

**DESIGNING A HOLISTIC PROTOTYPE AND EVALUATING THE
REQUIREMENTS OF LONG-TERM CARE ELECTRONIC HEALTH RECORD**

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REQUIREMENTS OF LONG-TERM CARE ELECTRONIC HHEALTH RECORD**

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Abstract

Our research is aimed at exploring the design requirements of long-term care information system or electronic health record based on the needs of the care providers. It helped in evaluating the current status of long-term care EHRs and how it could be enhanced through data collected by interviews with long-term care providers. The considerations for the design was framed by investigating the current long-term care electronic health record status and how it could be improved by analyzing an aging in place model of care, TigerPlace that supports independent living for the elderly. Evaluation was done on the technology employed at TigerPlace and how can be extended to other long-term care facilities. TigerPlace is equipped with three disparate systems for storing residents' health information. A prototype was designed through a single interface, using a human-centered framework to holistically represent information from three disparate systems at TigerPlace, and by conducting face-to-face interviews with a couple of care providers in the long-term care, in order to understand their information needs. The information collected through interviews was used to understand the problems and concerns of long-term care providers and how it could be used to enhance current long-term care electronic health record systems.

1. Introduction

1.1. Aging and Long-Term Care

Information technology can assist patients with self-management, communication with their doctors and participate in prevention and treatment programs. Information systems are needed in current healthcare settings to assist providers with the care process. Use of electronic health record (EHR) and electronic medical record (EMR) in healthcare systems, hospitals, and clinics are being mandated by healthcare reforms to meet the standards that improve patient-care and interoperability of health information across the healthcare systems. The health information systems are essential in long-term care (LTC). LTC refers to the patients' care process for chronic diseases and often multiple chronic conditions, either from home, an institution or an acute care setting, which includes both inpatient and ambulatory care settings. LTC includes all the support services needed, i.e. physical therapy, rehabilitation etc. by the elderly to stay healthy. LTC and chronic disease management has special implication for the elderly population who have co-morbidities and need enhanced avenues to take care of their health and stay functionally (physically and mentally) active. At present, the numbers of elderly population in the United States are on an increase due to the aging of the baby boomer's generation (Knickman & Snell, 2002) and are the highest users of healthcare in the United States (Chandra & Gong, 2012).

1.2. TigerPlace

TigerPlace, is a retirement community that has the Aging in place care model which aims senior residents to live a more independent life and allows them to live in an environment of their choice and take supportive services as needed by them to stay functionally active (Skubic, Alexander, Popescu, Rantz, & Keller, 2009). To address common aging problems different kind of assistive technology are used to support the elderly with their functional decline. The information generated by using assistive technologies can be used as a tool to detect early changes in health conditions to determining the need of early intervention, monitoring and continuation of customized healthcare needs of the elderly (G. Demiris, Oliver, Dickey, Skubic, & Rantz, 2008). It is believed that by using an appropriate program that uses supportive, restorative, and assistive services by the elderly, can improve their health and well-being without the need of moving them to a traditional nursing home care-setup (Cowan & Turner-Smith, 1999; Yang Gong & Chandra, 2011b).

TigerPlace is an independent living facility for the elderly is also equipped with technology i.e., sensors, to monitor residents' health condition, mobility, and activity level, helping to enhance aging in place. Collaboration with different multidisciplinary teams at the School of Nursing, School of Medicine, and College of Engineering, at the University of Missouri at Columbia, different kind of research is being conducted at TigerPlace (Yang Gong & Chandra, 2011b; M. Rantz, et al., 2005).

34 elderly residents between the age of 70 and 94 live at TigerPlace.

Approximately 90% of the them have a chronic illness; 60% have co-morbid conditions i.e., heart diseases, problems with mobility, problem with cognition etc. (Rantz, Skubic, Miller, & Krampe, 2008). The encounters faced by the elderly residents at TigerPlace is similar to the ones faced by most elderly, like falls or fear of falling, incontinence in urination, assistive hearing, complete hearing loss, partial or absolute blindness, reduced mobility, reduced muscle strength, social isolation, cognitive impairments, and problems with medication administration, especially for the ones with dementia (M. Aud, et al., 2010; Yang Gong & Chandra, 2011b).

