awareness to patients about their medical data, and thus we chose to focus on the factors of control and awareness in the context of our system design.

- Concern for control: We used a system described by Malhotra et al. [52] to describe patient control of medical data.
- Concern for awareness: Foxman et al. [90] argued that information privacy only exists if someone has control over their information and is informed about activities

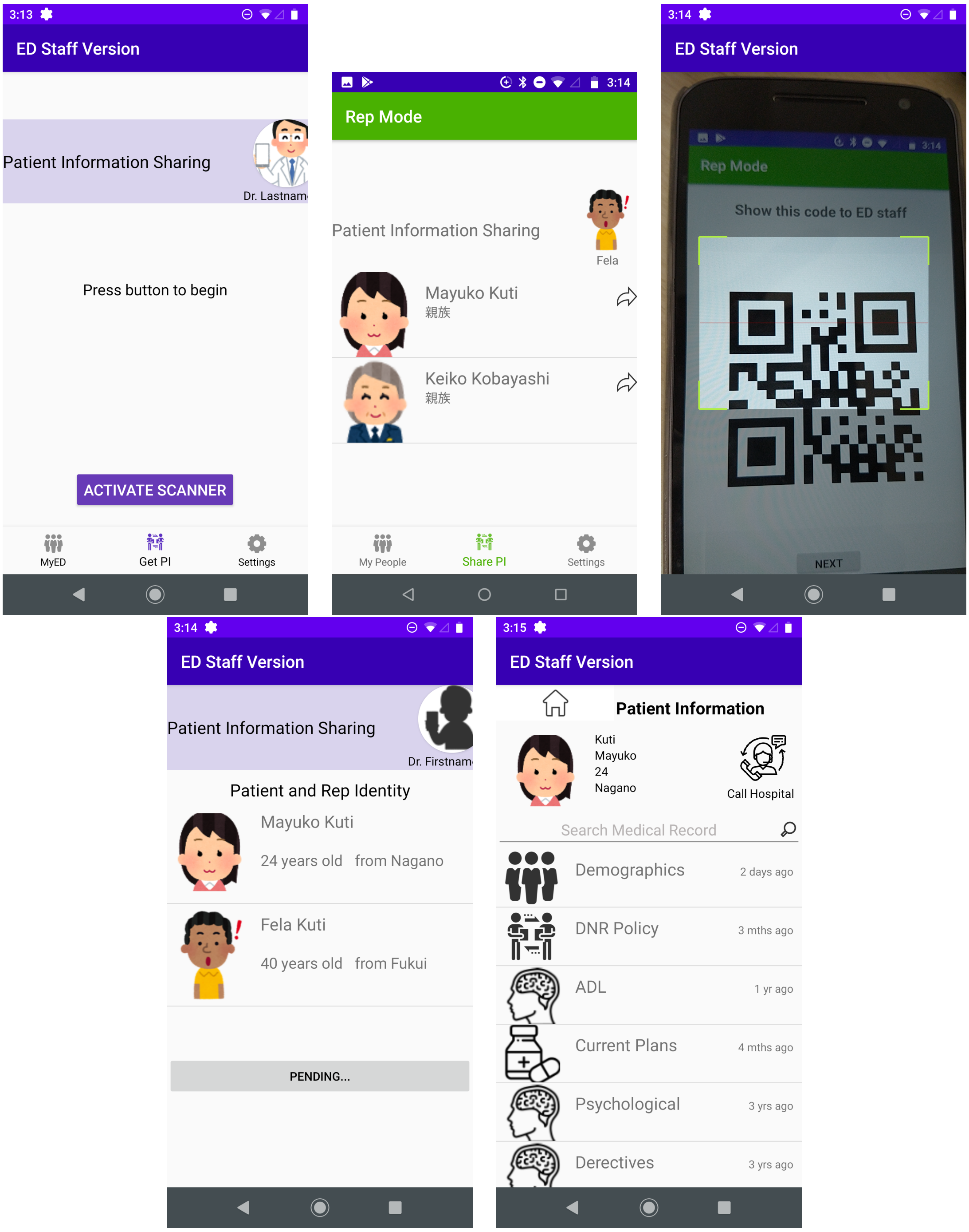


FIGURE 5.16: Screenshots showing physician's proximal interaction with representative using prototype

regarding their information. Our system design also focuses on this dimension, and thus it was adapted as part of this evaluation.

A factor that has been highlighted by previous studies is concern for collection of information [52]. This concern includes the merging of various data sources containing information about the individual into a central location. The culmination of the data leads to additional information being determined about the individuals' private life. For the evaluation in this research, we chose to omit concern for collection as a factor to evaluate. This is because in the context of EHR systems, the medical data are collected and centralized for adequate medical care.

5.4.1.2 Evaluation Criteria

Concern for control of information by patients is well established [4, 5]. A patient who is concerned about use of their medical data will want to act, which in this case will be access control. A conscious patient can make their individual medical decisions and should have the freedom to choose options relating to their medical data if desired. This led us to the creation of the following hypothesis:

H1-1: Patients concerned about control when they are conscious will choose access control

Some situations arise where the patient may need medical care but may not be in a mental or physical state to decide about release their medical data. The level of emergency can affect patients' decision-making ability [94, 95]. Thus, we assumed that with the assistance of a trusted patient representative, our system can provide the option to preserve access control choice of patients when they are unconscious. The level of consciousness of a patient varies and their decisions about access control may also vary depending on situations. For example, a patient may want control when they are conscious but not want control of their medical data if unconscious; another patient may be concerned about access control when they are unconscious but may not be concerned about such if they are unconscious from a life-threatening event. Measurement scales have been used to quantify the emergency levels and the level of unconsciousness of patients [94, 95]. We assume that in the cases in which our system will be used, the representative is someone the patient chooses; therefore, the level of control the representative is still determined by the patient. The need to know the impact of our system design on situations in the event the patient is unconscious but may still want access control led to the following hypotheses:

H1-2: Patients concerned about control in the event they become unconscious will choose access control via a trusted representative
H1-3: Patients concerned about control in the event they are in a life-threatening situation will choose access control via a trusted representative

The need to know the impact of our system design on situations where the patient is unconscious but may still want to be aware of activities relating their medical record after when they become conscious led to the following hypotheses:

H2-1: Patients concerned about awareness of activities regarding their medical data will choose to be informed about those activities
H2-2: Patients concerned about awareness of activities regarding their medical data in the event they become unconscious will choose to be informed about those activities

These hypotheses (H1 and H2) formed the foundation of the design and intention to evaluation our design.

5.4.2 Evaluation Method

5.4.2.1 Experiment Design

Since our system design was based on assumptions derived from the literature, the opinion and feedback from members of the Japanese population were required to further customize our system design for use in Japan. The covariate questions were related to the use of a smartphone, knowledge about using a smartphone and knowledge about security actions if a new smartphone is received (Appendix C). Three scenarios were created to reflect our hypotheses. These scenarios were RS1, RS2 and RS3. Henceforth, the questions will be referred to using the letter Q, e.g. Q1 will mean question one. Questions measuring the patient preference for control or no control were used for RS1. Questions measuring patients’ choice for representative control or no representative control (using an alternative), were created. The alternative that indicates no representative control was the use of an emergency card. This is a pre-registered emergency card we assumed to have a unique number that can be used to identify patients when taken from their personal belongings. The emergency card also assumed to be a key the physician can use to access the patient’ s medical record.

5.4.2.2 Survey Method

A commercial online survey organization was chosen to administer the survey. The survey period was from June 29th to June 30th, 2017. The sample population consisted of four groups based on their frequency of visit to the hospitals, as shown in Table 5.1.

5.4.2.3 Survey Analysis

Respondents were divided into several groups:

- Based on initial subgroups (n=310)

Table 5.1: Composition of designed survey; Age and Sex were excluded from covariates in the survey design

Frequency of Hospital Visits	Sample Expected	Sample Obtained
Often	94	97
Sometimes	94	97
Seldom	94	97
Never	18	19
Total	300	**n=310**

- Age groups

  Less than 65 versus 65 years and older (n=310)

  Based on the median age (47.7); 47 years or less versus over 47 years (n=310)

  Age ranges 20-49, 40-59 and 60-79 (n=305)

- Intra Scenarios

  Questions in each scenario to be compared with all other questions within the scenarios only

- Inter Scenarios

  Each question from one scenario to be compared with all questions outside of given scenario only.

The test for goodness-of-fit (χ^2) was used to determine the presence of correlation between the previously mentioned groups and every question except questions 1,2,3 and 15. This test is used regularly in statistical analysis to establish that there is correlation between variables. This test can be used for various sizes of the contingency table [96].

$$\chi^2 = \sum_{i=1}^{g} \frac{(n_i - E_i)^2}{E_i}$$

The equation above obeys χ^2 with g-1 level of freedom (ni = observed frequency, Ei = theoretical frequency).

The fishers exact test was then used to confirm the significance of the p value to be less than 0.05 [97].

$$p = \frac{((a+b)!(c+d)!(a+c)!(b+d)!)}{a!b!c!d!N!}$$

Variables 'a,' 'b,' 'c' and 'd' are the individual frequencies of the 2X2 contingency table, and 'N' is the total frequency. This test confirmed the correlation between the variables tested using the X2 test. Cramer’ s independent coefficient test (r_c) was then used to quantify the level of correlation between the variables that were significant [96]. This test results in a value ranging from 0 to 1 with 0 signifying no correlation and 1 signifying strong correlation.

$$r_c = \sqrt{\frac{X^2}{n(k-1)}}$$

n = sample size
k = number of categories

Residual analysis was then performed to determine which items in belonging to the variables contribute to the significant correlation between the variables. Using this analysis helped us determine the exact cell from which the correlation originated [98]. In this analysis, we used the adjusted residual (z).

$$z = \frac{f_0 - f_e}{\sqrt{f_e(1 - rowproportion)(1 - Columnproportion)}}$$

fo = observed values for a given cell in the matrix
fe = number of categories
rowproportion = total number of items a given row
Columnproportion = total number of items in each column

5.4.3 Results

Three hundred and ten respondents (age range: 19-91, mean age: 47.79, male: 50.3%) responded to the survey (Table 5.2); most respondents were users of mobile devices.

5.4.3.1 Patient Preferences

Control Preferences Less respondents concerned about control when they are conscious preferred representative control in the event they become unconscious, as shown in Table 5.3. The focus of our research was the patients who choose representative control in the event they become unconscious.

Preference for Awareness Based on Table 5.4, the respondents who chose awareness of any form instead of no awareness were considered as supporters of awareness, as shown

Table 5.2: Composition of respondents to the online survey

Variable		%
Sex	Male	50.3
	Female	49.7
Age Range	Over 60	21.6
	40 - 59	49.7
	19 - 39	21.6
Mobile Device User	Yes	81.3
	No	18.7

Table 5.3: Patient preference for personal (RS1) and representative (R) control (RS2, RS3)

Scenario	Information	Preference	%
Conscious Patient (RS1)	Basic	Control	59.1
		No Control	48.1
	Clinical	Control	61.3
		No Control	38.7
Unconscious Patient (RS2)	Clinical	R Control	30.0
		No R Control	70.0
Unconscious Patient-Life threatening (RS3)	Clinical	R Control	31.3
		No R Control	68.7

Table 5.4: Patient preference for personal and representative awareness

Scenario	Stakeholder	Awareness Preferences (%)			
		Full	Went wanted	Sensitive	None
Conscious Patient (RS1)	Patient	48.5	28.1	16.5	7.1
Unconscious Patient (RS2)	Patient	49	31.9	13.2	5.8
	Representative	28.1	23.2	30.6	18.1
Unconscious Patient (RS3)	Patient	48.7	28.1	16.5	6.8
	Representative	28.1	26.1	28.7	17.1

in Figure 5.17. These results suggest that our system design should have flexibility of access control of granular parts of the patient medical record to consider the varying privacy concerns expressed by respondents. The same level of granularity, in our design, can be applied to the choices of patients concerned about awareness.

Respondent Opinions Respondents who chose no representative control in the event they become unconscious, did so because of various reasons including their belief that

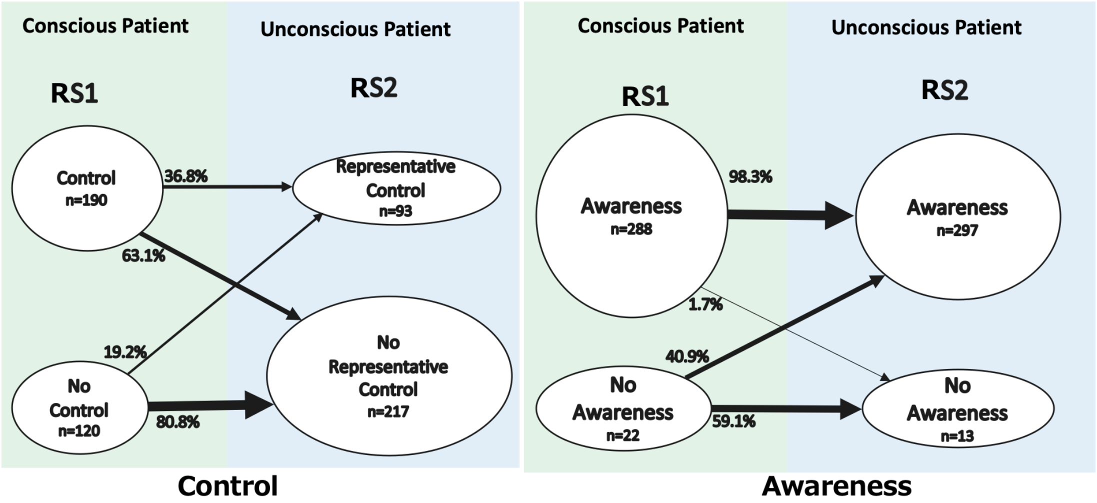


FIGURE 5.17: Relationship between the respondents' choice for control and awareness among scenarios; it shows the percentage of respondents who switched their preference for control in the event they become unconscious

life is more important than control over their information, their trust in the physician, and their belief that using the representative is troublesome among others. Some respondents chose no representative control because they believe that the alternative method (emergency card), is safer, easier and reliable. These respondents need to be considered in our system design since they may not prefer a trusted representative but may want to use an alternative form of control. Some respondents who chose representative control mentioned trust in the representative as their reason. Other respondents mentioned security concerns, safety concerns and that the representative gives them a level of certainty and peace of mind. The reasons expressed by this group of respondents support the design of our access control approach.

5.4.3.2 Significant Findings

Tables 5.5 to 5.22 show the residuals (z) for each cell of the cross tabulated variables. The column and row headings are as follows:

- Q -question e.g. Q1 signifies question one (Appendix C.3)
- Control -preference that requires the patients control (when conscious)
- No control -preference that does not require patient's control for (when conscious)
- Representative control (RC) -preference that requires representative control (when patient is unconscious)

- No representative control (NRC) -preference that does not require representative’s control (when patient is unconscious)
- Full -full awareness of activities regarding medical data; PA signifies patient awareness and RA signifies representative awareness.
- When wanted -awareness of activities only when requested by the patient
- Sensitive Only -awareness of activities regarding sensitive parts of medical record only
- None - no awareness desired

The options, “when wanted” and “sensitive only”, suggests respondent’ s preference for a granular level of awareness. The adjusted residuals are based on the following z-scores, (1) $|z| > 1.96$ ($p < 0.05$) and (2) $|z| > 2.58$ ($p < 0.01$). The following legend shows the colour codes used for the results.

Pearson Adjusted Residuals	z < -2.58	z < -1.96	-1.96 < z < 1.96	z > 1.96	z > 2.58

Intra-scenario Correlation Tables 5.5 to 5.8 show the significant intra-scenario correlations based on the survey questions.

Table 5.5: Scenario one where patient is conscious; correlation between questions 5 and 6

n=310		Q10 - Patient Awareness			
		Full	When Wanted	Sensitive Only	None
Q7	Control	3.048	-0.343	-1.025	-3.853
	No Control	-3.048	0.343	1.025	3.853

Table 5.6: Scenario two where patient is unconscious; correlation between questions 7 and 10; No Representative Control

n=310		Q10 - Patient Awareness			
		Full	When Wanted	Sensitive Only	None
Q7	RC	3.050	1.047	-2.613	-1.579
	No RC	-3.050	-1.047	2.613	1.579

Table 5.7: Scenario two where patient is unconscious; correlation between question 9 and 10

n=310		Q10 - Representative Awareness			
		Full	When Wanted	Sensitive Only	None
Q9 PA	Full	9.442	-3.041	-4.333	-2.498
	When Wanted	-5.906	6.349	0.439	-0.597
	Sensitive Only	-4.293	-2.590	7.432	-1.049
	None	-2.190	-2.404	-2.379	8.047

Table 5.8: Scenario three where patient is unconscious; correlation between question 13 and 14

n=310		Q14 - Representative Awareness			
		Full	When Wanted	Sensitive Only	None
Q13 PA	Full	9.262	-2.187	-4.358	-3.265
	When Wanted	-4.900	6.982	-1.670	-0.294
	Sensitive Only	-4.539	-3.949	9.941	-1.920
	None	-2.964	-2.308	-3.012	9.851

Inter-scenario Correlation - Preferences for Control Since the questions relating to control were contained in a 2x2 contingency table, the residuals are not needed to show significance. The results of the X^2 test show the significant items relating to control, as shown in Figure D.1.

Inter-scenario Correlation - Preferences for Awareness Tables 5.9 to 5.16 show the significant inter-scenario correlations based on the survey questions.

Table 5.9: Correlation between questions 6 (RS1) and 9 (RS2)

n=310		Q9 - Patient Awareness			
		Full	When Wanted	Sensitive Only	None
Q6 PA	Full	14.425	-9.971	-5.985	-2.289
	When Wanted	-9.522	13.615	-2.801	-2.730
	Sensitive Only	-5.212	-2.394	11.873	-1.285
	None	-3.888	-0.961	-0.594	11.087

Age Groups Tables 5.17 to 5.22 show the significant inter-scenario correlations based on the survey questions.

Table 5.10: Correlation between questions 6 (RS1) and 10(RS2)

n=310		Q10 - Representative Awareness			
		Full	When Wanted	Sensitive Only	None
Q6 PA	Full	6.805	-2.648	-3.690	-0.619
	When Wanted	-4.337	5.326	-0.456	-0.235
	Sensitive Only	-2.493	-2.121	6.437	-2.474
	None	-2.055	-1.105	-1.316	5.189

Table 5.11: Correlation between questions 6 (RS1) and 13 (RS2)

n=310		Q13 - Patient Awareness			
		Full	When Wanted	Sensitive Only	None
Q6 PA	Full	14.083	-9.636	-6.032	-1.882
	When Wanted	-8.947	12.262	-1.471	-1.958
	Sensitive Only	-5.468	-1.471	10.169	-1.496
	None	-3.857	-0.578	-0.370	9.251

Table 5.12: Correlation between questions 6 (RS1) and 14 (RS3)

n=310		Q14 - Representative Awareness			
		Full	When Wanted	Sensitive Only	None
Q6 PA	Full	6.552	-2.378	-3.533	-0.799
	When Wanted	-4.618	5.544	-0.553	-0.294
	Sensitive Only	-1.811	-2.554	6.555	-2.734
	None	-2.055	-1.384	-1.621	6.016

Table 5.13: Correlation between questions 9 (RS2) and 13 (RS3)

n=310		Q13 - Patient Awareness			
		Full	When Wanted	Sensitive Only	None
Q9 PA	Full	15.675	-9.775	-6.744	-3.751
	When Wanted	-10.047	13.886	-2.394	-1.312
	Sensitive Only	-6.699	3.547	14.134	-1.186
	None	-3.774	-1.649	-1.285	12.351

Group 1: respondents less than 65 and individuals 65 years and older (Table 5.17).

Group 2: respondents less than or equal to the median 47.7 and individuals older than 47.7 years old (Tables 5.18 and 5.19).