2. Theoretical Framework

2.1. Method Used for Literature Review and Background Work

Thorough literature review was done from the manuscript publications available with the 'Center for Eldercare and Rehabilitation Technology' at the University of Missouri. Searches on Medline Ovid were also done to find information related to use of technology for the elderly in healthcare. Various topics were searched related to eldercare, use of electronic medical record (EMR), electronic health record (EHR), long-term care (LTC) living setups and nursing homes.

From the research papers available on 'Aging in Place' model of care, TigerPlace, gave detailed overview about the facility and the technology used there for assistive living for the elderly (M. Aud, et al., 2010; Cowan & Turner-Smith, 1999; Rantz, Skubic, Alexander, Aud, et al., 2010; Rantz, Skubic, Alexander, Popescu, et al., 2010; Skubic, et al., 2009). There has been a lot of research already done in Tigerplace by people from different streams of healthcare and science. Variety of sensors have been installed at the residents for monitoring the health and daily activity of the patients, backed up by a EMR to store the health related information (Florea, 2009). They also have the telemedicine system, which helps in effective medicine administration and collecting daily vitals of the residents (M. J. Rantz, et al., 2005).

Information was also collected from data managers who work with the data collected at TigerPlace at the intervention level, which helped in

understanding the kinds of data or information collected and used there, and gave a good understanding of the workflow of the clinical setting at TigerPlace, relevant to our research. To continue the research, it was important to understand the relationship of the data with each other and how it was related to the workflow at TigerPlace. It also provided us an understanding about how the historical data is stored and viewed by the clinicians. Managing the data to get the required information in the correct format is the most important aspect for clinical decision-making and patient care (Cowan & Turner-Smith, 1999).

Initially a field-trip interaction was also conducted for collection of information from nurses. It proved to be beneficial in understanding the setup, the problems they face with resident care, and the shortcomings of the system as a whole. It provided pointers for future implementation that would help make the system user-friendly and more convenient.

2.2. Aging Population Trends

The projected socioeconomic and demographic patterns by the year 2030 shows increased challenges for caring for the seniors that the society has to face. The elderly population is expected to double from what it is today and there are not enough assurances of sufficient resources and effective service system available for the elderly to cater to their needs (Knickman & Snell, 2002).

It is expected that much of this demographics pushed in 2030 will be by 'Baby Boomers' or "young old" aged 66 to 84, and will number about sixty one million. In addition to them are the "oldest old" born before 1946 who will number

nine million by 2030. The main challenges involving the elderly stressed on the economy would be the ability to meet the increased expenditure in the form of payment systems, advantages in the advancement of in medicine, behavioral health and technology to keep them healthy and active, organized communities for living for the elderly where they can have easy access to eldercare services, and making sure that the elderly get a well integrated community life irrespective of aging (Knickman & Snell, 2002).

2.3. Background for Long-Term Care

2.3.1. Needs of Long-Term Care

The key for long-term care patients with co-morbidities and multiple disabilities is nursing documentation for healthcare quality and nursing assessments to evaluate outcomes and risks. The providers in these facilities require improved avenues to deal with the deteriorating health conditions of the elderly, especially for pain management, pressure-ulcers etc. (Chandra & Gong, 2012).

Implementing an EHR with templates with pre-formulated assessment variables related to various nursing assessments need to be developed for pressure ulcers to facilitate user-friendly documentation and for recording pressure-ulcer prevalence and prevention (L. Gunningberg, Dahm, & Ehrenberg, 2008; Lena Gunningberg, Fogelberg-Dahm, & Ehrenberg, 2006). The accuracy in recording pressure-ulcer improves in the EHR compared to the paper-based

health records as it gives accurate and reliable feedback to the healthcare organization. High priority has to be given to develop standardized documentation practices in various areas of care in nursing the practice (L. Gunningberg, et al., 2008; Lena Gunningberg, Fogelberg-Dahm, & Ehrenberg, 2009) and evidence-based pressure ulcer prevention resources should be provided to the nurses (Chandra & Gong, 2012; Lena Gunningberg, et al., 2009).

Chronic pain is also a common and costly syndrome effecting almost one in every three United States adults. Factors such as shortened length of the medical visit, increased availability of technological approaches to care, and more informed patient suggest for a new paradigm for chronic pain management (Marceau, Link, Jamison, & Carolan, 2007). Using pain management documentation and its results can be implemented into clinical nursing practice, which requires an unified way of maintaining and recording the documentation to process the information (Asteljoki, Kesanen, Pykalamaki, Korpela, & Montin, 2009). Structured and classified documentation can help utilize different reports from electronic patient record in nursing management. The knowledge of pain management in the electronic patient record can be utilized for nursing management (Chandra & Gong, 2012; Kesanen, Asteljoki, Pykalamaki, Korpela, & Montin, 2009).

2.3.2. Current Status of Long-Term Care Facilities

The success of the treatment for the elderly depends on repeated modification of the patient's treatment regimen or simply ongoing assistance with applying a static treatment plan, which requires optimal frequency of use or

degree of involvement by health professionals. Ultimately, the consumer's perception of benefit, convenience, and integration into daily activities facilitates successful use of the interactive technologies for the elderly, chronically ill, and the underserved (Jimison, et al., 2008). Additionally, the care management plans of residents needs to be adjusted often and this change has to be clearly communicated back to the patient with tailored recommendations. Present systems have usability problems and are also unreliable in nature. The convenience of using the technology in hand has become an important factor for successful implementation and use of the system. Data entry by providers is often a cumbersome task and the intervention needs to fit into the user's daily routine. It has been noted that the frequency of interactions with a clinician helps in improving the patients satisfaction level (Chandra & Gong, 2012; Jimison, et al., 2008)

At present, most information systems being used lack a holistic view to see the relevant or most important health information related to a patient's condition. Personalized information for patients is often not available to the providers that can aide in enhanced clinical decision support. Most systems are not interoperable and do not have the facility to share information or communicate among themselves. The patient information is not portable and the user view of the data is not tailored according to the information or treatment needs of the patient. Many believe that a shared understanding of medical conditions between patients and their health care providers may improve self-care and outcomes (Chandra & Gong, 2012; Malik, et al., 2011).

2.4. Background of Tigerplace

2.4.1. TigerPlace as an Independent Living Facility

TigerPlace is an “Aging in Place” (M. J. Rantz, et al., 2005) retirement community helping seniors living independently with the help of assistive technology that addresses their common problems related to old age and general health decline i.e. functional decline (Cowan & Turner-Smith, 1999). Aging in Place model has environmental and health supportive services that promote the health of older adults and also provides options for advanced senior healthcare research. Aging in Place at Columbia, Missouri has two major parts: senior care and TigerPlace (M. J. Rantz, et al., 2005).

The senior care has been designed for senior independent living, which has different care options for the residents of TigerPlace and residents from other private congregate senior housing, public senior housing, and private homes of community-dwelling seniors in Boone County, Missouri. The needed care for the elderly is provided by specially designed ‘independent life’. For promoting the health of the older adults, the aging in place model has an environmental and health supportive services in place (M. J. Rantz, et al., 2005). The wellness center operated by senior care has ongoing health assessments and improvement classes i.e. exercise, yoga, Tai Chi for the resident health-promotion activities that helps in keeping residents active. Other home care services are also provided at the senior care facilities i.e. medication

management, assistance with daily living activities, and care-coordination of health conditions with the help of health care providers and residents' physicians. It also has the provision to provide Medicare home health for residents who qualify for the services. TigerPlace is equipped with several other facilities i.e. large community room, exercise room, wellness center, clinical space for residents' use when they are with other health care providers, and office space to facilitate senior care (George Demiris, et al., 2006).

Different types of assistive technologies have also been employed at TigerPlace to address the common aging problems related to the functional decline of the elderly residents (Cowan & Turner-Smith, 1999). The chronic illnesses of the residents are monitored in a smart-home environment (Skubic, et al., 2009) from multiple perspectives as technology and informatics has the ability to provide creative options over mainstream healthcare facilities for the residents at TigerPlace.

The researchers at TigerPlace observed that for the resident seniors the most common healthcare problems and outcomes are: falls or related to fear of falling, incontinency in urination, assistive hearing using hearing devices, complete hearing loss for some seniors, partial or absolute blindness, reduced mobility, very less muscle strength to do normal activities of the day, social isolation due to lack of connectedness with other people, partial or complete cognitive impairment and problems in medication management especially for patients with dementia or partial cognitive impairments.