Table 5.14: Correlation between questions 9 (RS2) and 14 (RS3)

n=310		Q14 - Patient Awareness			
		Full	When Wanted	Sensitive Only	None
Q9 PA	Full	8.431	-2.771	-3.676	-2.410
	When Wanted	-5.364	-6.137	-0.383	-1.300
	Sensitive Only	-3.547	-2.943	7.867	-1.786
	None	-2.190	-2.047	-2.774	8.336

Table 5.15: Correlation between questions 10 (RS2) and 13 (RS3)

n=310		Q13 - Patient Awareness			
		Full	When Wanted	Sensitive Only	None
Q10 PA	Full	9.515	-5.181	-4.880	-2.416
	When Wanted	-2.979	8.021	-3.934	-2.610
	Sensitive Only	-4.011	-1.552	9.428	-3.155
	None	-3.035	-0.892	-1.279	9.521

Table 5.16: Correlation between questions 10 (RS2) and 14 (RS3)

n=310		Q14 - Representative Awareness			
		Full	When Wanted	Sensitive Only	None
Q10 RA	Full	15.637	-5.102	-6.420	-4.994
	When Wanted	-5.450	15.058	-5.848	-4.040
	Sensitive Only	-5.939	-5.278	15.175	-4.988
	None	-5.164	-4.245	-4.267	16.244

Table 5.17: Correlation between Group 1 and 14

n=310	Q14 - Representative Awareness			
	Full	When Wanted	Sensitive Only	None
age < 65	-1.804	0.088	2.668	-1.156
age >= 65	1.804	-0.088	-2.668	1.156

Group 3 The 20 -39 range consists of people who are 20 years and older but less than 40 years old. The 40 -59 range consists of people who are 40 years and older but less than 60 years old. The 60 -79 range consists of people who are 60 years and older but less than 80 years old (Table 5.20 to 5.22).

Table 5.18: Correlation between Group 2 and question 10 (RS2)

n=310	Q10 - Representative Awareness			
	Full	When Wanted	Sensitive Only	None
age <= 47	-2.149	0.538	3.080	-1.772
age > 47	2.149	-0.538	-3.080	1.772

Table 5.19: Correlation between Group 2 and question 14 (RS3)

n=310	Q14 - Representative Awareness			
	Full	When Wanted	Sensitive Only	None
age <= 47	-2.149	0.646	3.139	-1.961
age > 47	2.149	-0.646	-3.139	1.961

Table 5.20: Correlation between Group 3 and question 7 (RS2)

n=310	Q7	
	Representative Control	No Representative Control
ages 20-39	2.788	-2.788
ages 40-49	-0.680	0.680
ages 60-79	-2.280	2.280

Table 5.21

n=305	Q7	
	Representative Control	No Representative Control
ages 20-39	2.788	-2.788
ages 40-49	-0.680	0.680
ages 60-79	-2.280	2.280

5.4.4 Discussion

Patient preferences were obtained for representatives for control and awareness for themselves and representatives. The following section is a discussion of the findings. Additional discussion of the result can be found in Appendix D.

Cramer’ s Independent Coefficient (r_c) shows the level of correlation between variables. Questions relating control only do not need to be further analysed to find where the strength of correlation is coming from since a 2x2 contingency table was used (See Figure D.1). There were significant correlations between every scenario about the respondents concerned for awareness and their consistency of choices [5]. The correlation between

Table 5.22: Correlation between Group 3 and question 10 (RS2)

n=305	Q10 - Representative Awareness			
	Full	When Wanted	Sensitive Only	None
ages 20-39	-2.967	1.649	2.156	-0.943
ages 40-49	0.787	-0.772	-0.115	0.068
ages 60-79	2.348	-0.892	-2.272	0.971

the respondents' choice for control and awareness when they are unconscious further supports the hypotheses H1 and H2.

Figure 5.17 shows that less respondents who choose control of their clinical data in scenario one, chose representative control in the event they become unconscious. More respondents chose no representative control using an alternative method of access control. Respondents who chose no representative control, in the event they become unconscious, did so because of various reasons including their belief that life is more important than control over their information, their trust in the physician, their belief that using the representative is 'troublesome' . Some respondents chose no representative control because they believe that the alternative method (emergency card), is safer, easier and reliable. These respondents need to be considered in our system design since they do not prefer a trusted representative but want to use an alternative form of control. Some respondents who chose representative control mentioned trust in the representative as their reason. Other respondents mentioned security concerns, safety concerns and that the representative gives them a level of certainty and peace of mind. The reasons expressed by this group of respondents support the design of our access control approach for remote information sharing using patient representatives.

Fewer respondents concerned about control when they are conscious preferred representative control in the event they become unconscious (Figure 5.17). The focus of our study was the patients who choose representative control in the event they become unconscious. The tendency of respondents concerned about awareness in the event they are unconscious to choose the representative control and awareness points to the usefulness of our system if it were to be realized in society as an opt-in access control option for concerned patients. Furthermore, less than twenty percent of respondents preferred no awareness for their representative. The preferences of patients for awareness suggest that patients who do not prefer representative control may prefer awareness of themselves and their representatives. There was no significant correlation between the sub-samples and questions 4 to 14. Additionally, there was no correlation between the sexes and their preferences for control and awareness under the conditions in which this survey was performed.

Having established patients preferences for using their representatives, the following experiments, EX2 and EX3, present physicians perceptions about using patient representatives for information sharing.

5.5 Experiment (EX2): Assessing Physicians' Perceptions

In the previous experiment, EX1, we confirmed that a fraction of patients are willing to use their representative for remote information sharing. The results led us to infer that these patients will also prefer their representative for proximal information sharing with physicians. We have an idea about the opinions of patients, but the opinions of physicians are also vital since they are the ones that utilize patient information to improve patient safety of patients, despite privacy concerns. Based on this assumption, this experiments present perceptions of physicians for proximal information sharing with patient representatives and our proposed mobile patient information sharing system.

5.5.1 Overview

Semi-structured interviews are ideal for gathering the opinions of participants while simultaneously obtaining observational data to enrich data collection [59]. Semi-structured interviews were done to achieve the following: (1) clarify assumptions in observations mentioned in Section 4.2; (2) obtain deeper understanding of physicians' perception about their experiences with patient representatives; (3) gather feedback and understand perceptions of physicians about using the representative in our proposed socio-technical system concept described in Section 5.3.

5.5.2 Study Design

Interview questions were designed in collaboration with two physicians whose feedback were used to refine questions to fit the understanding of physicians using the Japanese language. Two translators and one physician assisted in translating the interview questions into Japanese after iterative discussions with collaborating physicians. The interviews were designed in two parts, Before Concept Introduction (BCI) and After Concept Introduction (ACI).

BCI focuses on gathering feedback about a representative and their role in the ED. Our goal in BCI was to understand physicians' perceptions and attitudes about representatives based on their professional experience. There is no mention of the design concept in BCI, and no hypotheses were made for BCI. Physicians were asked questions based on three simulated scenarios about their patient information requirements. BCI was focused on the experiences and opinions of physicians about their interactions with patient representatives.

The aim of ACI was to obtain physicians' perceptions and attitudes about the usefulness of our design concept in the ED and physicians' willingness to use it in the future ED. ACI was used to present the design concept to participants and get their feedback on the concept and the representative as part of that concept. ACI was designed based on DH2 and DH3. Additionally, another hypothesis was created: *physicians will be willing to use this proposed concept in the future ED* (EH1). EH1 was also created based on the observer's understanding of the ED setting and discussions with collaborating physicians. During ACI, the design concept was explained, and mockups were shown to the interviewees. After the explanation, we gathered physicians' opinions about the design concept and our inclusion of patients' representatives.

5.5.3 Sampling and Data Collection:

Purposeful sampling was used to recruit three physicians [59]. Senior staff members were targeted since our goal was to get information about their experiences and opinions. Two participants were interviewed face-to-face, and one was interviewed using a video chat platform. The online interview followed the same interview process of the first two interviews. The types of questions used in the interview mainly focused on experience, opinions and knowledge about their interactions with patient representatives [59]. However, one question was asked about their feelings when they repeatedly searched for patient information; this question was based on the observer' s findings.

5.5.4 Analysis

For qualitative analysis of the interview notes, we began with reflection of the interviews and checked the data. [59]. The data were then read multiple times for familiarization. Two native Japanese, one informatician and one physician, transcribed and translated the interview recordings before deeper analysis began.

Inductive analysis was used for ACI responses to identify common themes. Deductive analysis was used to analyze the responses based on the proposed hypotheses (DH2, DH3, and EH1) mentioned in Section 5.3.1. Afterwards we switched to inductive analysis and analyzed the questions. The codes derived from analysis of ACI were then compared with codes to ACI.

5.5.5 Ensuring Credibility

Throughout the design of the interview, questions were iteratively updated before each interview. Since this author is not fluent in Japanese, to ensure the quality of the interview, the interview questions were checked by four Japanese who are proficient in English; two of them were physicians. Some interview questions, although seen as straight forward in English, had to be rephrased to fit the Japanese context while at the same time not losing the original intention of the author. Additionally, triangulation was used to enhance the credibility of the study [59]. Multiple strategies of information of data collection were used; observations were used to get initial subjective understanding the ED setting [59], information behavior of ED staff and their interactions with patient representatives. Iterative discussions were held with two physicians and one informatician who worked closely with physicians; they are native Japanese with professional English level proficiency. Additionally, written and verbal informed consent were received from each interviewee before the interview and recording began.

5.5.6 Results

Three physicians were interviewed. Each participant had 10 - 15 years of experience in the ED setting. Interviews lasted on average 1 hour and 15 minutes. Physicians sometimes referred to a patient's representative using the term, "key person"; one physician explained "key person" as "*someone who makes the main decisions on behalf patients with or without input from other family members.*"

5.5.6.1 Before Concept Introduction

We focused on the problems physicians experience relating to the patient representative in BCI. Conversations about problems were inductively placed into three themes (Table 5.23). Problems mentioned by physician during interaction with representatives were based on their experience in the ED.

During Interaction Physicians commented that the behaviour and attitudes of some representatives during interaction made the task of getting patient information much more difficult. In most mentions of this theme, physicians were referring attitudes that did not seem like the representative was willing to cooperate with physicians. One physician mentioned that "*some family members are unfriendly*" , and this problem makes interacting with these family members a more difficult task. Unfavourable behaviours

Table 5.23: BCI Themes relating to problems experienced by physicians in the ED relating to the patient representative

Themes	Quotes
During Interaction	“Sometimes family members are unfriendly” (physician1) “[Interacting] face-to-face”doesn't make sense if the person [representative] does not have patient information” (physician1, similar statement by physician2) “Even if we talk to someone who doesn't know better, sometimes the information we get turns out to be wrong information.” (physician2)
Perceived Causes	“If patients and their representative are not on good terms,the family usually may have enough information and sometimes do not want to contact us.” (physician1) “We [physician and colleagues] were told that they had no medical history, but in fact we did. It comes down to not being able to get reliable information” (physician2)
Impact of Problems	“For unconscious patients case it is difficult to get their medical information, so we must do more tests” (physician1, similar statement by physician3) “The lack of understanding of the medical background and the DNR policy is quite a problem. When it's an emergency, decisions are made in a hurry, so the lack of this kind of information can affect decision making. It is a burden for us to check with the family while performing the treatment in such a case” (physician2) “We have to use more time and effort to get patient information, which affects the amount of time we have to treat the patient” (physician3, similar statement from physician1) “After [a] patient was exposed to a poisonous substance, it is necessary to wear an personal protective equipment while attending to a patient, however we were not aware of the danger...” (physician3)

related to actions of representative made patient information information-seeking difficult. For example, “*a patient's close friend returned home with the patient's belongings. Upon regaining consciousness, the patient was also unwilling to share information*”. Despite unfavourable attitudes, physicians highlighted instances when patient representatives assisted physicians in searching for and/or provide missing patient information; one physician recalled, “*the most recent experience I had was where a mother brought the relevant history of the child and had a positive attitude during our interaction. The support from her was really helpful.*” Each physician shared the sentiment that patient information shared by representatives was, although useful, not sufficient. Apart from the general consensus about this problem, one physician also commented about the incorrect patient information sometimes shared by representatives.

Perceived Causes One cause mentioned by physicians for insufficient patient information shared during interaction was *patient-family tensions* that preexisted before the patients' arrival; this cause also affected the attitudes of representatives during interaction, sometimes leading to unwillingness to share patient information. Patients sometimes withheld patient information from their representative, who in turn were willing to share patient information that they were aware of at the time. However although knowing patient information, patient representatives in other instances sometimes withheld sensitive (perceived shameful) patient information from physicians; one instance was recalled by an physician, "*There was a case of an unconsciousness patient. We did many kinds of tests but we didn't know the cause. Finally we detected the cause was drug overdose. The patient kept his medical history and drug history from his family*". Physicians that *misinformed representatives* were people who thought that they had the right patient information when in fact the patient information was inaccurate. For example, one physician commented that "*we [physician and colleagues] were told that they [patient] had no medical history, but in fact they did. It comes down to not being able to get reliable information*".

Impact of Problems Along with the above problems shared by physicians, consequences were also shared. Physicians mentioned that additional resources are used as a result of insufficient patient information; this theme relates to both human and medical supplies available in the ED. Additional patient information seeking was also a sub-theme that came up during the interviews; this was mainly attributed to *insufficient/unreliable patient information.* All of the above problems lead to higher stress levels among physicians who had to engage in the non-clinical task of additional searching for patient information. "*In the busy ED, my stress level gets higher for patients with circulation and respiratory problems*" . A physician mentioned the feelings of "*frustration, anxiousness and desperation*" when searching for patient information in and outside of the ED.

One physician mentioned increased risks to physicians and their colleagues caused by insufficient patient information because a representative was withholding information. Furthermore, insufficient patient information leads to misinformed treatment decisions and greater uncertainty among physicians about a possible change in patients' future condition. For example, a physician mentioned that"*if they [patient] have diabetes and they feel pain in a certain area, if we know patient information, we can predict from their patterns that they will probably have a myocardial infarction*".

5.5.6.2 After Concept Introduction

Physicians shared many opinions primarily about their perceptions of the system and the use of the representative in this system. Themes for the ACI stage were mainly related to perceived benefits, perceived shortcomings and concerns about using the proposed application system designed in Section 5.3, as shown in Table 5.24. Two physicians expressed interest in using our proposed system in their personal lives, while one physician was neutral but open to trying to system in the future.

Table 5.24: ACI themes relating to physicians perceptions about proposed system design involving the patient representative

Themes	Quotes
Perceived Benefits	"This system eliminates waiting on a physician to type summaries [in a patient's primary hospital]" (physician1) "The sharing of patient information is fast and somewhat comprehensive" (physician2) "The system is useful although it really depends on the quality of information received"(physician3)
Perceived Shortcomings	"If patients and their representative are not on good terms,the family usually may have enough information and sometimes do not want to contact us." (physician1) "It seems difficult to reserve all medical data. I want to reserve [patients'] family contact information, activity of daily living (ADL) and do-not-resuscitate (DNR) policies." (physician3) "There is no features to allow me to share patient information with my colleagues in the ED" (physician2, similar statement from physician1)
Concerns	"When the representative is another person's representative simultaneously, perhaps they can share the wrong information to medical staff." (physician3) "I think we need a separate person to manage the data, such as who is responsible for editing the data and who is responsible for managing it." (physician2) "I am concerned about information leaks and the correct timestamps for the [patient] information (physician1, similar sentiment expressed by physician2) "Some older physicians do not own a smartphone, how will they use this system?" (physician3)

Perceived Benefits Physicians highlighted several perceived benefits of using our proposed concept: With regards to *reduced time*, physicians remarked that using this system can reduce the time taken for him to make a request for patient information and obtain patient information; this suggests that the system is perceived as easy to use by physicians, thus supporting hypothesis DH2. Concerning *reduced searching*, one physician commented that using our system can help physicians "*avoid the trouble of contacting the patient's primary care facility*" . Because of the improvement to the interaction with representative, a physician commented that the system can help him avoid "*waiting on physicians in the primary care facilities of patients to write patient summaries*" ; this supports DH3 since physicians did not have any concerns about the process of getting patient information using our system. With regards to *reduced stress*, physician mentioned using our system can lead to "*less frustration*" since additional searching is not needed to obtain patient information. One problem mentioned by the physician was the increased stress of searching for patient information for patients with circulatory and respiratory problems. Physician' s perceptions based on their information needs and experiences supports DH2 and DH3. *More Convenience* relates to physicians' thoughts about using the system that was convenient during interaction with the patient's representative. One physician perceived our proposed design as "a *better than just speaking to a family member*".

Perceived Shortcomings Physicians perceived our proposed system's shortcomings based on the explanation given to them and the mock-ups shown before ACI questioning began. Perceived shortcomings were related to mainly the *features* and the target *patient information* included during the system design. Two physicians mentioned that although the system is useful, there is no feature to assist in sharing patient information with other HCPs in the ED after reception from the representative. The lack of a feature to support remote patient information sharing was also mentioned by another physician; although this feature was not included in our scope and was part of our previous work, this comment was very valuable. Concerning patient information, physicians mostly mentioned the social background, activity of daily living (ADL) and do-not-resuscitate (DNR) policy as shortcomings of the target patient information that can be obtained using our proposed concept.

Concerns ACI Physicians had various concerns about the proposed system. With regards to patient information, physicians were concerned about the management (information updates, reliability, update transparency) of the clinical patient information to be obtained prior to emergencies and after patient information is received using our proposed system. Concerning information updates, a physician remarked that the information needs to be updated for any patient or the information integrity and usefulness of the system will be problematic. Additionally, *information security* (patient information privacy, patient information integrity) was also a concern. Concerning security, one physician mentioned that he had privacy concerns for patients, "*If the physician can* *see [patient information] but the friend [of the patient] cannot see, then the system is useful*" . A next set of concerns was related to the ED. One physician was concerned with the use of smartphones in the ED, since many senior physicians may not be able to use smartphones efficiently and do not own a smartphone for personal or professional uses. Although the system was perceived as useful by all physicians, one physician also had concerns about reliability of patient information obtained, which made him assume that additional patient information seeking will still be needed after using our proposed concept. The capability of the representative to share patient information was a concern highlighted by two physicians. Features design for physicians were also a concern for one physician who stated, "*I don't like the idea of the [proposed] system if [it is] connected to [my] personal information such as GPS (location information)*".

5.5.7 Comment

Physicians remarked that the system is perceived as useful in the ED. However, physicians also highlighted some shortcomings of the proposed system which serve as suggestions for improving our system design; two of such shortcomings were the lack of features for writing and sharing patient information with other ED colleagues. Although this is outside our scope in this stage, it is important to develop features to help physicians find meaningful use of patient information obtained from the representative. A physician also mentioned that "*it's not very good for anyone to write [patient information] when you think about security. A trade-off between security and information updates needs to be considered.*" ; physicians in a previous study expressed similar sentiments [99].

Results suggest that physicians are willing to use the system when interacting with representative, which supports DH2, DH3 and EH1. Based on the system mockups shown, a physician mentioned that the system is perceived to be easy to use and helpful in reducing searches for patient information when they are busy. However, one of the concerns was about the integrity of the patient information obtained using our system. One physician was concerned about the wrong patient information being shared by representatives; a possible solution can be the inclusions of a confirmation screen with the photo of the patient and representative so that physicians can clarify the right patient before clinical patient information can be obtained from representatives (Figure 5.12). Results suggest that physicians would like to improve the interaction process with patient representatives by receiving not just our assumed comprehensive and reliable patient information, but also up-to-date patient information that includes a history of each HCP who made patient information updates prior to the emergency situation.

The following experiment in the next section builds upon this section by presenting a usability evaluation to confirm that our proposal is usable, as it useful.

5.6 Experiment (EX3): Usability Evaluation

Based on the ISO standard 9241-11 (1998) usability is defined as "the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use" [100]. Effectiveness is defined as the accuracy and completeness with which users achieve specified goals and efficiency as the resources used to achieve goals of effectiveness. Satisfaction is defined as "freedom from discomfort, and positive attitudes towards the use of the product".