2.4.2. Technology at TigerPlace to Assist ‘Aging in Place’

TigerPlace is equipped with advanced technology that helps senior residents and care providers monitor progress of healthcare and understand their general well being in the presence of multiple chronic diseases and problems. Three systems have been employed at TigerPlace: an electronic medical record (EMR) system which stores the medical records of patients from different clinical encounters that assists in proper diagnosis and treatment of the patients, a telemedicine system that helps in tracking the daily or weekly progress of the patients in the form of questionnaire which is in turn stores the vital signs and related information in the EMR system, and a sensor system that monitors the mobility and daily activities of the senior residents, effective in tracking and collecting their activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Florea, 2009). These tasks of capturing the mobility information of patients are aimed towards achieving independent living for the residents and detecting risks of injury (Skubic, et al., 2009). These three systems are independent and have their individual database systems (M. Aud, et al., 2010) preventing the clinicians to see a more holistic view of the entire information present in each of them.

The EMR system provides overall information related to the vital signs of the patient i.e. body weight, systolic blood pressure, pulse, heart rate, temperature etc., symptoms of diseases, records and tracks chronic illnesses of the senior residents, general well-being of the residents i.e. discomfort, falling, appetite, shortness of breath, chest pain, head-ache, edema etc.

In the telemedicine system, the vitals and daily general health assessment of the residents are recorded and the data is interpreted over a time range i.e. weekly or monthly basis, to track progress or decline of health for the resident. The care providers need to be able to record the general feel and well being of the resident as well in the system, which is closely related to their existing symptoms and illness for proper clinical diagnosis. Different graphical charts are available to help the care providers track the progress of a problem. Changes in these parameters alarm them of the associated health-risks (Skubic, et al., 2009).

Different kind of sensors i.e. infrared sensors, pressure sensors, electrical sensors, microphone-based sensors, imaging sensors, wireless motion sensors, etc. are installed in TigerPlace and are connected wirelessly to small personal computers in the residents living rooms (Florea, 2009). These computers are linked together to produce a sensor network. The personal computers in residents' rooms are connected to a main server to store incoming data and computation is done so that parameters related to urgent situations can be initiated. In situations where the input is beyond the defined parameter or threshold for a resident, an alert is generated in relation to the potential problem (M. J. Rantz, et al., 2005). These sensors help in deriving various physiological and outcomes measurements that has potential for a risk. Assessment of the risk factors associated of individual residents is obtained by combination of these sensors (Florea, 2009).

2.4.3. Defining the Problem at TigerPlace Related to Disparate Systems

The huge amount of information present in the EMR, the telemedicine system, and the sensor system can easily overwhelm any healthcare provider. It may decrease their understandability and create confusions when looking at the information. The system lacks a tool that can provide the caregivers a holistic view to see relevant information necessary for checking the health status of resident, and may reduce the care providers' ability to see trends or make quick decisions, adversely prolonging the clinical decision-making process (Yang Gong & Chandra, 2011a, 2011b).

Though it was realized that TigerPlace requires sophisticated technology to monitor the daily activities of the residents, it also requires efficient tools that helps residents with medication management, save the health records of the residents electronically for easy retrieval and diagnosis, aid in easy progress tracking on their daily activities, mobility, general health, chronic diseases, signs of functional decline of the residents due to aging, etc. (M. Aud, et al., 2010). The care providers, i.e. nurses and physicians at TigerPlace need to have a more holistic view of the health and well being of the residents. This could be only provided to them by employing a well-integrated web-based tool that supports clinical decision-support in conjugation with patient care. This requirement became the basis for our project for designing and employing a user-friendly tool that would provide an overall holistic view of the important clinical details of the residents (M. Aud, et al., 2010) in the future.

The preliminary goal of our research was to design a single interface that

can represent different types of ADL data along with their related vital signs for individual residents. The integrated interface for viewing related information will help healthcare providers to inspect the health status of individual residents according to the needs of the resident and in the correct time. It also can form a basis for providing effective response to the questions and queries of the senior residents as how these technologies may benefit them in their well-being (Yang Gong & Chandra, 2011b).

2.5. Design Framework for the Solution

2.5.1. Literature on CHF Scenario

Congestive heart failure (CHF) is a chronic condition effects the most elderly due to bad lifestyle management and/or family history, which has been considered as our sample scenario for the development of the human-centered integrated single interface health data display. The CHF clinical guidelines (MedlinePlus, 2011; NIH, 2010) were examined to find the relation between symptoms and the vital signs i.e., systolic blood pressure, heart rate, pulse rate etc. of a CHF patient in order to determine the criticality of the diagnosis and treatment regimen to their condition. From the clinical meanings and concept associations of the CHF condition, the vital signs and the CHF related symptoms were grouped as variables for designing a holistic and convenient data display to be used for monitoring residents with the CHF health condition (Yang Gong & Chandra, 2011b).