Usability testing is one of several techniques utilized to confirm user-centered design principles [101] with the goal of ensuring that the prototype under evaluation is easy to use, satisfying to use and provides value to the target population [58]. To be considered usable, a system must follow at least one of the four following factors, as posited by Booth [101]:

- **Usefulness** assess the motivation of the user to use the artefact under the target use case.
- **Effectiveness** (ease of use) relates the ability of the user to operated the artefact effectively without intense guidance or explanations.
- **Learnability** relates to the competence of the user to operate the artefact based a predefined level of training.
- **Attitude** (likability) relates to the feelings and perceptions of users about the prototype

5.6.1 Prototype Development

The scope of our concept design was improving the proximal interaction between physicians and representative in the ED; in line with this scope, a prototype was developed which focused on ease of interaction. The results of the previous chapter confirmed that the design concept was useful and physicians were willing to use the proposed system during interactions with patient representatives. Information needs were based on specific emergency scenarios. The results of the interview confirmed that although the system focuses on interaction between representatives and physicians, physicians were mainly concerned about the following after receiving patient information:

- Knowing who updated patients' information
- Knowing what time patient information was updated
- Remote information sharing feature to obtain patient information from representatives; this was addressed in Section 5.3 where we designed a remote information sharing application based on patient preferences.
- Ability to share received patient information with colleagues in the ED within the same system

Based on interviews in Section 5.5 some additional features were included for consideration in our system; although some of these features are outside our scope, they are seen as useful towards having an integrated patient information sharing system that goes beyond the point of interaction between representatives and physicians. Information about the update history of different parts of patients' clinical information was added. Additionally, the categories were refined to include patients activity-of-daily living (ADL) as a separate category.

5.6.2 Evaluation Factors

In this study, we conducted an exploratory usability test to confirm the effectiveness of our design assumptions derived from the results of EX2 in Section 5.5. We wanted to know if the proposed design concept prototype, although useful, is usable for physicians and representatives during patient information sharing. Our objectives focused on the tasks during interaction between representatives and physicians for the purpose of patient information sharing. The following are usability factors of evaluation based on our objectives:

- **Learnability** does the designed interaction tasks mimic physicians' natural interaction process? We wanted to know to what extent does the tasks for interaction need improvement based on physician preference.
- **Ease of Use** does the system facilitates intuitive performance of tasks?
- **Satisfaction** are physicians satisfied with the current proposed interaction tasks during patient information sharing?

5.6.3 Study Design

Similar to the interviews in Section 5.5, emergency medicine physicians with at least 10 years experience in the ED were recruited using purposeful sampling [59]. Questions were designed based on our design objectives. The proximal-sharing scenarios, PS1 and PS2, mentioned in Section 5.3.3.2 were used in this experiment.

PS1 The first scenario involving the simulated patient named "Mayuko" contained no explanation; this was to confirm that the tasks we created in the system design could be intuitively performed without any formal explanation.

PS2 In the second scenario involving the simulated patient named "Taro", the participants was allowed to asked questions if they required assistance with performing the given tasks.

A post-experiment questionnaire was designed based on a 5-point likert scale; these questions targeted factors related to ease of use and satisfaction of participants. To obtain an idea about the general usability of the system, we used the System Usability Scale (SUS) [102]; this is a scale that can be used for designers to ascertain the general usability requirements of a system under evaluation.

SUS is a simple usability likert scale developed by John Brooke in 1986 and has been widely utilized in a variety of applications such as mobile device [103], websites [104], medical systems [105] and wearable devices [106]; it is a scale that has been well established [107]. The SUS, which is based on a likert five-point scale, has 10 questions; questions 1, 3, 5, 7, and 9 are positive and questions 2, 4, 6, 8, and 10 are negative. A higher SUS score indicates better artefact usability.

5.6.4 Data Collection

After completing the pre-experiment questionnaire, the background and purpose of the experiment was explained to the participants before the experiment started. For each scenario, participants were given a goal to obtain patient information from the representative who was the experimenter. Ideally, the participants had to follow the steps outlined in Section 5.3.5. After completing the task of obtain patient information, participants where interviewed about the steps taken and their suggestions for improvement based on their information needs and personal opinions. The interview was conducted in English; however, a Japanese translator was used to translate complex opinions of physicians. Time taken for participants to complete their tasks was recorded; the timer was started as soon as the physician began the conversation and stopped as soon as the patients clinical information was loaded on the physicians application. The following is a list of informal questions used at the end of each scenario:

1. How was the interaction process with the representative?
2. How were the tasks before during the interaction process?
3. If you had to change the tasks in this prototype, what would you include or remove?
4. Is the basic information shown about the patient and representative enough?
5. What category of clinical information would you search for initially after receiving the patient information?

Participants then completed a post-experiment questionnaire.

5.6.5 Analysis

Interviews notes were used to generate suggestions, problems and other categories based on the responses and topics under discussion with the physicians. The average time for each scenario also calculated using standard analysis software. SUS was calculated using the following equation:

$$SUS = 2.5 \times \left[\sum_{n-1}^{5} (U_{2n-1} - 1) + (5 - U_{2n}) \right]$$

5.6.6 Results

A preliminary experiment with three emergency physicians with over 10 years experience in the ED was conducted (Table 5.25).

5.6.6.1 Scenarios

Physicians were shared favourable attitudes during interaction using the prototype. The update information in the list view near each category of patient information received a favourable response. Additionally, P2 required the identification of the person who updated the category of patient information along with the actual original source of latest information update. The DNR policy was also seen as vague since physicians explained that a younger patient may need a signature attached to their DNR policy

Table 5.25: Participant demographics; literacy levels used a five-point Likert scale

Variables		Score	Participant Count
Clinical Experience	Max	20 years	–
	Min	12 years	–
Smartphone Literacy	Max	4	2
	Min	3	1
Computer Literacy	Max	4	1
	Min	3	2
Time	PS1	1.27 minutes	–
	PS2	0.83 minutes	–

as opposed to elderly patients. P3's comments also supported this with the question, "*Who created this DNR policy? Was it Taro or his daughter?*". P3 mentioned that using the prototype, " *I can understand the information about the patient faster*". Conversely, regarding the basic information, P3 preferred a clearer indication to distinguish the incapable patient from the representative.

During the experiment, physicians seemed more focused on the quality of the information received after the interaction and were comfortable with doing the interaction. Most of the comment related to the received information and not the interaction process itself, thus supporting our assumption that they were comfortable. Physicians did not see the need for formal training to use the prototype since they were able to intuitively use it during their first attempt when interacting with the patient representative.

After the interaction with the representative, physicians also asked questions for an additional 2 to 3 minutes to clarify the information received.

PS1 No explanation or assistance was provided to participants in this scenario. There were no perceived problems with the interaction process which was our main point of focus; minor shortcoming were related to the interface of the basic information which made P1 confused. The button showed the label "pending" while the physician waited for representative approval. After approval, the button changed to "View medical record", but the change was not clearly visible to the physician, thus increasing the time of the interaction (Table 5.26). The basic information screen was then updated before experiments were conducted with P2 and P3.

P1 expressed interest in searching for the past medical history (PMH) of the patient before searching for more detailed clinical information. P2 was interested in the patients surgical, pregnancy and smoking history.

PS2 In this scenario, the interaction was faster than scenario one, although the representative took an additional 5 seconds before approving the physician. Physicians appeared more confident in using the prototype in the PS2. There was faster reception of information. Similar to PS1, the physician went to search for PMH first after information reception, then allergies of the simulated patient.

P2 mentioned a distinction between PS1 and PS2, "In the first scenario [PS1], Fela was not in the same location with the patient when she [Mayuko] fell. So I can estimate that Fela does not have more information more than the application has. There is not much communication to get the information. In the case of Erika [representative], then I can get more information about the event because she was there."

TABLE 5.26: Time difference between scenarios

Participant	Interaction Duration in Minutes (seconds)		
	Scenario One	Scenario Two	Difference
P1	1.73 (104)	.78 (47)	.95 (57)
P2	1.07 (64)	.77 (46)	.30 (18)
P3	1 (60)	.93 (56)	.07 (4)

5.6.6.2 Questionnaire

SUS scores based on each participant and the average SUS scores per question are shown in Table 5.27. With regards to satisfaction based on each step during interaction, physicians were generally satisfied (Figure 5.18)

5.6.7 Discussion

The aim of this study was to ascertain the usability of a prototype developed based on the design specifications outlined in Section 5.3. Based on the results, the proposed system with the representative is usable to physicians in the ED during interaction. The system was designed to improve interaction between representatives and physicians; the results suggest that interaction can be improved using our system without a negative impact on the natural operations currently in the ED.

Based on our design goals, the findings suggest that our proposed system is usable by physicians in the ED. These findings provide a basis for future detailed development activities surrounding the concept of using the patient representatives.

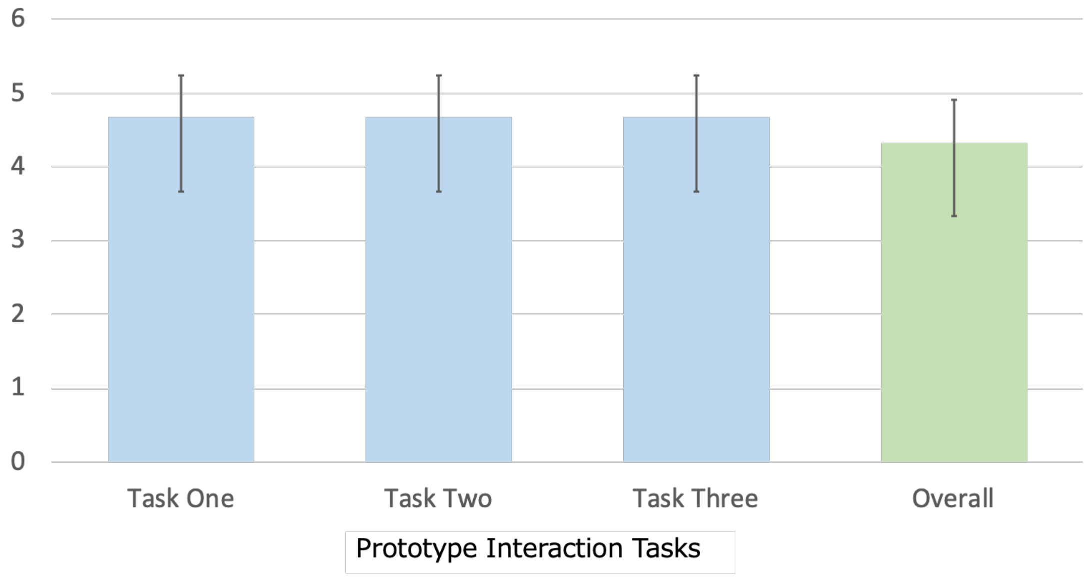


FIGURE 5.18: Physicians' average satisfaction score per task during the interaction process using the prototype; SD = 0.58

TABLE 5.27: SUS scores per participant; questions 1, 3, 5, 7, and 9 are positive and questions 2, 4, 6, 8, and 10 are negative. "5" is the best score for positive questions and "1" is best for negative ones

#	Questions Topics	Physician1	Physician2	Physician3	Average
1	Frequently Use	5	4	4	4.3
2	System complexity	1	3	2	2
3	Ease of use	5	5	4	4.7
4	Support required	1	3	3	2.3
5	Well integrated	4	4	3	3.7
6	Inconsistent	1	2	2	1.7
7	Quick learning	4	4	4	4
8	Cumbersome	1	3	2	2
9	Confidence in use	5	5	4	4.7
10	Ease of learning	1	2	2	1.7
SUS Score		95	72.5	70	79.2

5.7 Discussion

5.7.1 Patient Privacy Concerns

Privacy concerns are one of the factors that contribute to tensions between the patient and healthcare community, thus affecting the flow of patient information. Other factors such as lack of patient involvement in medical decision making can also affect these tensions; however, our scope was patient privacy concerns based on their information sharing preferences.

5.7.1.1 Global Concerns

Studies suggest that concerns of patients about their electronic health record privacy span every continent of the world. The levels of privacy concerns differ between countries; however, the concerns of patients universally point to the collecting entities, lack of patient control and the patient' s awareness of their medical record. It must be highlighted that in the realm of electronic health records, the patient is not the sole owner of their medical information; the entity that stores and manages the patient' s data is the owner. Thus, our design approach was patient-centred and not patient-centric. In the context of this present subtheme, patient privacy concerns are specifically focused on the confidentiality of their medical data [108]; the present study supports their premise.

5.7.1.2 Concerns in Japan

Our survey gives new insights about the privacy concerns and perceptions of Japanese citizens. The variation of control and awareness preferences of the different age groups and the variability in choices contribute new suggestions for designing our system. For example, a patient may not be concerned about awareness after recovering from unconsciousness but in they event the become unconscious, they may want their representative to have a granular level of awareness. Another example is that patients between the ages of 20 and 39 may want representative control when in the event they become unconscious but do not want the representative to know all the information concerning their medical data. A recent study found that 62% patients had privacy concerns about access to their medical record [109]. We infer that this result supports the 61% of patients in RS1 who chose control.

Differences found in preferences highlight the need for greater flexibility of our system design, since different age groups have varying preferences about concern and awareness for situations where patient is conscious or unconscious. The overall preference for the use of an emergency card for people who are not concerned about control suggests that our approach needs to be updated to facilitate the varying preferences of members of society.

Overall, the percentage of patients who prefer no representative control in the event they are unconscious supersedes the percentage of people concerned about control of their medical record if they were to become unconscious. This does not dismiss the fact that the concerned respondents make up a considerable percentage of the population of Japan. The results also suggest that there is a greater percentage of people who choose awareness. The diversity in the choices for awareness needs to be included in our system to support the patients varying concerns for awareness. The granularity of awareness and the question of whether or not patients can interpret the medical data is another issue concerning patient awareness of the activities recording their medical information. To address this, efforts are being made to have the same data available to both physician and patients for better readability [6].

5.7.1.3 Societal Impact

The problem presented in our introduction cannot be addressed with a technical solution only. This is because privacy concerns have social and legal overlaps that are tied deeply into the cultures, including Japan. One challenge that arises is building societal trust while allowing the medical professional to perform their role effectively. Keeping the patient and their representative in the information loop and involving them directly into the patient information sharing process as proposed in this research can contribute to the reduction in privacy concerns and thus increase the societal trust in use of a nationwide centralized systems such as EHRs.

5.7.2 Impact of Proposed System

Our proposed approach was designed to consider patient preferences with informational privacy as the dimension of focus. However, the effects of our proposed design cannot be measured based on informational privacy alone since the other dimensions of privacy defined by Burgoon [110] will be also affected through and compounded by the many stakeholders involved in the successful functioning of EHR systems.

Although not considered within our scope, our proposed socio-technical system can have potential political impact. This system requires that it be overseen by a non-governmental organization with the guarantee to the public that there is no direct government interference.

Policies to support the implementation of our socio-technical approach are required, an aspect similar to other countries [111, 112]. Some respondents mentioned that they will prefer an emergency card if it does not have the recently implemented ‘myNumber’ system. This suggests that political concerns are covariates to patient privacy concerns. Twenty one percent of respondents in the survey mentioned lack of trust as the reason for choosing control in RS2. A further forty percent of the respondents choosing the representative mentioned reasons that are related to trust as an outcome e.g. security concerns, safer choice, certainty, access control, and concerns for control. This supports previous claims that privacy concerns affect trusting beliefs [52].

The system we proposed may require modification in clinical practice and administrative procedures. This may in some instances change the decision time and protocol of the physician when trying determine the appropriate treatment to give the patient [113]. It also gives rise to the argument about privacy concerns versus saving a patient’s life since an individual has to be alive in the first place to be concerned. The design of our system also contributes to the discussion of family medicine in Japan and other countries since it involves a trusted representative who can be a family member [114]. Family medicine is concerned with each family having a dedicated physician. In this case, the physician can also be the representative of the patient and can grant access to other physicians using our approach in family medicine.

5.7.3 System Alternatives

One alternative is using an emergency card that the physician can find in the belongings of the patient. In the survey results, many respondents preferred the emergency card over representative control. These cards can have a unique code the physician can use to access the patients record. The card however, cannot think and make decisions and thus, anyone that has it can access the patient record. Additonally, people currently possess ATM cards which can be lost or stolen. In that case the notified bank blocks the card. This can work in the case of using a personalized emergency card for the patient in the event they become unconscious. Although there is lower security, there is a greater level of availability, i.e. quicker access to patient record by the physician.

Another interesting solution is the use of the blockchain network. However, the various EHRs may have to be decentralized. This gives a greater legal and political overlap, since this takes control away from private and governmental organizations and increases the control society has over the flow and access to important medical data. The blockchain network has been successfully used to support the Bitcoin cryptocurrency network which has a high level of security that was built on trust of the large network of users who are a part the Bitcoin usage community.

5.7.4 Design Proposal

We consider physicians’ colleagues as part of the healthcare community and the patient and their representative belonging to the patient’ s community; both communities are regarded as part of society with important roles. Our design concept assumes that a patient has at least one person they can trust to represent them during emergencies. The patient representative is seen as an extension of the patient in the system design; the representative must be assigned to a patient. Each stakeholder needs to be aware of their role(s) in the system before registration can be complete in stage 1. Additionally, inter-community understanding is necessary to ensure the long term support and use of the implementation of our proposed concept in the future. Trust between the patient community and healthcare community is necessary to ensure that patient information is available to physicians while considering the confidentiality of patient information [92]. In the future, to support the technical part of the system, it is necessary that HCPs, patients and patient representatives have an understanding of the system at the registration stage to obtain meaningful use whole maintaining patient privacy [37]. Based on the patient information integrity concerns of interviewed physicians, collected patient information should be accurate [115]; physicians did not perceive the proposed system as useful in the future ED if patient information was not up-to-date.

Simultaneously to understanding the roles that healthcare systems have on the users [116] is the necessity for designers to understand the users and their expectations regarding proposed technological solutions in the ED. Direct access to EHRs is ideal for physicians; however, many countries still face challenges in implementing nationwide EHR systems due to more social than technical barriers. During emergencies, patients' primary care physician can also provide useful patient information. Sharing the patient record was a major barrier to obtaining comprehensive patient information. As noted by a physician, "*It is really a burden to be calling [primary care] hospitals while we try to treat and diagnose patients simultaneously*".

The observations and iterative discussions with various physicians shaped our design ideas. We chose to design a socio-technical system because it is not our aim to replace the current verbal interactions that occur between physicians and representatives in the ED. We aim to supplement the social interaction with a faster way of sharing more comprehensive patient information. Our proposed system is part of action which is the proposal of a solution to improve a current work situation [117].

5.7.5 Socio-technical Approach

Patients representatives are very useful in the event either patient information or the patient is not directly accessible to the HCPs. Early principles about socio-technical systems inspired our socio-technical design basis for the proposed system [30]. Based on the Information Seeking Model reported by T. D. Wilson [15], we assume that the representative will be willing to share patient information with physicians since the rewards for better patient care and physicians’ physical proximity in the ED are at a high level.

5.7.6 Example of Use Case involving Children

In section 4.3.2, three categories for patient representative were defined based on the observation findings; these were:

1. Patient Appointed Representative who is an adult chosen by the patient, e.g., a family member, close friend or co-worker.
2. Professional Representative is a healthcare professional who is professionally allowed to act of behalf of a patient, e.g. primary care nurse or caregiver.
3. Legal Representative is someone legally responsible for the patient, e.g., parent or legal guardian for children.

Hypothetical scenarios used in the evaluation of the proposed prototype system focused primarily on the patient appointed representative since the aim was to support patient information sharing based on pre-defined patient preferences. However, we present a scenario involving a minor which includes an every-day situation where our system will be ideal.

> Anthony, an elementary student in Kyoto, has just began the school year and is assigned a new class teacher who will contact parents in case there is an emergency. One day, during a field trip to Ehime prefecture, Anthony collapsed after complaining to his friend of having a tight chest about sixty seconds before. Anthony’s class teacher rushes him to the ED of the nearest hospital and Anthony is admitted in his unconscious state. That same day, Anthony’s parents are on a business trip in Tokyo and cannot return to Kyoto immediately.

Based on the above scenario involving a minor, our proposed system, can be use for remote or proximal information sharing:

Remote Sharing: Anthony’s Parents The attending physician can contact Anthony’s parents and obtain Anthony’s medical information remotely. In this case Anthony’s parents are legal representatives for Anthony.

Proximal Sharing: Anthony's Teacher Before the emergency, based on Anthony's parents preferences, Anthony's teacher can be added as a representative; in this case Anthony's teacher is a patient appointed representative for Anthony. Although Anthony did not make the choice, his parents added the teacher as one-year representative. The attending physician can obtain Anthony's medical information from the teacher in the ED.

5.7.7 Limitations

Limitations of this research include the availability of representatives which cannot be clearly measured. In our design, it is assumed that multiple representatives for one patient can increase the likeliness of the physician obtaining a response; yet the challenge of the availability of the representatives remains present and cannot be clearly measured. The reliability of the internet based frameworks cannot be controlled since there are many external influences inherent in the internet general use.

This shortcoming needs to be addressed to include an alternative method of notifying representatives in the design of our approach. One limitation in scenario two, based on the devices used, was the inability of our system to activate the ‘loud’ volume setting on the representatives’ phone when the emergency notification is received. Our design did not consider patients who may not have a trusted representative. Some respondents chose no representative control because they lived alone. This shortcoming also supports the need for another alternative to be considered in our approach. Another limitation is the way the health care systems are set up and governed in various countries. The regulations and the decisions of governing bodies will also affect the outcome as to the number of representatives a patient can have. Furthermore, these regulations will also affect the way the responses from the representatives are handled by our system.

The design for remote sharing within our system can be adaptable for use in other countries because it does not concretely define the number of representative(s) a patient can register since various countries have different rules. The design of our patient-centred approach is focused on justifying the feasibility of our idea before defining functionality of the system. Furthermore, the registration of a representative by patients requires both parties to understand the importance of impact of using our system before registration. The representative must be aware of their role before accepting it.

In the future, our approach needs be updated to include three abstractions of control before implementation; these are access control policies, mechanisms to support the policies and models to theoretically define the mechanism [118]; within our design, the control and awareness given to patients and their representative are part of the mechanism. However, this is not sufficient to provide control to concerned patients. Our research scope must be expanded to include a more precise access control approach for patients and their representatives. To date, it is difficult within an EHR system to identify if a patient is unconscious. We included the representative in our patient-centred design to have access control in the event a concerned patient becomes unconscious. Approximately half of the patients concerned about control in RS1 did not choose representative control in RS2 and RS3. These respondents need to be considered in the design of our approach. Alternative methods of access control need to be explored when our approach is improved for the patients who may be concerned about control of their medical data in the event they become conscious but do not prefer the use of the representative. Additionally, the varying preferences for awareness for patients and their representative need to be considered since some patients did not want representative control but preferred representative awareness in the event they become unconscious.

Within our system, patients can choose a trusted person to be their representative, but trust may change overtime. This is not a new limitation since traditional systems where one person represents the other is also prone to such shortcoming. A patient-centred patient information sharing system that is useful and usable to HCPs should be considered by including the perceptions of nurses and administrative support staff whose invaluable role contributes to continued patient safety. Another limitation was validation of the opinions shared by physicians with colleagues in other hospitals.

These experiments focused on establishing a social basis for the future development of a mobile patient information sharing application with the involvement of patients' representatives. Our scope was limited to experienced emergency physicians in one ED setting. The opinions of physicians and HCPs of other healthcare facilities were not included in this study. Thus, the findings of the observations and interviews cannot be generalized.

5.8 Conclusion

Observations in Chapter 4 showed that other than remote interaction, proximal interaction was also a challenge since similar to telephone conversations, proximal conversations yield useful but limited patient information when physicians interact with patient representatives in the ED. Using the observation findings, we designed a system to improve the remote and proximal interaction between physicians and representatives based on patient preferences.

Semi-structured interviews with three experienced physicians revealed their experiences with patient representatives and their perceptions about using our proposed design concept. Physicians' main problems *during interaction* with patient information were the attitudes of patient representatives and insufficient patient information. Physicians' *perceived benefits* were related to reduced information-seeking time, reduced patient information search actions, reduced stress and more convenience when obtaining patient information. Physicians' *perceived shortcomings* of our proposed system were related system features and patient information that we did not consider during the system design stage. Physicians' *concerns* about our proposed system were mostly related to the management, security and privacy of patient information. Despite the concerns, the proposed system was seen as useful by physicians, two of whom are willing to use it in their personal lives as well as the future ED. Contributions of Chapters 4 and 5 were published [89, 119–121].

During the observation mentioned in Chapter 4.2, after receiving patient information, physicians interacted with other colleagues for discussion. The next chapter shows a data driven analysis of the discussions between physicians that utilized patient information in various forms. We now turn to the healthcare community to understand their use of patient information using their conversation history, supplemented with the observation results to propose data-driven features to improve their use and discussions relating to patient information and additional topics.

Chapter 6

Information Sharing within Healthcare Community: SNS based Feature Proposal

In Chapter 5, we focused on the interaction between patients' community and the healthcare community for remote and proximal patient information sharing. This chapter, based insights from our observations in Chapter 4, focuses solely on the healthcare community in an attempted to answer the third overarching research question: *What design features are required to share patient information within the healthcare community?* Chapter 5 results also support this chapter by expanding upon physicians request be able to share patient information easily with colleagues in the ED. We focus on understanding physicians through their data (instant-messaging history) as opposed to the previous chapters which had a social approach to understanding. This chapter presents social network service (SNS) features based on a data-driven understanding of emergency physicians. We focus on features and not system design because SNS system design is already established, but in healthcare, extensive meaningful use is still yet to be obtained. To this end, knowing what features are needed in the SNS system design was seen as more important at the time of conducting the research.

6.1 SNS Communication among Physicians

Communication within the healthcare community has improved with the advent of online social platforms [122]. Using online social platforms, physicians can communicate effectively with patients and other physicians [123]. Pervasive smartphone use has further transformed healthcare communication between physicians via SNS applications [124, 125]. In the emergency setting, physicians can transfer large amounts of data within short periods of time [126]; this is valuable because emergency physicians need timely and reliable information. Recent use of SNS applications for healthcare communication has been reported by several studies [126–128]. Galacti et al. [126] and Jain et al. [127] reported the use of SNS applications by emergency and consulting physicians for consultation with patients. They retrospectively categorized physicians' communication data based on message type into images, text, video, and audio. Using a prospective approach, Johnston et al. [128] compared communication types and clinical domains by frequency of interactions between surgical teams using SNS. They also measured the interaction between various ranks of physicians and its frequency. SNS applications have been in other fields including physician education in healthcare [129–131].

6.2 Objectives

Such studies have provided valuable insights through analysis of healthcare communication between physicians using SNS applications. While Johnston et al. [128] categorized text data by clinical domain, data were not analyzed retrospectively, and the scope of the study did not include additional topics discussed by physicians. To the best of our knowledge, no study has categorized text data based on topics discussed by emergency physicians using SNS applications. This study analyzed text message communication topics discussed by physicians who used an SNS application during day- and night-shifts, and qualitatively categorized similar message topics that arose during these communications. The proposal of physician-centered feature specification towards designing an SNS platform is also discussed in this chapter.

6.3 Methods

6.3.1 Study Design

We performed a retrospective study focusing on physicians in Kyoto University Hospital (KUHP), for whom timely communication is important during emergencies. The personal accounts of physicians were added on a voluntary basis to a LINE group chat. LINE is an SNS application originally built to facilitate communication [1]. LINE became widely adopted in Japan with a variety of free and paid services; instant messaging and audio/video call services remain free. Previous studies used WhatsApp[2] but we chose

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[1] http://official-blog.line.me/en/archives/1006892897.html

[2] An SNS application which is popular in many countries. Similar to LINE, instant messaging and audio/ video calls are free. Also, chat groups can be created.

LINE because it is widely used in Japan, and many physicians were not familiar with the former. Physicians not physically present used LINE to communicate with physicians working in the ED during their shifts. This study was performed with approval from physicians. Due to the nature of this study, approval from an ethical committee was not required. Physicians continued to use traditional mobile phones to discuss work-related matters on a one-to-one basis, i.e., a physician may make an inquiry on the group chat but discuss verbally with another physician about a confidential matter relating to a patient.

6.3.2 Data Collection

We extracted LINE data from April 2017 to March 2018. The LINE group is managed by physicians based on a professional guideline which prohibit physicians from sending messages containing patients' identifiable data. The topics discussed were unrestricted in this professional SNS communication environment. Prior to analysis, both the patient identifiable information and the messenger identifiable information, including those of the physicians, were anonymized by the data manager at ED and subsequently provided to third-party coders. Data contained no images of patients.

6.3.3 Analysis

Coders used content analysis to code the data (1752 lines) [132]. Each sentence was coded based on the topic represented. Two coders participated; both have a background in medical informatics. Coders coded messages into category names after mutual agreement. Context of similar codes was considered during categorization. Categories were evaluated using Python version 3.5.2 (packages included pandas 0.24.2; re 2.2.1; matplotlib 3.0.3). We evaluated the day(s) most messages were sent, the frequencies of communication per day- and night-shift, numbers of messages during day-shift, night-shift, weekdays and weekends. Day-shift is from 9 am to 5 pm with a transition period from 8 am to 9 am. Night-shift is from 5 pm to 9 am with T from 4 pm to 5 pm. Weekdays are Monday through Friday, and week-ends are Saturday and Sunday.

6.4 Results

Twenty-two physicians sent 1752 messages between April 2017 and March 2018. The majority containing text data (82.1%) and the remaining containing media (17.9%), as shown in Table 6.1; media included images (72.6%), LINE stamps (22.9%), and LINE albums (2.3%).

TABLE 6.1: Table with message characteristics(1752)

Variable		Count [%]
Message Type	Text	1438 [82.1]
	Media	314 [17.9]
Media	Image	228 [72.6]
	LINE stamp	72[22.9]
	Files	5 [1.6]
	Video	1 [0.3]
	LINE note	1 [0.3]
Total messages	Day-shift	832 [47.5]
	Night-shift	920 [52.5]
	Weekday	1338 [76.4]
	Weekend	414 [23.6]

6.4.1 Message Categories

The text data messages were classified into 13 categories as shown in Table 6.2. '*Miscellaneous*' included any message unrelated to the professional role of emergency physicians. '*Patient*' included messages in which a patient was mentioned directly or indirectly. 'Team' included messages about the emergency team, colleagues (inside and outside hospitals) and issues, e.g. team shortages. '*Treatment*' contained messages about treatment and medical procedures. '*Event*' included messages about events such as meetings and conferences. '*Situation*' included messages concerning a situation that occurred or is occurring. '*Reference*' included messages with reference to printed or online resources such as medical guidelines and journals that contained useful information to support discussions between physicians and/or treatment of patients. '*Announcement*' included news, notices, updates about situations or resources. '*Schedule*' included messages concerning physicians' schedule and their availability during unexpected situations. '*Resource*' contained messages regarding equipment or supplies used by physicians. '*Policy*' included messages concerning rules, regulations, procedures or policies. '*Transport*' included messages about any form of transport used for transporting patients or healthcare professionals. '*Unknown*' included other messages not agreed upon by coders during categorization.

TABLE 6.2: Categories of text data messages (1438) among emergency physicians

	Message Category	Count [%]
1.	Miscellaneous	323 [22.5]
2.	Patient	274 [19.1]
3.	Team	205 [14.3]
4.	Treatment	170 [11.8]
5.	Event	95 [6.6]
6.	Situation	72 [5.0]
7.	Reference	63 [4.4]
8.	Announcement	60 [4.2]
9.	Schedule	50 [3.5]
10.	Resource	37 [2.6]
11.	Policy	27 [1.9]
12.	Transport	21 [1.5]
13.	Unknown	41 [2.9]

6.4.2 Messages by Time of Communication

A total of 1338 messages were sent on weekdays (76.4%) and 414 during weekends (23.6%). The highest number of messages sent was during the last weekday, Fridays (23%), and the second highest was during Mondays. Messages sent on Tuesdays and Wednesdays were about 50% fewer compared to Fridays; the messages sent on these days were also less than the numbers of messages sent during other weekends (Figure 6.1).

The transition period (T) was the hour preceding a main shift (M) when incoming physicians discussed matters with outgoing physicians. As shown in Figure 6.2, the numbers of messages sent between one hour before and one hour after T (15 pm to 18 pm, 7 am to 9 am) were similar. Additionally, 119 messages were sent during T preceding night-shift, which was 53% more compared to T preceding day-shift. During night-shifts, the number of messages sent declined steadily after 19:00. No messages were sent between 2:00 and 4:00.

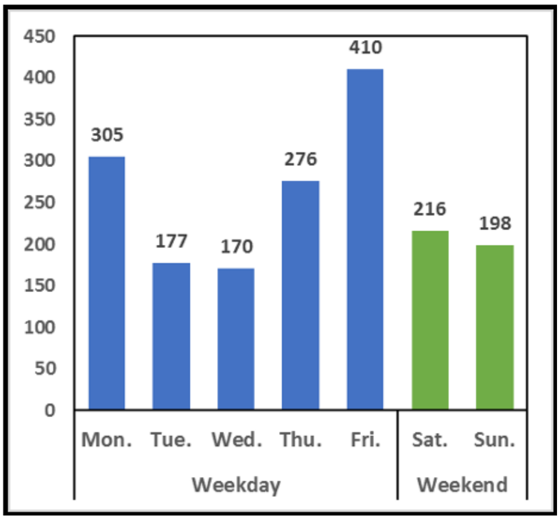

FIGURE 6.1: Total occurrence of messages per day

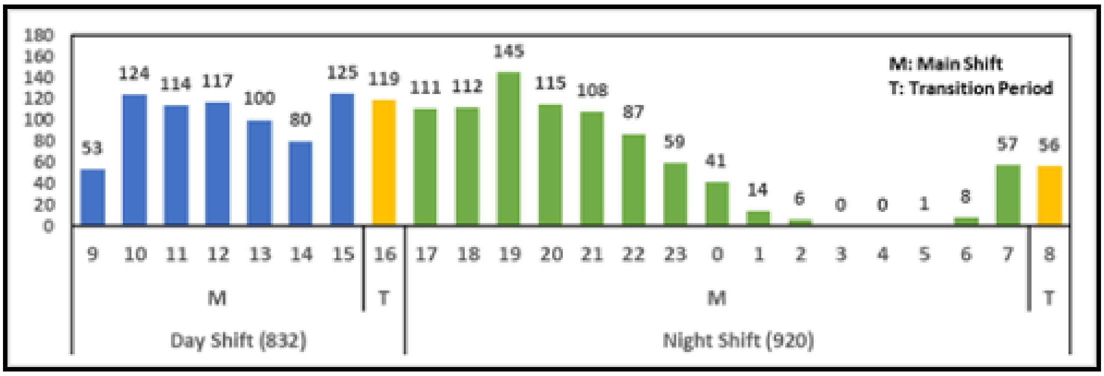

FIGURE 6.2: Total number of messages (1752) per hour

6.5 Discussion

6.5.1 Findings

'*Miscellaneous*' messages were the most frequent (18.4%). Although this category included messages unrelated to physicians' roles, it was included because the social environment shared by people in professional settings will involve communication unrelated to their profession. An SNS platform should not limit the conversations between physicians since they are by virtue of their job description bound by professional guidelines. The high frequency of '*Miscellaneous*' messages suggests the importance of communication between physicians for purposes beyond their professional roles [133]. The focus of this study was to retrospectively categorize text messages, and the importance or implications of miscellaneous chat among physicians was outside the scope of this study. '*Media*' messages comprised the second highest frequency (17.9%). In consideration of an SNS platform for hundreds of physicians, it is important to prevent the existence of redundant images to improve the management, search and retrieval of large amounts of images. Additionally, some images are considered sensitive. Analysis of image contents was outside the scope of this study. As mentioned in section 6.3.2, in this retrospective study actual images were removed to safeguard the identities of patients. Some messages contained topics that overlapped, such as discussions about a patient (Category 2) including medical guidelines (Category 7) and treatment option (Category 4). Also, discussions about ‘teams’ sometimes referred to ‘schedule’. Each category was deemed necessary in the context of medical emergencies which is unpredictable. To utilize an SNS system for communication between physicians, features within the SNS application should support day-to-day activities and discussions between physicians. In the case of physicians, these features should ensure that effective and efficient communication is achieved. The resulting categories suggest that an SNS application system is useful for physicians to facilitate both professional and informal conversation.

6.5.2 Design Proposal

The emergency domain often involves unpredictable scenarios. This study allowed us to obtain better understanding of how physicians in EDs use SNS applications to communicate. To design a user-centered system, it is important to first know the users and their preferences [134]. To the best of our knowledge, design specifications for a physician-centered SNS system are yet to be explored based on features derived from analysis of communication data among physicians. To date, there are no reported feature specifications that should be included in an SNS platform for physicians. Through this study, we are developing an understanding of physicians’ communication using SNS applications by retrospectively categorizing their messages [57]. The present results were shown to and discussed with the physicians at KUHP.

6.5.3 Medical-oriented Design

This study is part of the design stage that precedes system development. The findings that contribute to our proposal of medical-oriented SNS features are based on categories derived from physician-to-physician communication. For physicians, use of SNS applications has contributed to improved communication with colleagues [126, 128]. Increased use of SNS among physicians suggests the necessity of physician-centered SNS platforms which contain features that supplement the physicians’ roles. An SNS application designed for physicians should not increase their workload. By considering topics categorized from physicians’ communications, designers can obtain an initial idea of which features may support inquiries and responses during physician-to-physician communication.

6.5.4 Feature Proposal

Communication between physicians involves the sharing of information about various topics that are mainly related to physicians' roles. SNS features that consider physicians' roles can improve healthcare communication using SNS applications.

Considering the categories shown in Section 6.4.1, discussions with physicians, and previous studies [57, 126, 128], we propose the following features: (F1) a structured tagging system for messages related to particular categories, (F2) an inquiry broadcast system for specific inquiries using F1, (F3) an image tagging system for images shared within groups, and (F4) summarized notifications. Familiarization with the data and the context surrounding the analyzed messages also influenced the coders' selection of these features.

6.5.4.1 Structure Tagging

Based on the results listed in Table 6.2 and Figure 6.1, F1 integrated in an SNS platform would help physicians navigate through large amounts of messages in a short time. This is not limited to healthcare communication using SNS applications but also includes social media websites [135]. Table 6.2 shows the categories that can form the basis of the structured tagging system. Physicians can create specialized tags that are based on formal and informal medical jargons used among medical teams. The tags would be easier to remember and adoptable for incoming physicians. According to Figure 6.1, larger numbers of messages are sent among physicians on some days, and a structured tagging system can assist with retrieving messages sent previously.

Figure 6.2 suggests the usefulness of F1, since physicians on night-shift can conveniently retrieve messages sent during day-shift. The largest number of messages sent during the day was 58. On that day, 72% of the messages were related to the 'patient' topic. F1 used with a detailed sub-category tagging system can assist physicians by filtering messages that may be about a 'treatment' option for a 'patient'. On a weekly basis, KUHP receives an average of 97 ambulance visits and treats an average of 229.4 patients. Although the number of participants in the present study was under 25, F1 can make the use of SNS applications more convenient for groups with larger numbers of physicians [136].

6.5.4.2 Inquiry Broadcast System

F2 can provide physicians treating patients with access to feedback about treatment options; it could assist physicians by broadcasting inquiries tagged using F1 to reach the relevant doctors [137, 138]. According to Figures 6.1 and 6.2, physicians utilized LINE during weekends more than Tuesday and Wednesday. Additionally, LINE was utilized during night-shifts, suggesting that F2 can be used by physicians on weekends, night-shifts and national holidays to retrieve specific inquiries about topics not limited to digital resources and guidelines. Current SNS group chats allow physicians to send specific inquiries which are seen by all group members, which is useful for information transparency within groups. However, there are cases where specific inquiries should be sent and discussed with specific physicians. Physicians should not have to use valuable time to check messages that are not related to them. F2 can improve efficient access to similar questions for medical students, interns, residents, and fellow physicians who use smartphones [34]. This feature can be useful for tagging messages of related topics presented in Section 6.4.1, especially ‘patient’, ‘treatment’, ‘team’, ‘reference’ and ‘resource’. F2 can assist physicians in sending inquiries to more experienced physicians who may not be in the hospital at the time of inquiry [139, 140].