2.5.2. Literature on Human-Centered Design and UFuRT

The research primarily was motivated by current interface present in the sensor data display used by healthcare providers to make clinical decisions for the elderly who live in TigerPlace. The healthcare delivery involves a lot of time-critical, life-relevant events, which are multitasking in nature. Undoubtedly, an effective way to be able to search of healthcare data can facilitate the decision-making process and enhances early detection, which together can successfully predict declining health status of seniors (M. Rantz, et al., 2008).

The human factors application aims to develop productive, safe, comfortable, and effective systems for human use (Strawderman & Koubek, 2008). Human-centered design has successful applications in automotive industry, nuclear power plants, etc. (Liao & Chang, 2011; Schulze, Brau, Haasis, Weyrich, & Rhatje, 2005). In healthcare, human-centered design has the potential to reduce medical errors and improve health care quality, which is very critical for both healthcare providers and patients (Yang Gong & Chandra, 2011a, 2011b). Relational data plays an indispensable role in healthcare delivery by affecting the efficiency of clinicians' perceptions of abnormalities through representations that are in various formats i.e., numbers, symbols, colors etc. (Y. Gong & Zhang, 2005; Zhang, 1996; Zhang & Norman, 1995). There are usually multiple records of vital signs and medical history of patients, as observed in the EMR, telemedicine system, and sensor data logs at TigerPlace. The multiple records of the patients have relations with each other and can be represented by a table, which can further be transformed into various other isomorphic formats

i.e., line graphs, bar charts, pie charts, scatter plots, matrices, etc. These display formats may carry same amount of information, though their representational effects may be different because of the difference in their distributive patterns of the internal and external information (Yang Gong & Chandra, 2011a, 2011b).

The information search task on relational data is highly complex and relevant to the distribution between internal and external information and depends on the pattern of interaction between these two types of information (Y. Gong & Zhang, 2005). For example, finding all bradycardiac firings of a senior resident over the past 12 months can be a typical task in the sensor data management system. In this example, if the required normal range (slow pulse rate of 1 to 30 beats per minute) is not presented on the screen, is known as internal information. External information comprises of the observed values presented in the sensor data record. The performance of the information search is affected by the distribution pattern between the internal and external representation. The observed values for the bradycardiac firings, for example, can be presented in a variety of formats i.e., table, graph, a mixture of both, symbols, etc. Different data scales also can be used to represent the observed. For examples symbols like (+/-), (\uparrow , \rightarrow , \downarrow), or even absolute values in Arabic numbers, etc. can be used. This helps in applying variety of representations to same set of data or information. The EMR, the telemedicine, and the sensor system at TigerPlace, were developed at different project stages by different groups of people. The data generated from each system are scattered and stored in different formats. At present, TigerPlace does not have a way to see the

information present in the different system in a holistic manner (Aud et al., 2010). In this project, our preliminary goal is to design a data representation that effectively helps search tasks done across the three different systems. To get the needed outcome, the existing data can be transformed into an optimal display using an algorithm that possible can meet the users' information needs. A human-centered approach needs to be used to design prototypes through a single interface that have the ability to display the human-interpretable relevant health information. Symbols and colors used in the design will represent the severity of the health information in the clinical context (Yang Gong & Chandra, 2011a, 2011b).

With the support of distributed cognition theory, UFuRT (User, Function, Representation, Task) framework was developed for the effective designing of relational data, which is based on the nature of each search task (Zhang & Butler, 2007). Distributed cognition is a branch of cognitive science, which proposes that elements of human knowledge and cognition are distributed across time, space, people, artifacts etc. rather being confined to individuals. The theory pays emphasis on the individual and his/her environment, and the system is viewed as a set of representations (Edwin Hutchins, 1995, 2000; E. Hutchins & Klausen, 1996). UFuRT is further supported by the theory of external representations. External representations is considered an indispensable part of cognition and not simply a peripheral aid by (Zhang, 1991). Representing external information in an appropriate format and supporting it with recognition-based memory or with perceptual judgments rather than using recall can reduce

the difficulty of a task. For example, in the search tasks based on the sensor data of bradycardia, using external artifacts, which are often created specifically for the remembering purpose, enhances internal memory. Task performance is enhanced when internal memories are supported by proper external representations. User performance when searching for information is effected by the distributing pattern explained by the internal and external requirements, and the information format available at the data scale levels (i.e., nominal, ordinal, interval, ratio) (Yang Gong & Chandra, 2011b; Zhang, 1991).