6.5.4.3 Image Tagging

The findings in Table 6.1 show that images comprised 72.6% of media messages sent between physicians, which suggest the need for a system that allows efficient retrieval of images previously sent between physicians. F3 is needed to associate images with topics for future reference. Although F1 uses text to associate topics to messages, F3, in addition, will automatically describe the contents of images, which can provide a better association of relevant images to specific inquiries [141]. Using F3 combined with F1 and F2, physicians can save time when searching for information that is not related to their role of treating patients, and it may contribute to reduction of non-clinical tasks [16, 142].

6.5.4.4 Summarized Notifications

Summarized notifications are needed to prioritize messages since physicians need to be able to access important information in most relevant messages. LINE is preferred by physicians because of its simple user interface; however, the notification feature is not convenient for large group chats. As shown in Table 6.2, miscellaneous messages make up the largest category of messages (18.4%); although this category is useful, an immediate response may not be required. Thus, from the notification, emergency physicians can determine whether it is feasible to open certain messages during a busy shift. Although miscellaneous conversations may be useful for the team, this feature can limit miscellaneous messages that can be seen as interrupting to physicians’ role [143]. F1 can contribute to summarized notifications from medical oriented SNS applications.

6.5.4.5 Additional Features

Additional features for consideration are (1) an opt-in location sharing system and (2) access to patient records via the medical oriented SNS application. These considerations are mainly influenced by the ‘patient’, ‘team’, and ‘situation’ categories. Since the additional features may contribute to privacy concerns, additional guidelines and safeguards should be included for physicians who wish to share their location; physicians should have the option of revoking access to their location. Prior to a physician receiving requested information, they need to access the holder(s) of the relevant information [16]. During emergencies (day-to-day and after disasters), physicians needed at a certain point in time can be located by their colleagues. Since rules and regulations regarding the handling of patient data vary among countries, additional guidelines are needed to govern access to patients’ clinical information via medical oriented SNS applications [144].

Kawai et al. [145] analyzed physicians’ use of SNS for communication after natural disasters; their results led to the design and implementation of a feature integrated into an SNS application to support disaster medical assistance teams. During emergencies such as a disaster aftermath, communication between physicians includes the use of medical information under certain guidelines. Using third-party communication platforms such as SNS applications, consideration must be given to how medical information is used [146] and shared among medical professionals. Additionally, during emergencies, physicians prefer communication tools that can be used beyond limitations of the internal hospital environment. Categories shown in section 3.1 and proposed features can address their preferences.

6.5.5 SNS in Hospitals

Integrating healthcare information that is user-centered is an ongoing challenge. Yu et al. [61] described characteristics of the healthcare domain towards improving interaction in EDs. Among the characteristics mentioned were non-routine, mobile, highly collaborative and information-rich. This study considers the mobile nature of physicians’ roles where use of cellular phones, although convenient, is limited to two participants at a time. Additionally, although a third-party SNS application such as LINE or WhatsApp can provide group communication between physicians, the features available are not physician-centered. Physicians cannot communicate freely using third-party applications partly due to privacy concerns and current medical guidelines [33]. A physician-centered SNS platform that can support medical information sharing without using third-party platforms is more appropriate for the healthcare setting [146, 147]. An integrated SNS platform in hospital can revolutionize how physicians access needed information using integrated SNS applications on mobile devices. This study focuses on improving physicians' communication, a subset of broader interactions that occur in the healthcare domain.

6.5.6 Limitations

This study focused on physicians in the medical emergency department of one hospital. However, to ensure flexibility of communication between physicians, a medical oriented SNS platform linking physicians in many hospitals is preferred. Furthermore, topics discussed by nurses and other health care professionals need to be investigated towards the design of an integrated SNS platform that considers various healthcare professionals.

6.6 Conclusion

Physicians' usage of SNS applications for health-related communication has increased recently and has revolutionized communication between physicians. In this retrospective study, we categorized 13 topics based on messages exchanged between emergency physicians, and we discussed their usefulness in the design a physician-centered SNS platform customized to the role of emergency physicians. The categories coded by two coders were 'miscellaneous' , 'patient' , 'team' , 'treatment' , 'event' , 'situation' , 'reference' , 'announcement' , 'schedule' , 'resource' , 'policy' , 'transport' and 'unknown' . Mondays and Fridays were the days where most messages were sent between physicians.

The coded categories and number of messages sent in relation to shifts and days influenced our proposal of the following features: (F1) a structured tagging system for messages related to relevant categories, (F2) an inquiry broadcast system for specific inquiries using F1, (F3) an image tagging system for images shared within groups, and (F4) summarized notifications. Additional features for consideration include an opt-in physician location sharing system and (2) access to patient records via the medical oriented SNS application.

The use of mobile SNS applications has improved healthcare communication between physicians. Improving the convenience of physicians' SNS discussions and access to information is possible using medical oriented SNS applications with SNS features designed in part by physicians, for physicians.

This chapter contributed a data-driven feature proposal based on physicians SNS discussions towards designing a medical oriented SNS system that is focused on the healthcare community [148, 149]. After receiving patient information from various sources, the proposed features support the design of an SNS application that enables physicians to support their colleagues and share patient information. This chapter concludes the detailed explanation of our research achievements presented in Chapters 4 through 6. The next chapter contains additional discussions related to this thesis.

Chapter 7

Discussion

Through an ethnographic understanding of the ED setting Chapter 4 showed our establishment of a social basis for Chapters 5 and 6. In Chapter 5, we designed a mobile patient information sharing system using patient representatives. The proposed design aimed at proximal and remote sharing interaction between physicians and representatives was evaluated using feedback from both the patient and healthcare community. Chapter 6 focused solely on the healthcare community by understanding physicians through their data (instant-messaging history) as opposed to the observations in Chapter 4 which had a social approach to understanding. This chapter presents discussions and possible future research directions based on this thesis.

7.1 Privacy and Security for Patient Information Sharing

Privacy in healthcare systems is paramount to healthcare system success. Considering this fact, the aspect of improving and tweaking security standards of centralized databases such as the Confidentiality Integrity Availability (CIA) triad forms a basis for the development of secure mechanisms for these systems. Informational dimension of privacy is related to the non-dispersion of private information concerning individuals [108]; when this idea is considered in this thesis, the individual is the patient who has their medical information collected and stored in an centralized system such as EHRs.

Privacy in centralized healthcare databases cannot be achieved without considering basic models like the CIA triad which can be considered the blue print of computer security and includes privacy [150]. A threat to confidentiality is unauthorized release of information. A threat to integrity of data is unauthorized information modification, and a threat to availability is the unauthorized denial of use of information [151]. Accountability dictates that all actions should be traceable to the person who committed them, and this should be focused on both internal (within the system) and external actions (outside of the system) [150].

A patient's medical information can be placed into two categories, sensitive and non-sensitive information [5]. Sensitive medical information is information about medical history that an individual does not want revealed to the public domain, e.g. domestic violence, sexually transmitted diseases, abortions etc. The sensitivity of medical information creates the necessity for privacy of patients' record by ensuring confidentiality. There still exists a lack of trust and acceptance because of concerns about the privacy of some centralized database systems. In light of these concerns, various efforts have been undertaken to ensure and preserve privacy in centralized database systems such as EHRs [7, 65, 152].

7.2 Trade-off between Stakeholder Preferences

Balancing stakeholder expectations and preference is one of the challenging parts of designing patient information sharing systems that are inclusive of both the patient and healthcare communities. Designing based on the mutual benefits to both communities is a starting point that can yield the social basis for future implementation of proposed community based deign concepts. Baxter and Sommerville [29] mentioned that *"the main concern of the system developers is usually whether the system meets the specified requirements. The main concern of the users is usually whether the system will help them do their job, without adversely affecting other parts of their work…Reconciling these different concerns is not a simple task"*. The task of iterative, inclusive design is far from simple since designers must establish a point of focus; should we focus on the healthcare or patient community? Considering the opinions of both communities sets a stronger basis for future research on the value an integrated community based patient sharing system can contribute benefits to healthcare organizations and society as a whole.

The patient expects certain attributes of a patient information system such as privacy, security, granular control and granular awareness. On the other hand, HCPs require up-to-date, confidential, relevant and efficient access to patient information. T. D. Wilson discussed some key concepts of information sharing, two of which were trust and benefit [15]; considering the benefits of patient information availability, trust has to be weighed against the benefits of using the representative to preserve patient preference while ensuring information availability to HCPs.

7.3 Design using Patients' Representatives

7.3.1 Benefits to Society

Having information available to the people authorized to use it satisfies the Availability factor of the CIA triad and, in the case of health care, can help physicians make more informed and timely decisions. The ability for the physician to access the clinical data of the patient gives rise to fewer expenses for both the hospital that the physician belongs to and the patient. Resources needed for the physician to perform various tests on the patient can be conserved, and the patient can have a lower medical bill at the end of their consultation; this may also affect the stability of their insurance premiums. For instance, a physician will use basic medical procedures to treat an unconscious patient before making an informed decision about the source of the problem which can be caused by multiple factors. The patient may have fainted because of diabetes, the use of narcotics, a mental disorder and even a lung problem. To make a more informed decision about the best procedure to use to treat the patient, the physician must perform a series of tests to make a better diagnosis. In the case of a perceived lung problem, the physician will need a to perform a computerized tomography (CT) scan. The need for these tests can be eliminated using an avenue where a representative can remotely or in proximate vouch for the physician' s access to the patient' s record.

Availability can be satisfied further by possibly expanding the our scope to include other members of the healthcare community research to include other medical professionals such as nurses. To achieve this, a collective, secure platform is required for HCPs to access the record of the patient using the professional trust networks that currently exist at health care institutions. However, when more sensitive information like patients' clinical data is made available, risks of confidentiality breach also increase since many actors are involved. The role of the representative can be expanded to have more features in the future as the system functionality is developed. It is hoped that in the future, health data protection will be not just a technical subject, but also a social one by a concerned portion of society.

7.3.2 Applicability Beyond Emergency Departments

In the context of patient information sharing and the field of Human Computer Interaction (HCI), no system has been proposed to improve the interaction between HCPs and patient representatives in situations where the physicians cannot access patient information directly during an episode of care. Within design sciences and the human computer interaction field, our contribution sets the foundation for future design activities using representative' s role in situations apart from emergencies; this provides a social background for design and implementation activities focused on improving the ability of patient community members to be more actively involved in supporting HCPs both socially and technologically. Developing countries, which may be highly community centered but cannot implement EHR systems, can use our concept to achieve higher patient information availability to physicians at a fraction of the cost taken to have a nationwide EHR system.

7.3.2.1 Healthcare Representatives: Additional Use Case

Our proposed system can also support physicians' treatment of domestic and foreign tourists who travel with family members. Regulations currently prevent cross border patient information sharing, and it is not our intention in this paper to argue for a change in regulations. However, the possibility exists for healthcare systems to be revolutionized to the point where a patient can travel with family members who can share patient information with authorized HCPs in different countries.

During the aftermath of disasters such typhoons or earthquakes, our design concept can be used to provide an alternative for physicians to obtain patient information if the EHR is not currently accessible. Since searching for patient information is actually a non-clinical task, our proposed system can reduce the time taken for HCPs to obtain patient information after disasters. Smartphones have been improved to become more resistant to natural elements like water. In the future we assumed that a larger number of elderly patients will have basic smartphone literacy that can allow them to use our system.

Apart from emergency situations in EDs and disaster aftermaths, our proposed system can be useful in telemedicine and regular consultations where capable patients can share their information with HCPs who cannot access their EHR. Parents and guardians of elderly persons and children can be able to actively share and revoke access to patient information.

The following is an example use-case for our proposed concept in a disaster aftermath:

> A typhoon hits the Kyuushuu Region during a busy summer season. Since it is summer, there are many domestic and international tourists stranded due to grounded flights. The local hospitals are overcrowded with patients who were severely injured during the flooding that occurred during the typhoon. Among the patients are a large number of elderly people, comprising of

> local residents, domestic tourists and foreign nationals. HCPs need patient information to assist in treatment and decision making since a considerable amount of patients are being encountered for the first time. Because of the flood, use of electrical equipment is done with caution and broken telephone lines have also affected internet access.

Based on the above scenario, our proposed system, can be use for proximal information sharing:

Proximal Sharing Some of the incapable domestic and foreign patients are accompanied by their family members (representatives). Assuming the representatives are situational aware of the ED setting and has patient information stored on their mobile device, HCPs can obtain patient information during verbal interaction. Representatives are able to share patient information but are not able to see the information. Thus if the mobile device of the representative is stolen, their application version does not have the functionality to view patient information.

Similar to the above example, in the case of a pandemic such as the recent COVID-19 outbreak, our concept can be applied used for proximal and remote patient sharing.

7.3.2.2 Banking Representatives

Along with information, money is also seen as valuable. There are many cases where representatives (family members) access the finances on behalf of another person who may be incapable. Our concept can support using *context-based* banking representatives in mobile banking. Based on the situation and preference of the account holder, a representative can access a certain amount of money for a particular predefined purpose; this can also be useful for parents/guardians and their children as representatives. Additionally, virtual banking representatives (VBR) can also act as gatekeepers for people with poor spending habits, and VBR role can also assist with managing cash flow of patients/children who live alone or maybe be hospitalized without family members. Additional situational regulations are needed to realize a similar version of our concept in banking and other fields.

7.3.2.3 Electoral Representatives

During country elections, many barriers exist for people incapable of voting. Some developed countries have systems allowing citizens to vote online; however, many countries have not implemented such systems. From a socio-technical viewpoint, our representative concept can be useful for citizens who are not physically present in the country of elections but want their vote to be counted (Voter A). After successful registration, Voter A can select the desired candidate and will so notify the representative (Voter B). Voter B is assumed to be in the country during elections. In this case, the representative (Voter B) will be held accountable for preserving Voter A's choice for a presidential candidate. In developed countries, although there is online voting for citizens in other countries, if the citizen becomes unconscious, their vote may not be counted (Voter 1). Our proposed concept, from a socio-technical viewpoint, can be adapted into this situation where Voter 1 can appoint a representative (Voter 2) to vote on behalf of Voter 1.

7.3.2.4 Education

When a patient chooses a representative, they utilize various factors, each factor depending on the patient. In education, choosing a mentor or tutor depends on various individual factors. As introduced by Lave et al. [153],'*Legitimate peripheral participation*' where a "learners intentions to learn are engaged and the meaning of learning is configured through the process of becoming a full participant in the socio-cultural practice". From a socio-technical point of view, mentor and tutor selection that is based not only on the accomplishments but also the shared backgrounds and experiences that can be used to create trust and comfort between the learner and the tutor, who can be seen as someone holding knowledge about a particular career path and is 'reminding' the learner about their abilities through close mentorship and teaching.

Another application in the education field is during student grade sharing where guardians of students can share grades of a student in the event a student is incapable.

7.3.2.5 Additional Applications

In each of the fields presented above, the goal of the representative will generally be to act in the best interest of the person being represented; however, roles vary based on the actual situation. For example, a representative can share information on behalf of an unconscious patient in an ED, but in banking, transferring money to someone who is authorized may still require an additional approval process. Some companies can automatically obtain the updated credit card information for persons who have changed their credit cards and can continue to charge the accounts of people for services that the account holder does not use or may have forgotten. This raises some ethical concerns although it may be legal. Our system concept can support people who may not be knowledgeable about these possibilities and have someone they trust represent them during similar confusing financial situations.

Additional fields that can be explored are agriculture (seed distribution and farming on behalf of a temporarily incapable farmer) and social media representation. Furthermore, in the fields of anthropology, the concept can be used as a basis of culturally specific research about intra- and inter-community support systems that serve as the "bedrock" of some indigenous and 'modern' communities.

Our definition of representative in this proposed system design is socio-technical; however, future research can extend this current research to design and test the use of virtual representatives, driven by AI to assist patients and citizens who live alone.

7.4 Open Issues for Future Implementation

To achieve an integrated patient information system that supports, it is necessary to consider many components. Each information source that physicians utilize requires consideration. In this thesis we focused mainly on the patients representative, one of the information sources. The proposed design concept relies on additional factors beyond the scope of this thesis to ensure future large-scale implementation.

Patient information needs to be created before it can be stored. Although we focus on the interaction between physicians and patient representatives, patient information has to be created by either patient or physicians and stored in PHR or EHR systems. The integrity of patient information needs to be ensured since it is assumed that many physicians will be able to access patient information. In Japan, inter-hospital cooperation is also required to ensure that updated patient information is collected and stored for future access using our proposed concept. In the case of Japan, since hospitals own patient information, an incentive system that provides realistic benefits must be created. However, creating international incentive systems pose an even greater challenge.

Additionally, regulations and policies at organizational and government levels requires consideration. Including the representative in system requires policy and regulatory measures to support the implementation of the system. Regulations about the use of patient information vary among countries. In Japan, patient information must be stored on a server located within the country. Although our proposed concept is ideal for sharing cross-broader patient information sharing based on patient preferences, government regulations is a current barrier.

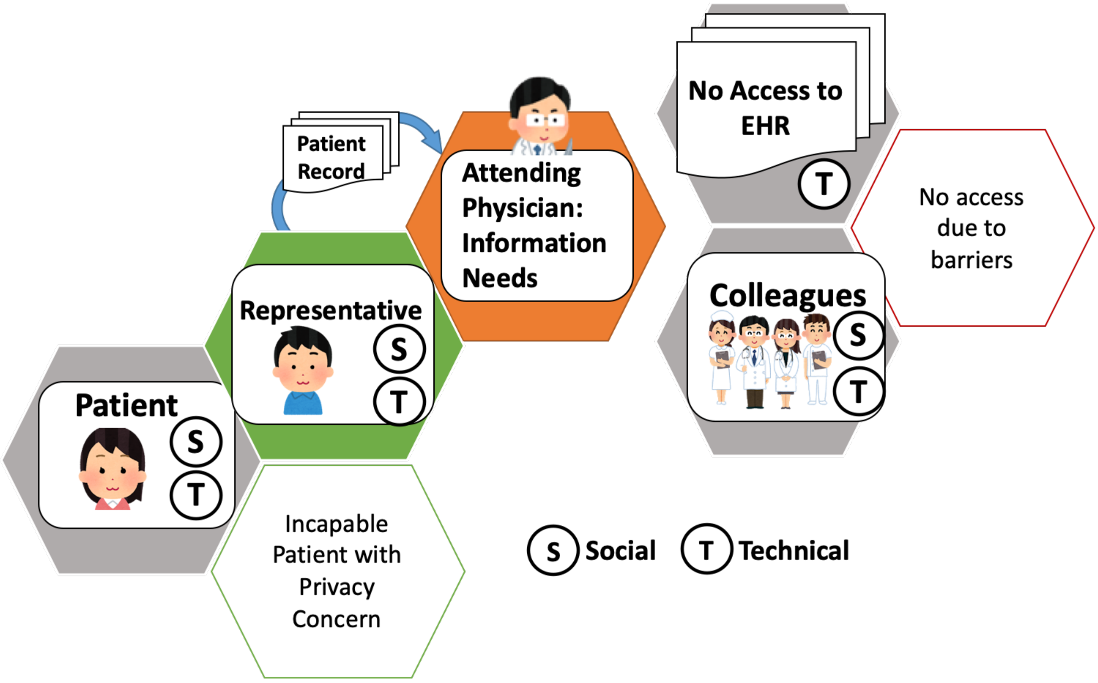

Figure 7.1: Situation where the use of our proposed concept is ideal for physicians and patients; socio-technical introduction representatives for patient information sharing can support future EHR system implementation

Based on the situation, physicians utilize the information source that is faster and more convenient. During situations where HCPs cannot directly access patient information from EHR systems, our concept provides an avenue for improved interaction between physicians and patient representatives using our socio-technical approach. Figure 7.1 illustrates where our proposed concept contributes to the acceptance of EHR systems to support future implementation of a community-based integrated patient information sharing system. This concept can also be utilized during daily emergencies and the aftermath of disasters where electricity and networks can not be available to physicians. In these cases, introducing a socio-technical role for patient representatives can support the implementation of nationwide EHR systems in countries where patient privacy concerns hinder implementation.

7.5 Future Directions

The scope of this thesis focuses on the design of a patient information sharing system that includes patient and healthcare communities; I recommend the following future research directions in the context of patient information sharing which are discussed in the remaining sections.

7.5.1 Patient Community Based

Autonomous Patient Representative Selection and Prioritization for Dynamic Communities

A fraction of patients usually have more than one entity to whom they can entrust the role of representative, but this may create barriers in the representative selection process. Future research into a method to select a remote patient representative who will respond in the shortest period of time can improve remote patient information sharing from patient representative.

Pricing Model for Patient Representative Performance

Many patients may not have direct access to someone that suits their preferences for a patient representative. Elderly patients may have access to a caregiver or someone who visits regularly to assist with shopping, cleaning and other activities. Younger adults may also have problems accessing a *contextual* representative. Research into methods to compensate non-family volunteer representatives can assist in increasing patients access to representatives who can share patient information based on a contractual agreement. Compensating the representatives may increase motivation; however, it leads to the question about, how can we balance motivation for compensation with genuine effort of representative to assist patients?

7.5.2 Patient and Healthcare Community Based

Integrated SNS system for patient and healthcare community information

SNS applications systems have revolutionized information sharing through direct instant messaging; however, SNS applications have mainly blossomed in the public domain. Utilizing the feature proposal in this thesis, future research can investigate patient community involvement with patient information sharing using a healthcare based SNS system.

Patient Social Information Extraction and Summarizing using SNS

Many patients utilize SNS on a day-to-day basis; the daily activities and events patients are involved in can serve as a rich source of summarized social information for use by HCPs. Future research should investigate a method that extracts the social activities of patients and integrate these activities into the ADL record of the patient. Results from this thesis support the need for improved social information sharing with HCPs.

This chapter presented discussions relating to healthcare system security, patient representatives and a broader view into other domains, open issues and future directions based on the contents of this thesis. The next chapter concludes this thesis by presenting our research contributions and my brief closing remarks.

Chapter 8

Conclusion

Patient and healthcare community cooperation is crucial to improved patient information sharing in healthcare. The healthcare community requires patient information to perform their professional role, whereas the patient community requires involvement, perceived control and awareness of activities relating to patient information. Considering these preferences, one information source that has not been explored in the context of patient information sharing is the patient representative, a member of the patient community.

This thesis examines the patient representative and introduces a *contextual* technological role that considers both communities in the context of patient information sharing. A mobile application was designed and prototype developed to include remote and proximal information sharing from patients' representatives in the event a patient is unable to do so.

To achieve a socio-technical mobile patient information sharing system, the following chapters in this thesis present four main parts to our community focus; Chapter 4 takes an ethnographic approach to understand the cultural context involving interactions between the patient and healthcare community in the ED. Chapter 5 focuses on the patient and healthcare community by introducing the design and prototyping of a mobile patient information application for remote and proximal sharing scenarios. Patient preferences for using their representatives for remote information sharing were obtained along physicians' perceptions about the system for proximal information sharing. Chapter 6 focuses on the healthcare community interactions in the emergency setting.

This thesis primarily contributes the design of an inclusive patient information sharing system that considers both patient and healthcare communities; the patient representative is introduced as a socio-technical "bridge" between these communities in a *contextual* role. I view representatives as supporters of patients and HCPs. Therefore future research is necessary to ensure that supporters are also supported; it is believed that this “meta-support” is vital for the patient community. The term, “meta-support”, was used because the physician is seen as the entity with information requirement who can be supported by various human information sources such as representatives. However, support for the supporters (representatives) are required; thus the term, “meta-support”. The next section summarizes in detail my research contributions in this thesis.

8.1 Contributions

Designed representative categories based on understanding of ED context
Little is known about how to categorize patient representatives for the purposes of designing patient information sharing systems. We present three categories in which representatives can be included based on a contextual ethnographic understanding of the ED setting. These categories are useful to establish a social basis for the design of future mHealth solutions that includes patient representatives. This contribution sets the basis for future research into designing systems based on the patient community that focuses beyond patients to consider other patient community members. The patient representative is an information source that is yet to be explored in detail. Future research can use this contribution as a basis to categorize and develop specific support systems for patient representatives.

Design for Remote and Proximal Patient Information Sharing using Patient Representatives
We present a novel socio-technical design of a patient information sharing application based patient representatives in the event a patient is incapable of sharing information; the use cases included were proximal and remote patient information sharing. In the context of patient information sharing via patient representatives; these use-cases have never been explored in previous studies. This can assist future research into technical and socio-technical systems that consider the patient community and are not solely limited to the healthcare domain. The research trends in using artificial intelligence can use this contribution to introduce virtual representatives for patients who live alone across in parts of the world where the appropriate infrastructure is available.

Described Patient Attitudes Towards using Patient Representatives for Remote Sharing
In the context of patient information sharing, we present the preferences of Japanese citizens towards using patient representatives in the event they become unconscious. The results show that a fraction of patients are willing to use their representatives and

desire granular preferences for controlling and being awareness of patient information sharing activities, even when they are unconscious. Previous research reported patients' granular preferences for sharing their information, but this did not extend to patient representatives. This contribution sheds light on patient preferences regarding their representatives.

Identified Physician Perceptions of Patient Representatives for Mobile Patient Information Sharing
In the context of patient information sharing, we present the preferences of physicians towards using patient representatives in the event patients are incapable. The results show that some physicians consider the proposed concept useful in the ED setting. Additionally, some physicians were willing to use the application in their personal lives. This contribution sets a basis for future research into healthcare based systems that involve interaction between HCPs and representatives of the patient community.

Performed a Usability Evaluation for Proximal Patient Information Sharing based on Physicians' Experience
We presented the development and usability evaluation of a prototype for proximal patient information sharing based on the proximal interaction between physicians and patient representatives. The results show that physicians are satisfied and find the proposed system usable in the ED setting based on its *ease of use* and *user satisfaction*.

Created a Data-driven Feature Proposal for SNS Interaction between Physicians
A list of features is reported based on a retrospective analysis of physicians instant messaging history. No study has previously been done to clarify what design features are required to implement an internal information sharing system that includes patient information sharing by physicians. This contribution can assist future policy-based research to develop guidelines to governs the use of patient information by HCPs; in turn this can assist designers in the design of a healthcare based SNS application system that can improve interactions within the healthcare community.

8.2 Closing remarks

Compiling the material for this thesis was a rewarding experience with both highs and lows that has indeed made my journey balanced. Basing the research in a cultural context that was different to mine gave me a fresh perspective of approaching solutions, a skill that can be applied in personal endeavours as well. My research combined both qualitative and quantitative evaluation methods during the design process. The challenge of balance creativity and a free flowing mind of ideas to existing problems with the rigidity of the research process has greatly affected my outlook on many current global and culturally specific issues. Furthermore, presenting the overall vision while at the same time having justifiable detailed evidence is my primary take-home message. The thesis began with the African proverb, "*Wisdom is like a baobab tree, no one man can embrace it completely*"; this proverb has driven my search for not just knowledge, but wisdom derived from various communities and cultures while knowing that the more I discover, the more I want to know. Let us continue along the path that lead to knowledge and understanding.

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Appendix A

Appendix A: Information Privacy Concerns

A.1 Privacy

Privacy is a basic human need [154] , and it is linked to the social contract theory dating back to ancient Greece. By this theory, privacy is part of morality which "consists in the set of rules governing behaviour, that rational people would accept, on the condition that others accept them as well" . Privacy concepts were developed long before the advent of informational technology. Privacy has multiple meanings and definitions. It relates to the right of an individual to control how, when and the amount of information about themselves is given to another individual [155]. Warren and Brandeis define privacy as "the right to be let alone" [156]. Privacy can also be the feeling that other persons should be excluded from anything that relates to an individual and also a consideration for the right to do such [157]. The complexity of determining a concrete definition gave rise to defining privacy using a multidimensional approach.

Traditional definitions cannot be comfortably applied to privacy because of rapid changes in technology and focuses regarding data use and data housing. Privacy has been defined in four dimensions that include physical, psychological, social and informational privacy [108, 110]. Within this paper, our reference to privacy refers to informational privacy. Definitions of informational privacy have long been under discussion; because of the rapid evolution of the information age, traditional ways of understanding privacy do not account for key aspects of unique problems the information age has introduced [158]. This means that previous understandings of information do not equate to the problems and concerns faced with the use of modern information systems. Informational privacy is believed by many to be the control an individual has over the outcome of their personal information [159].

A.2 Privacy Concerns

Privacy concerns are related to the heart of the definition of privacy [155], and these were present long before the implementation of electronic information systems [51, 155]. Privacy and privacy concerns are so intertwined that one cannot exist without the other. Understanding privacy concerns is not a simple definitive process. Privacy concerns have introduced new factors in the advent of the modern information age, and these supersede traditional privacy concerns about digital information. In this dissertation, privacy concerns refer specifically to informational privacy concerns.

Privacy concern literature began expanding in the 1960s; in the decade of 1990 quantification of privacy concerns occurred that led to proposals of the Concern for Internet Privacy scale (CFIP) and the Medical Privacy Concern Index (MPCI). More recently the CFIP has been validated and a proposal for the Internet Users Information Privacy Concern (IUIPC) scale has been developed.

Smith et al. [51], based on the social contract (SC) theory, developed and validated the Internet Users'Privacy Concerns (IUIPC) scale which had three dimensions as opposed to the CFIP and Global Internet Privacy Concerns (GIPC) scale [52]; these were collection, control and awareness. Smith et al. [51] stated that "the dimensionality of CFIP is neither absolute or static, since perceptions of advocates, consumers, and scholars could shift over time" . This statement was used as a basis to develop the IUIPC; "given the fundamental change in the marketing environment caused by the widespread adoption of the Internet" . They aimed to achieve three goals (1) Examine the nature and dimensionality of IUIPC, (2) attempt to operationalize the multidimensional nature of IUIPC using a second-order factor construct and develop a scale for it, and (3) propose and test a causal model that focuses on IUIPC. Malhotra et al. [52] was of the view that "when applied to information privacy, SC theory suggests that a firm' s collection of personally identifiable data is perceived to be fair only when the consumer is granted control over the information and the consumer is informed about the firm' s intended use of the information". The collection factor is considered central theme of information exchange based on the SC theory. This factor was seen to be like the collection dimension of the CFIP and thus it remained a dimension in the IUIPC scale. The control factor represented individuals' freedom to voice their opinions and opt-out. The individual can be able to control the collected information about them. The awareness factor indicates the understanding about existing conditions and organizational practices. Individuals awareness of the use of collected information incorporated two justices -interactional (transparency of information) and informational (disclosure of specific information). Apart from Collection which remains the same, Malhotra et al. [52] argued that control and awareness summarizes unauthorized secondary use, improper access, and error which were the dimensions of the CFIP. A causal model was developed to illustrate the notion of IUIPC as shown in Figure 4. In Figure 4, personal dispositions contain the three dimensions of IUIPC. Context-specific factors show the relationship between privacy concerns of internet users and their trusting beliefs, risk beliefs and actions they will take based on behavioural intentions. These factors are based on previous studies which proposed frameworks based on trust, risk beliefs and behavioural intentions of concerned individuals [160–162]. Malhotra et al. [52] used previous studies to define trusting beliefs as the extent to which individuals' beliefs in an organization' s ability to protect personal information [163, 164]. Risk beliefs refer to an individual' s anticipation of possible information loss related to personal information collected by the organization from the individual [165]. Malhotra et al. (cite) hypothesized that IUIPC will have a negative effect on trusting beliefs but a positive effect on risk beliefs (H1 & H2). H3 indicates that trusting beliefs negatively affect risk beliefs. H4 indicate that trusting beliefs increase the behavioural intentions. They mentioned the contextual variable as the type of information (sensitive vs. not sensitive). Covariates are factors outside the scope of IUPC that may affect IUIPC e.g., IUIPC can be affected by invasion of privacy in the past.

Appendix B

Remote Sharing Prototype Development

A prototype was created to demonstrate the proposed system design shown in Figure B.1.

B.1 Database Structure

The initial design of the database relies on the central EHR database to house the accounts of doctors, patients and the representative. Within the database of conventional

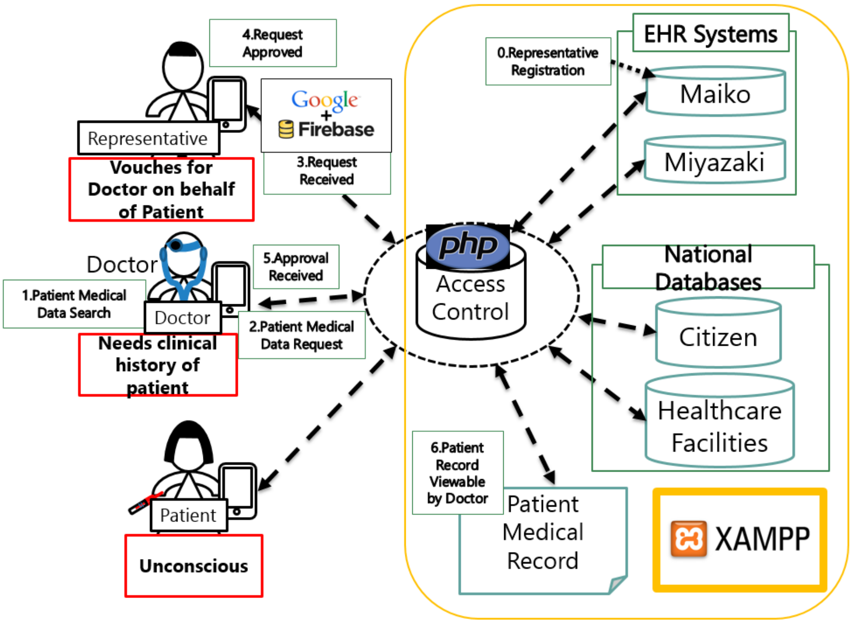


FIGURE B.1: Structure of Demonstration Prototype for Remote Patient Information Sharing

EHR systems, a table for representatives with the EHR IDs of the patients they represent need to be included. For demonstration purposes, the simulation was built with a maximum of 5 representatives as the limit for the patient. In this database, it is assumed that a representative can also be a patient or a doctor. This the national ID of the person is used as a foreign key in the EHR database to uniquely identify the individual.

B.2 Server-side Application

Based on the conceptual idea designed in Figure B.1, this demonstration for an EHR system was created with its base in the Kyoto University Hospital. Using local Apache HTTP server software, a MySQL database was created along with a prototype linked to the database using PHP, a server programming language. Databases were created to simulate two EHR systems. A citizen database was created with a sample list of actors and their national IDs. Database registration was done for the actors, and unique IDs were assigned to doctors in each EHR. User accounts were also made using username-password method for the actors. At the server level, access control was simulated to validate the users’ accounts during the requested sessions to ensure that the two actors accounts have signed into before requests can be sent or received. Views for the actors were created to show their main roles after they have logged in.

B.3 Client-side Application

In scenario one, a desktop computer was designated to the doctor and an iPad was used for the patient views. Using the server-client model, the request from doctor was sent to the patient. In scenario two, a desktop computer was designated to the doctor and the representative was assigned a mobile phone which used an android platform. A mobile application was created to facilitate the push notifications to the representative’ s phone and allow faster access to the request view within a preinstalled prototype application. The awareness of the patient and their representative(s) was facilitated using Google’ s Gmail service. A messaging service was used to facilitate the real-time push notifications to the representative’ s phone for situation two.

Appendix C

Evaluation Scenarios and Questions

C.1 Survey Scenarios

Scenario One (S1): The patient is conscious and visits the hospital for a consultation with the doctor. The patient and doctor are assumed to have logged in before using our system and to have access to the Internet via their devices. The patient visits a doctor because the patient has been experiencing chest pains. Upon consultation, the doctor decides to view their clinical history before performing a CT scan (Figure C.1).

Scenario Two (S2): The patient is assumed to have registered representative(s) in our system before the emergency occurs. The patient and the doctor have logged in before

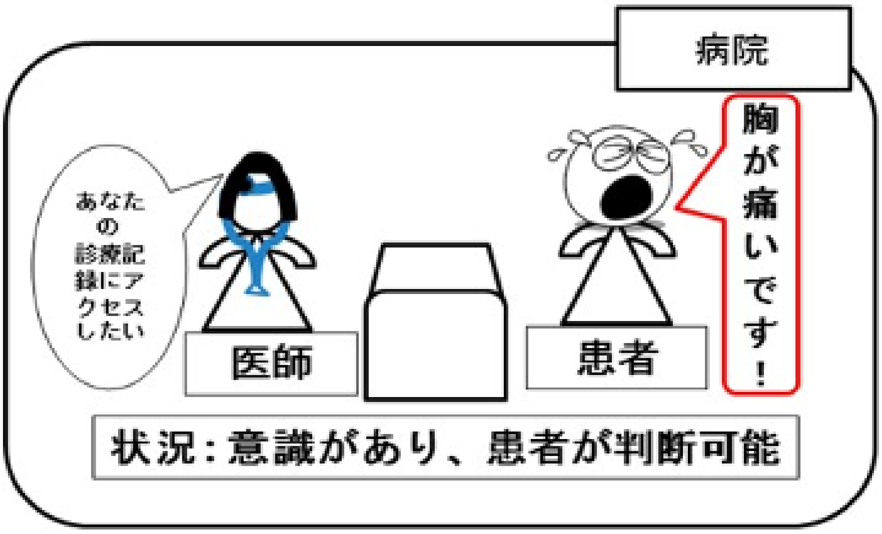


Figure C.1: Illustration of Scenario One

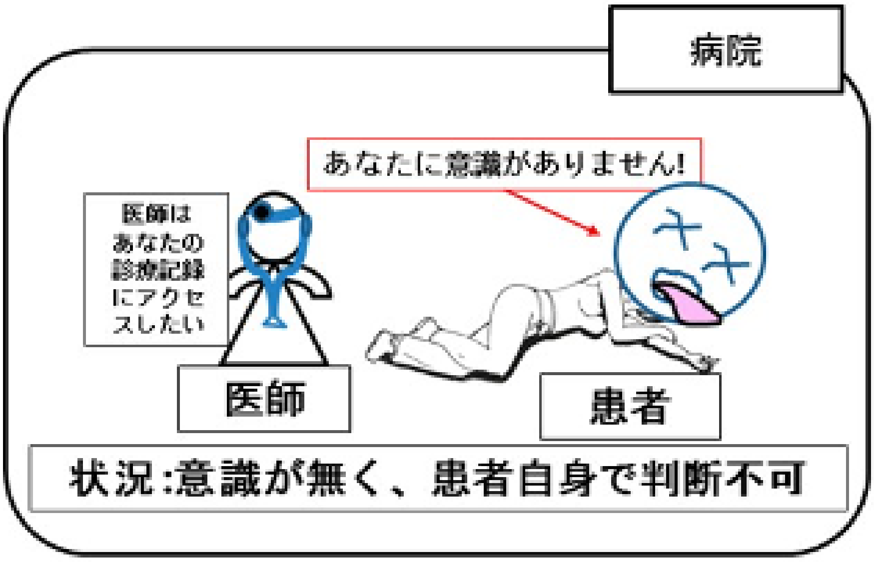


Figure C.2: Illustration of Scenario Two

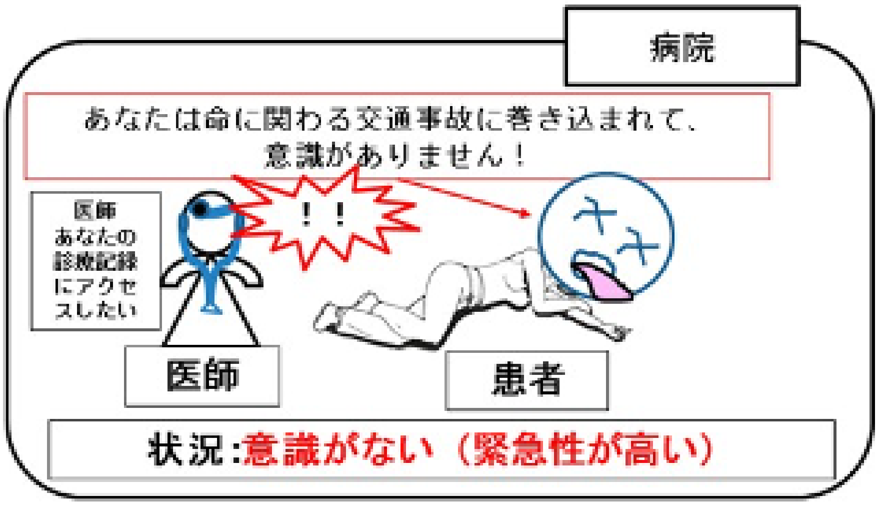


Figure C.3: Illustration of Scenario Three

using our system and have access to the Internet via their devices. The doctor can use a unique number to search for the patients' medical record. In this situation, the patient is not in a life-threatening situation (Figure C.2).

Scenario Three (S3): The patient is assumed to have registered a representative in our system before the emergency occurs. The patient and the doctor have logged in before using our system and have access to the Internet via their devices. In this situation, the patient is in a life-threatening situation, e.g. brain injury from a car accident (Figure C.3).

C.2 Survey Scenarios - Japanese

シナリオ1 (S1): あなたと医師の両者ともがシステムにログインし，またインターネットにアクセスできる状況を想定してください．あなたは胸に痛みを覚えたため医師の元へ診察を受けに行きます．診察において，医師はCTスキャンを実施する前にあなたの診療記録を確認しようとします (Figure C.1)

シナリオ2 (S2): あなたは，緊急事態が生じる前に，我々のシステムにおいて代理人を登録している状況を想定してください．あなたと医師はシステムを使用する前に既にログインしており，インターネットにも各自のデバイスを通してアクセスできる状況です．医師はあなたの固有の番号を使ってあなたの診療記録を検索します．ここでは，あなたは生命の危機にさらされている状況ではありません．(Figure C.2)

シナリオ3: あなたは，緊急事態が生じる前に，我々のシステムにおいて代理人を登録している状況を想定してください．あなたと医師はシステムを使用する前に既にログインしており，インターネットにも各自のデバイスを通してアクセスできる状況です．ここで，あなたは生命の危険にさらされている状況です（例えば，自動車事故による脳震盪）(Figure C.3)

C.3 Survey Questions

Overview

We are currently doing research on the privacy concerns of patients. Privacy concerns exist wherever uniquely identifiable data relating to a person or persons are collected and stored, in digital form or otherwise. We designed a system for patients to control and be aware of who accesses their data.

To test the usefulness of our system design before the implementation, we would like to have your feedback about your privacy concerns. This survey is expected to take approximately 10 – 15 minutes of your time. The following diagram illustrates the purpose of our system.

Privacy Notice

Your personal data will not be disclosed to any organizations. The results will be collectively used for academic analysis only.

1. Do you use a smartphone or tablet? 1-Yes, 2-No
2. When using a smartphone, which of the following best describes your ability?
   a. 1 – I have no experience using a smartphone
   b. 2 – I know how to turn a smartphone on/off and use it for making calls only
   c. 3 – I can make calls, handle emails and use the web browser
   d. 4 – I can make calls, handle emails, use the web browser and change my device settings
   e. 5 - I can make calls, handle emails, use the web browser, change my device settings, download and use applications
3. If you were to receive a new smartphone, after turning it on, which of the following items best describes your preferences?
   a. 1 – Change security settings to include a lock code **before** connecting to the internet
   b. 2 - Change security settings to include a lock code **after** connecting to the internet
   c. 3 – I use the smartphone **without changing** the security settings
   d. 4 – I don't know what security settings are

Definitions

Basic information – information that can be used to know or verify your identity, e.g. name, address, age, photo etc.

Medical record - a record of a patient's medical information (as medical history, care or treatments received, test results, diagnoses, and medications taken).

Medical history - an account of all medical events and problems a person has experienced.

Emergency card – a card that has a unique number that can be used to identify yourself. The emergency card also is a key the doctor can use to access your medical record.

Sensitive information – important information about your medical history that you may not want to be revealed to the public, e.g. domestic violence, sexually transmitted diseases, abortions etc.

Scenario One – You are conscious (in a state to make your own medical decisions)

4. First, the doctor needs to access your basic information. How would you prefer the doctor to identify you and search for your basic information?

    a. Doctor uses your ID number to search for your basic information and, after that, will continue to have access to your information when needed in the future. The medical care can be faster since the doctor will not require your permission to access your basic information.

    b. Instead of using your ID, you use your smart phone to generate a temporary number and show to it to the doctor. The doctor then uses this number to identify you and search for your basic information only this time, if he needs to access your information in the future, he will need to ask for your permission and you'll generate a new number. This alternative will work even when you forget your identification cards since your identity is linked to the generated number.

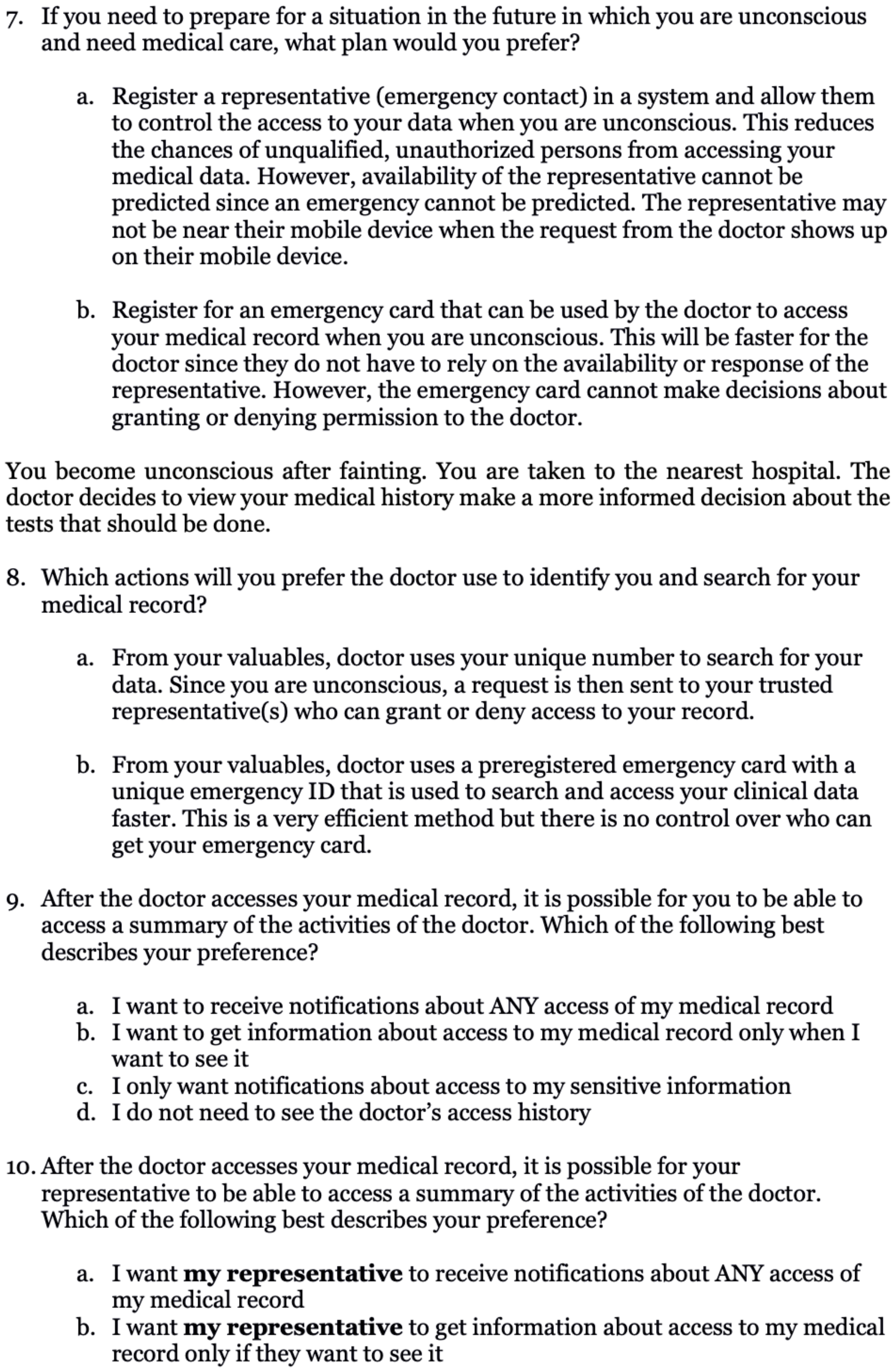
5. The doctor has now identified you, can see your basic information and wants to access your medical record. Which action do you prefer?
    a. Doctor requires your permission to access your clinical data, since you have full control of it. The doctor sends a request to your device. You decide whether or not the doctor can access your data. This increases consultation time, as the doctor will require your permission before accessing your medical record but gives you more control over who can access your data.

    b. Doctor can access your clinical data without requiring your intervention. This reduces the consultation time since the doctor can access your data and form an opinion about the next treatment process in a shorter time, but you won't have control over when they access your record.

6. After the consultation, it is possible for you to be able to access a summary of the activities of the doctor about treatment used and the data they required during the consultation. Which of the following best describes your preference?

    a. I want to receive notifications about ANY access of my medical record
    b. I want to get information about access to my medical record only when I want to see it
    c. I only want notifications about access to my sensitive information
    d. I do not need to see a summary of the consultation and the doctor's access history

Scenario Two – You become unconscious but not in a fatal condition
A representative is the emergency contact the patient chooses to make medical decisions on their behalf in the event of an emergency. We designed a system that includes the representative as an alternative person that can grant access to the requesting doctor in the event that the patient is unable to do so.



7. If you need to prepare for a situation in the future in which you are unconscious and need medical care, what plan would you prefer?

    a. Register a representative (emergency contact) in a system and allow them to control the access to your data when you are unconscious. This reduces the chances of unqualified, unauthorized persons from accessing your medical data. However, availability of the representative cannot be predicted since an emergency cannot be predicted. The representative may not be near their mobile device when the request from the doctor shows up on their mobile device.

    b. Register for an emergency card that can be used by the doctor to access your medical record when you are unconscious. This will be faster for the doctor since they do not have to rely on the availability or response of the representative. However, the emergency card cannot make decisions about granting or denying permission to the doctor.

You become unconscious after fainting. You are taken to the nearest hospital. The doctor decides to view your medical history make a more informed decision about the tests that should be done.

8. Which actions will you prefer the doctor use to identify you and search for your medical record?

    a. From your valuables, doctor uses your unique number to search for your data. Since you are unconscious, a request is then sent to your trusted representative(s) who can grant or deny access to your record.

    b. From your valuables, doctor uses a preregistered emergency card with a unique emergency ID that is used to search and access your clinical data faster. This is a very efficient method but there is no control over who can get your emergency card.

9. After the doctor accesses your medical record, it is possible for you to be able to access a summary of the activities of the doctor. Which of the following best describes your preference?

    a. I want to receive notifications about ANY access of my medical record
    b. I want to get information about access to my medical record only when I want to see it
    c. I only want notifications about access to my sensitive information
    d. I do not need to see the doctor's access history

10. After the doctor accesses your medical record, it is possible for your representative to be able to access a summary of the activities of the doctor. Which of the following best describes your preference?

    a. I want **my representative** to receive notifications about ANY access of my medical record
    b. I want **my representative** to get information about access to my medical record only if they want to see it

   c. I only want **my representative** to get notifications about access to my sensitive information
   d. I do not want **my representative** to see the doctor's access history

Scenario Three – You become unconscious and is in a fatal situation

11. If you need to prepare for a situation in the future in which you are unconscious and need medical care, what plan would you prefer?

    a. Register a representative (emergency contact) in a system and allow them to control the access to your data when you are unconscious. This reduces the chances of unqualified, unauthorized persons from accessing your medical data.

    b. Register for an emergency card that can be used by the doctor to access your medical data when you are unconscious. This will be faster for the doctor since they do not have to rely on the availability or response of the representative.

12. Which actions will you prefer the doctor use to identify and search for your medical information?

    a. From your valuables, doctor uses your unique number to search for your data. Since you are unconscious, a request is then sent to your trusted representative(s) who can grant or deny access to your record.

    b. From your valuables, Doctor uses a preregistered emergency card with a unique emergency ID that is used to search and access your clinical data completely and efficiently. This is a very efficient method but there is no control over who can get your emergency card.

13. After the doctor accesses your medical record, it is possible for you to be able to access a summary of the activities of the doctor. Which of the following best describes your preference?

    a. I do not need to see the doctor's access history
    b. I only want notifications about access to my sensitive information
    c. I want to get information about access to my medical record only when I want to see it
    d. I want to receive notifications about ANY access of my medical record

14. After the doctor accesses your medical record, it is possible for your representative to be able to access a summary of the activities of the doctor. Which of the following best describes your preference?

    a. I do not want my representative to see the doctor's access history
    b. I only want my representative to get notifications about access to my sensitive information
    c. I want my representative to get information about access to my medical record only if they want to see it

d. I want my representative to receive notifications about ANY access of my medical record

General Question

15. Do you have any additional comments or concerns? (Free Response)

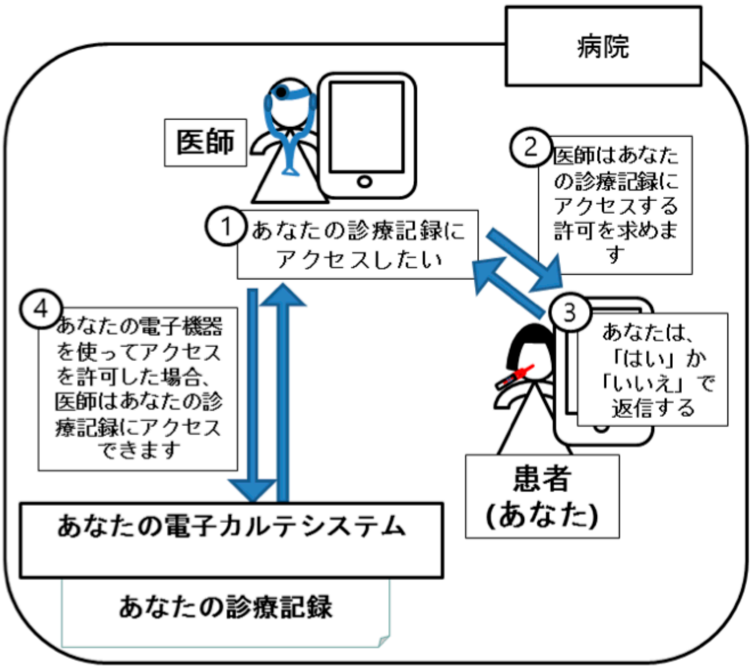
1.1 Survey Questions (アンケートの質問ー日本語)

概要

本研究では，診察時に医師が患者の診療記録等のデータにアクセスする状況における，患者観点でのプライバシーに関する懸念事項について調査しています．

デジタルという形式に関係なく，個人や組織などを一意に特定可能なデータを収集または保管するいかなる場合においてもプライバシーに関する懸念は存在します．そこで，私たちは患者自身に本人に関連するデータへのアクセスを管理したり，気づきを与えたりするシステムを設計しました．このシステム設計はプライバシーに関する懸念を削減することを目的としています．私たちのシステム設計の有用性を確認するために，あなたの思うプライバシーに関する懸念について教えてください．この調査は約１５分くらいかかります．

下図は私たちの提案するシステムを示していますので参考にしてください．



プライバシーに関する声明

この調査で得たあなたの個人データはどこにも開示しません．ご回答の結果は，学術用途にのみ使用します．

1. あなたはスマートフォンまたはタブレットを使用しますか？2 いいえを選択された方は，次の 2 と 3 への回答は不要です．
   1- はい，使用します, 2- いいえ，使用しません

2. スマートフォンを使用するとき，あなたの能力として適合するものを選択してください
    a. スマートフォンと使用した経験がない
    b. 電源のオン・オフと電話の掛け方は知っている
    c. 電話，メール，ウェブブラウザを使用できる
    d. 電話，メール，ウェブブラウザの使用はもちろんのこと，デバイスのセッティングの変更も行える
    e. 電話，メール，ウェブブラウザ，セッティングに加え，ソフトウェアのダウンロードなどもできる
3. もし新しいスマートフォンを受け取ったら，電源を入れた後，あなたの好みに適合するものを選択してください
    a. インターネットに接続する前にロックコードを含むセキュリティの設定を行う
    b. インターネットへの接続後，ロックコードを含むセキュリティの設定を行う
    c. セキュリティの設定変更を行うことなくスマートフォンを利用する
    d. セキュリティの設定が何かわからない

定義

基本情報 - 個人の身元を特定することのできる情報；例）名前，住所，年齢，電話番号など.

診療記録 - 患者の診療情報の記録（病歴，治療，検査結果，診断結果，薬剤など）.

病歴 - 患者が体験した全ての医療事象や問題の記録.

緊急連絡カード - 個人を特定できる固有の番号を記載したカード．このカードは医師があなたの診療記録にアクセスできるようになるキーです.

保護必要情報 - 公になって欲しくないであろうあなたの病歴など，扱いを慎重に行うべき重要な情報（家庭内暴力，性的感染症，中絶など）.

シナリオ１ー 患者に意識がある場合（患者自身で症状を伝えることができる）

4. まず，医師はあなたの基本情報（氏名，年齢，住所など）にアクセスする必要があります．医師があなたを特定し，基本情報にアクセスする方法としてどちらを好みますか？

    a. 医師はあなたの ID 番号を使ってあなたの基本情報を検索する．その後も ID 番号を知っている限り，必要に応じてあなたの情報にアクセスできる．医師は毎度あなたの許可を得ずとも基本情報にアクセスできるため，即時性の高い医療を提供できる.

    b. あなたの固有の ID を使用するのに代わり，スマートフォンを使用し，一時的な番号を発行して医師に見せる．医師は一定期間中のみ，その番号を使ってあなたを特定し，基本情報を検索できる．以降，医師があなたの情

報にアクセスしたい場合，医師からの要求に応じて，再度あなたが新たな一時的番号を発行するという手順となる．生成された番号はあなたに紐付けられているため，たとえあなたが ID カードを忘れたとしてもスマートフォンがある限りこの方法は有効である．

5. 医師があなたを特定後，あなたの基本情報を閲覧し，診療記録にアクセスできる状態です．この場合，どちらの行動を好みますか？

    a. あなたが制御権を保持しているため，医師はあなたの臨床データにアクセスするためにアクセス権を要求することになる．具体的には，コンピュータなどの機器を通して要求が行われる．その後，あなたが医師のアクセスに関して判断を行う．この方法では，医師があなたの診療記録にアクセスする前に必ずあなたに許可を得る必要があるため，そのやりとりに時間を要することになる．しかしながら，あなたは誰があなたのデータにアクセスできるのかをきちんと管理することができる．

    b. 医師は，あなたの介在を必要とせず，あなたの臨床データにアクセスできる．これによって，医師が短い時間であなたのデータにアクセスし，次の治療過程に関する意見をまとめられるため，診察にかかる時間が短縮される．しかしながら，医師があなたの記録にアクセスする際に，あなたはそれらを管理することができない

6. 診察後，その診察中に行われた診療や医師が要求したデータに関して，医師が行なった診療行為のまとめを確認することができます．下記のうち，どれがあなたの好みに適合しますか？

    a. 自身の診療記録への全アクセスに関する通知を受け取りたい
    b. 見たいときだけ，アクセス情報を閲覧したい
    c. 慎重に確認すべき事項のみ通知を受け取りたい
    d. 診察のまとめや医師のアクセス記録を見る必要はない

シナリオ 2 - 患者に意識は無いが，致命的では無い場合

"代理人"は緊急連絡先となります．緊急時に限り，患者自身に代わって医療判断を行うことのできる人として，患者が事前に選出します．我々は，患者本人が対応不可能な場合に，その代理人を患者本人に代わって医師にアクセス権を譲渡できる権限を持つ仕組みを設計しました．

7. 意識不明になり，治療を必要とする状況に備える必要があるとしたら，次のうちどの行動を選択しますか？

    a. 代理人をシステムに登録し，自身が意識不明の状態の時に限り，代理人らにデータへのアクセス権の管理を譲渡する．これによって，許可を得ていない人があなたの診療データにアクセスする機会を減らすことができる．しかしながら，緊急事態の発生予測は難しく，さらには代理人の都合

も考慮しなければならない．医師からの要求が携帯機器に送られたとしても，そのときに代理人が携帯機器の近くにいないかもしれない．

b. あなたが緊急連絡カードに登録することで，医師はそのカードを使って，あなたが無意識のときにあなたの診療記録にアクセスすることができる．これは代理人の都合や返答に頼る必要がないため，医師にとって素早くことを進められる．しかしながら，その緊急連絡カードでは，その場に応じて医師からのアクセス要求を許容したり，拒んだりする意思決定は難しい．

あなたは失神を起こし，意識不明の状態に陥り，近くの病院に運ばれました．そこの医師は実施すべき検査についてより見聞の広い判断を行うために，あなたの病歴を閲覧しようとします．

8. あなたを特定し，診療記録を検索するために医師が行う行動として，次のどちらを好みますか？

    a. あなたの貴重品の入った鞄等から，医師はあなたの固有の番号を使用してあなたのデータを検索する．あなたは意識不明であるため，医師からの要求はあなたが信頼を置く代理人に送られる．代理人は，あなたの記録へのアクセス権を管理している．

    b. あなたの貴重品の入った鞄等から，医師は事前に登された緊急連絡カード（固有の緊急用 ID も記載）を使用する．このカードによって検索やあなたの診療データへのアクセスも素早く行える．これはとても効率的な方法ではあるが，あなたの緊急連絡カードを手にする人を管理することはできない．

9. 医師があなたの診療記録にアクセスしたあと，医師の診療行為のまとめにアクセスすることができます．次のうち，どれがあなたの好みに適合しますか？

    a. 自身の診療記録への全アクセスに関する通知を受け取りたい．
    b. 見たいときだけ，アクサス情報を閲覧したい
    c. 慎重に確認すべき事項のみ通知を受け取りたい
    d. 診察のまとめや医師のアクセス記録を見る必要はない

10. 医師があなたの診療記録にアクセスしたあと，あなたの代理人が医師の診療行為のまとめにアクセスすることができます．次のうち，どれがあなたの好みに適合しますか？

    a. 代理人に自身の診療記録への全アクセスに関する通知を受け取ってもらいたい
    b. 代理人が見たいときだけ，代理人がアクセス情報を閲覧できるようにしたい
    c. 慎重に確認すべき事項のみ代理人に通知したい

d. 診察のまとめや医師のアクセス記録を代理人に見せる必要はない

シナリオ 3 - 重大な事態によって意識を失った場合

11. 意識不明になり，治療を必要とする状況に備える必要があるとしたら，次のうちどの行動を選択しますか？
    a. 緊急連絡先として代理人をシステム上で登録し，意識不明時には彼らにあなた自身のデータへのアクセス管理を任せる．これによって，あなたの許可を得ていない人による診療データへのアクセスの機会を減らす.
    b. 意識不明時に医師があなたの診療データにアクセスするのに使用できる緊急連絡カードを登録する．医師にとっては，代理人の都合や返答に頼らなくても良いため，治療が素早く行える

あなたは自動車事故によって脳震盪を起こし，近くの病院に運ばれました．あなたの状態が安定したあと，医師は，輸血必要になる患者の血液型やその輸血の結果に応じた手術について，より見聞の広い判断をするためにあなたの病歴にアクセスしようとします.

12. あなたを特定し，診療記録を検索するために医師が行う行動として，次のどちらを好みますか？

    a. あなたの貴重品の入った鞄等から，医師はあなたの固有の番号を使用してあなたのデータを検索する．あなたは意識不明であるため，医師からの要求はあなたが信頼を置く代理人に送られる．代理人は，あなたの記録へのアクセス権を管理している.

    b. あなたの貴重品の入った鞄等から，医師は事前に登された緊急連絡カード（固有の緊急用 ID も記載）を使用する．このカードによって検索やあなたの診療データへのアクセスも素早く行える．これはとても効率的な方法ではあるが，あなたの緊急連絡カードを手にする人を管理することはできない.

13. 医師があなたの診療記録にアクセスしたあと，医師の診療行為のまとめにアクセスすることができます．次のうち，どれがあなたの好みに適合しますか？

    a. 自身の診療記録への全アクセスに関する通知を受け取りたい.
    b. 見たいときだけ，アクサス情報を閲覧したい
    c. 慎重に確認すべき事項のみ通知を受け取りたい
    d. 診察のまとめや医師のアクセス記録を見る必要はない

14. 医師があなたの診療記録にアクセスしたあと，あなたの代理人が医師の診療行為のまとめにアクセスすることができます．次のうち，どれがあなたの好みに適合しますか？

    a. 代理人に自身の診療記録への全アクセスに関する通知を受け取ってもらいたい

- b. 代理人が見たいときだけ，代理人がアクセス情報を閲覧できるようにしたい
- c. 慎重に確認すべき事項のみ代理人に通知したい
- d. 診察のまとめや医師のアクセス記録を代理人に見せる必要はない

その他

15. 本件に関して，その他のご意見やお気付きの点，懸念事項等ありましたらこちらに記入してください.

Appendix D

Patient Preferences: Significant Results

D.1 Inter-Scenario Relation

There was significance of respondents concerned about control and their preference of patient control and representative control for all scenarios. The most significance came from the correlation between S1 and S3 (Figure D.1). The same significance was present for respondents who had no concern for control and their preference for no control for themselves and their representatives. Figure 5.17 shows that about half of respondents who choose control in scenario one, chose representative control in the event they become unconscious. Half of those respondents chose no representative control using an alternative.

D.2 Conscious Patient (RS1)

In Table 5.5 the data shows that patients concerned about their clinical data are likewise concerned about awareness ($z > 2.58$). It was also found that they were mostly likely to not choose no awareness. These results in S1 suggests that patients concerned about control may also choose full awareness of activities regarding their medical data.

D.3 Unconscious Patient (RS2)

Tables 5.6 and 5.7 shows that patients who chose representative control are least likely to choose representative awareness of sensitive information access only ($z > 2.58$). This

	Item	Group	Fisher Exact Test	X^2	X^2 Value	*p*-value				Cramer Coefficient	Questions
						Fisher		X^2			
						value	Confidence	value	df		
	2	<65, =>65	1	1	8.5281	$p < .05$	--	$p < .05$	3	0.165861	Q14
	2	<=47.7, 47.7>	3	3	18.329	$p < .01$	2.081060 8.894173	$p < .01$	1	0.2431572	Q7
					12.694	$p < .01$	--	$p < .01$	3	0.2023606	Q10
					13.842	$p < .01$	--	$p < .01$	3	0.2113065	Q14
	3	20-39, 40-49, 50-79	3	3	19.8836	$p < .01$	--	$p < .01$	2	0.1800144	Q7
					16.348	$p < .05$	--	$p < .05$	6	0.1637078	Q10
					16.06	$p < .05$	--	$p < .05$	6	0.1622587	Q14
Intra-Scenario	2	S1	2*	2*	19.297	$p < .01$	0.259057 0.5623216	$p < .01$	1	0.2494982	Q4 vs Q5
					19.548	$p < .01$	--	$p < .01$	3	0.251112	Q5 vs Q6
	2	S2	3	3	40.277	$p < .01$	3.52137 13.64263	$p < .01$	1	0.3604506	Q7 vs Q8
					14.315	$p < .01$	--	$p < .01$	3	0.2148906	Q7 vs Q10
					195.08	$p < .01$	--	$p < .01$	9	0.4580011	Q9 vs Q10
	2	S3	2	2	79.298	$p < .01$	8.021685 39.196197	$p < .01$	1	0.5057659	Q11 vsQ12
					258.77	$p < .01$	--	$p < .01$	9	0.5274919	Q13 vsQ14
Inter-Scenario (Control)	2	S1 vs S2	2	2	11.477	$p < .01$	1.649973 8.138435	$p < .01$	1	0.1924088	Q5 vs Q7
					10.116	$p < .01$	1.393195 4.435597	$p < .01$	1	0.1806479	Q5 vs Q8
	2	S1 vs S3	2	2	8.8534	$p < .01$	1.409993 6.241529	$p < .01$	1	0.1689949	Q5 vs Q11
					10.767	$p < .01$	1.424234 4.457804	$p < .01$	1	0.1863698	Q5 vs Q12
	2	S2 vs S3	4	4	69.498	$p < .01$	6.342797 27.224249	$p < .01$	1	0.4734834	Q7 vs Q11
					29.218	$p < .01$	2.681867 10.021108	$p < .01$	1	0.307006	Q7 vs Q12
					40.804	$p < .01$	3.514845 13.319191	$p < .01$	1	0.3628041	Q8 vs Q11
					94.666	$p < .01$	7.838158 27.585293	$p < .01$	1	0.5526066	Q8 vsQ12
Inter-Scenario (Awareness)	2	S1 vs S2	2	2	476.13	$p < .01$	--	$p < .01$	9	0.7155176	Q6 vs Q9
					110.67	$p < .01$	--	$p < .01$	9	0.3449676	Q6 vs Q10
	2	S1 vs S3	2	2	385.15	$p < .01$	--	$p < .01$	9	0.6435379	Q6 vs Q13
					121.06	$p < .01$	--	$p < .01$	9	0.3607894	Q6 vs Q14
	2	S2 vs S3	4	4	577.09	$p < .01$	--	$p < .01$	9	0.7877353	Q9 vs Q13
					189.05	$p < .01$	--	$p < .01$	9	0.450862	Q9 vs Q14
					259.06	$p < .01$	--	$p < .01$	9	0.5277847	Q10 vs Q13
					727.03	$p < .01$	--	$p < .01$	9	0.8841688	Q10 vs Q14

FIGURE D.1: Significant correlations and the corresponding values (p < .05, p < .01) suggests that respondents concerned about control are also concerned about awareness of their representative in the event they fall unconscious. Individuals who chose no representative control also tend to choose awareness of sensitive data access only of their representative ($z > 2.58$). This suggests that respondents who are not concerned about control still want a level for awareness of their sensitive medical information.

D.4 Unconscious Patient: Life-threatening Situation (RS3)

Table 5.8 suggests that patients concerned about awareness prefer the same level of awareness for their representative in the event the patient is unconscious ($z > 2.58$). These results from S3 support our hypotheses H1-3 and H2-2, but do not justify the argument that people choosing control have a stronger tendency to prefer awareness because there was no correlation between the control and awareness questions in the conditions under which they collected within this survey. Future investigations may be able to clarify this finding.

D.5 Age Groups

Group 1 : The data in Table 5.20 suggests that respondents 65 and older tend to prefer granular awareness for their representative in the event they are unconscious from a life-threatening event ($z > 2.58$).

Group 2 : Data from Figure D.1 suggests that people 47 years and younger prefer representative control in the event they become unconscious ($r_c = 0.24$). In this group, people 47 years and younger chose awareness of sensitive data access only ($z > 2.58$). This suggests that people 47 years and less tend to prefer a granular level of representative awareness in the event they are unconscious for S1 and S2 (Table 5.21 and 5.22). This result is similar to the preference of respondents who are less than 65 years old (Table 5.20).

Group 3 : Data from Table 20 indicate that respondents in the age range of 20-39 choose representative control at the pre-registration phase in S2. Table 5.22 data indicate that the same age group concerned about control tend to not prefer full awareness of their representative.

Appendix E

Representative and Physicians: Design Scenarios for Proximal Information Sharing

E.1 Unconscious Patient (PS1)

Patient is unconscious based on the Glasgow Coma Scale, as shown in Figure E.1.

E.2 Conscious but Incapable (PS2)

Patient is conscious but has a psychological problem, as shown in Figure E.2.

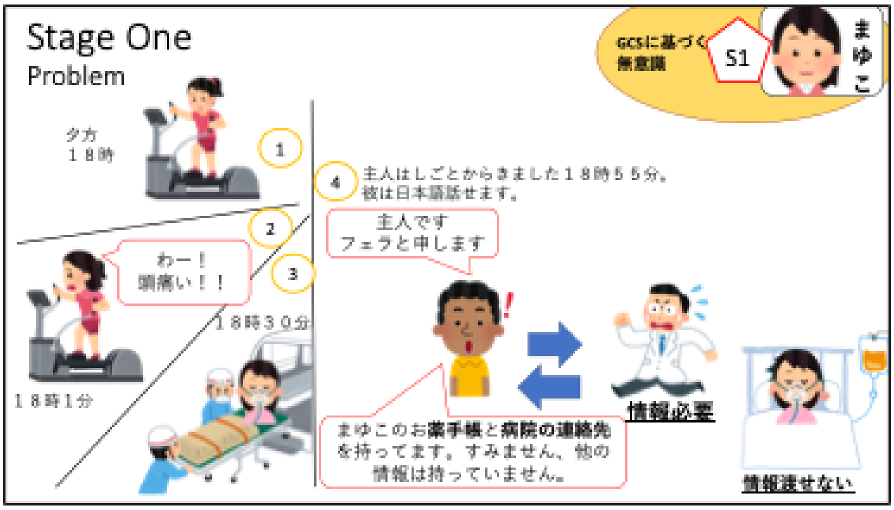


Figure E.1: Proximal Information Sharing: PS1

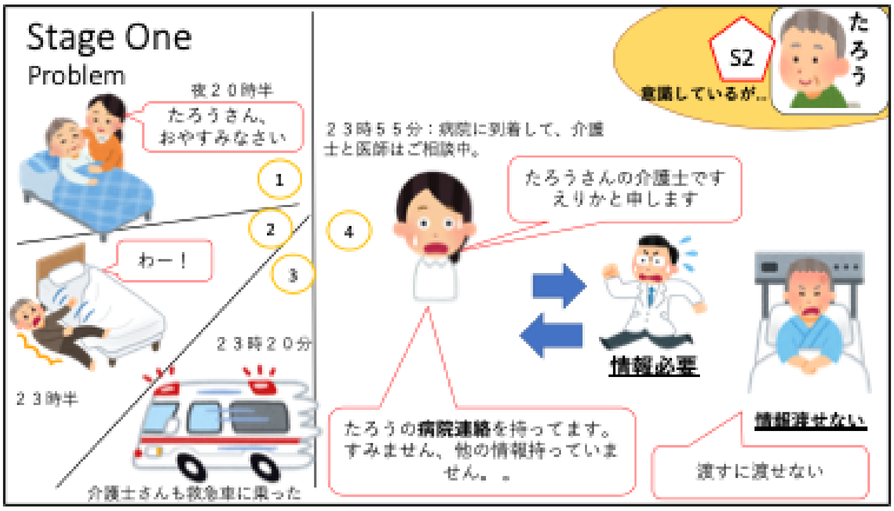


Figure E.2: Proximal Information Sharing: PS2

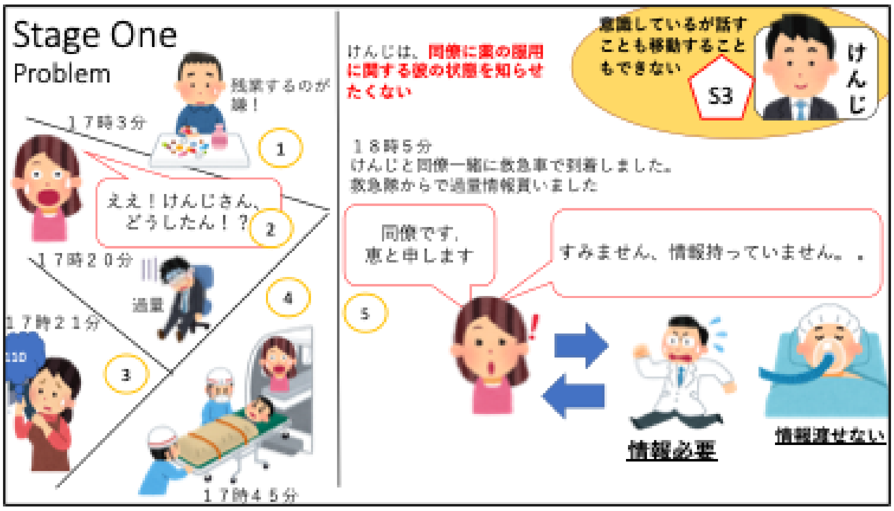


Figure E.3: Proximal Information Sharing: PS3

E.3 Conscious but Incapable (PS3)

Patient is conscious but in an impaired mental state from drug abuse, as shown in Figure E.3.

List of Publications

Journals

1. Kensuke Morris, Goshiro Yamamoto, Osamu Sugiyama, Luciano H.O Santos, Takahiko Tsutsumi, Ohtsuki Ryo, Kato Genta, Hiragi Shusuke, Okamoto Kazuya, Nambu Masayuki, and Tomohiro Kuroda. “Designing a Mobile Patient Information Sharing System using Patient’ s Community Members: Perceptions of Emergency Physicians”. In: *EJBI* 16.2 (2020).
2. Kensuke Morris, Osamu Sugiyama, Goshiro Yamamoto, Manabu Shimoto, Genta Kato, Shigeru Ohtsuru, Masayuki Nambu, and Tomohiro Kuroda. “Towards a Medical Oriented Social Network Service: Analysis of Instant Messaging Communication among Emergency Physicians”. In: *Advanced Biomedical Engineering* 9.0 (2020), pp. 35–42. ISSN: 2187-5219.

International Conferences

1. Kensuke Morris, Goshiro Yamamoto, Shusuke Hiragi, Shosuke Ohtera, Michi Sakai, Osamu Sugiyama, Kazuya Okamoto, Masayuki Nambu, and Tomohiro Kuroda. “Designing an authorization system based on patient privacy preferences in Japan”. In: *Studies in Health Technology and Informatics*. Vol. 247. 2018, pp. 71–75. ISBN: 9781614998518.
2. Kensuke Morris, Naoto Kume, Goshiro Yamamoto, Shinji Kobayashi, Kazuya Okamoto, Hiroshi Tamura, and Tomohiro Kuroda. “Authenticating Unknown Doctors for Access to EHRs Based on Societal Trust.” In: *Studies in health technology and informatics*. Vol. 245. 2017, p. 1308. ISBN: 9781614998297.

Domestic Conferences

1. Kensuke Morris, Osamu Sugiyama, Goshiro Yamamoto, Manabu Shimoto, Genta Kato, Shigeru Ohtsuru, Masayuki Nambu, and Tomohiro Kuroda. “Analysis of Instant Messaging Communication among Emergency Physicians”. In: *Biomedical Engineering Symposium*. Tokushima: Japanese Society for Medical and Biological Engineering, 2019.
2. Kensuke Morris, Goshiro Yamamoto, Shosuke Ohtera, Michi Sakai, Shusuke Hiragi, Kazuya Okamoto, Osamu Sugiyama, Naoto Kume, Masayuki Nambu, and Tomohiro Kuroda. “Reducing Patient Privacy Concerns via Access Control to EHRs”. In: *37th Joint Conference on Medical Informatics*. Osaka: Japan Association for Medical Informatics, Oct. 2017, pp. 512–517.

Patents

1. 直人 粂, 晴俊 矢崎, 純三 佐藤, and モリス ケンスケ. 提供システム及び提供プログラム.