The relationship between dimensions is represented by Relational Information Displays (RIDs). Norman (1993) explains that the two basic types of dimensions are represented dimensions (the dimensions of an original domain in the real world) and representing dimensions (the physical dimensions representing the dimensions of the original domain in the real world). Nominal, ordinal, interval, or ratio data scales can be used to match these two dimensions to have a guaranteed efficient and accurate representation between the displays and the world (Zhang, 1996). For representing the dimensions in RIDs, four kinds of data scales (nominal, ordinal, interval, and ratio) can be used (Petersen & May, 2006). The four scales has different strengths in operations, so which operations can be applied to them legitimately is determined by the data scales (Petersen & May, 2006). The operation list in the later paragraph descried why the ratio scale is the most powerful and has the capability to allow entire set of operations. However, in practice information users may request lower level scale to represent the actual meaning of that data as they may not have the capability

to interpret real the meaning through the ratio data scale. For example, an interval scale may also allow all the operations that either a nominal or ordinal scale can allow. For information searching tasks, the notion of data scale can be applied to each type of search task by expanded it as a set of operations legitimately applicable to data on different type of scales (Yang Gong & Chandra, 2011a, 2011b).

For the operations 1 thorough 4 shown below are accumulative (bigger number of operations includes operations in smaller numbers):

1. Determining equality of two instances on the scale (=) (nominal scale);
2. Determining the rank-order (greater or less) of two instances on the scale (>, <) (ordinal scale);
3. Determining equality of differences on the scale (+, -) (interval scale); and
4. Determining equality of ratios on the scale (/, ×) (ratio scale).

User, function, representation, and task for effective design is examined by UFuRT and in evaluating human-centered distributed information systems. For designing human-centered information systems, UFuRT provides systematic principles, guidelines, and procedures. Theoretically, an UFuRT designed information search interface ensures that the design meets the information needs and supports the search task through a user-friendly data display. Users' characteristics, preferences, cognitive workload, routine and non-routine tasks, functions etc. we analyzed using UFuRT to support these tasks and the optimal data representation in RIDs. Thus, an interface designed with the principles of UFuRT should lead to better performance (efficiency and effectiveness) in doing

tasks (Yang Gong & Chandra, 2011b; Y. Gong & Zhang, 2005)

The same set of data may be examined by different type of user differently. Due to this reason for search performances, certain types of displays are more superior to other isomorphic representations (Elting, Martin, Cantor, & Rubenstein, 1999). Various studies have identified that different type of users like clinicians and medical researchers may use the same data set in different ways (Gorman, 1995, 2003; Hersh & Hickam, 1998; Mendonca, Cimino, Johnson, & Seol, 2001; Petersen & May, 2006; Song & Soukoreff, 1994; Wilson, 2004). For example, a clinician group may comprise of, but not limited to physicians, nurses, dieticians, and pharmacists. In a clinical researcher group, may comprise of, but not be limited to clinical informaticians, epidemiologists, and statisticians. Each type of user may have questions answers to address for certain situations where they need to solve a problem or make certain decision (treatment and diagnosis); check background information of diseases (etiology), or keep up with the latest information on a given subject, to keep abreast with the professional development and medical education continuation.

Different set of users may use different set of approaches to conduct research or examine the same electronic medical record or sensor data. Clinicians are typically interested in the various aspects of a patient at the individual level; therefore, their key tasks are their within-patient searches. Whereas, clinical researchers may view the patient records at the collective level, that reveals their trends or epidemic disease status. A diverse group of researchers i.e., electronic engineers, nurses, social workers, physicians,

physical therapists, occupational therapists, health informaticians etc. are involved in monitoring the health status of residents and do research activities at TigerPlace (M Rantz, et al., 2008; M. Rantz, et al., 2005). They may have common interests in healthcare data, but the level of details may vary (Yang Gong & Chandra, 2011a, 2011b).

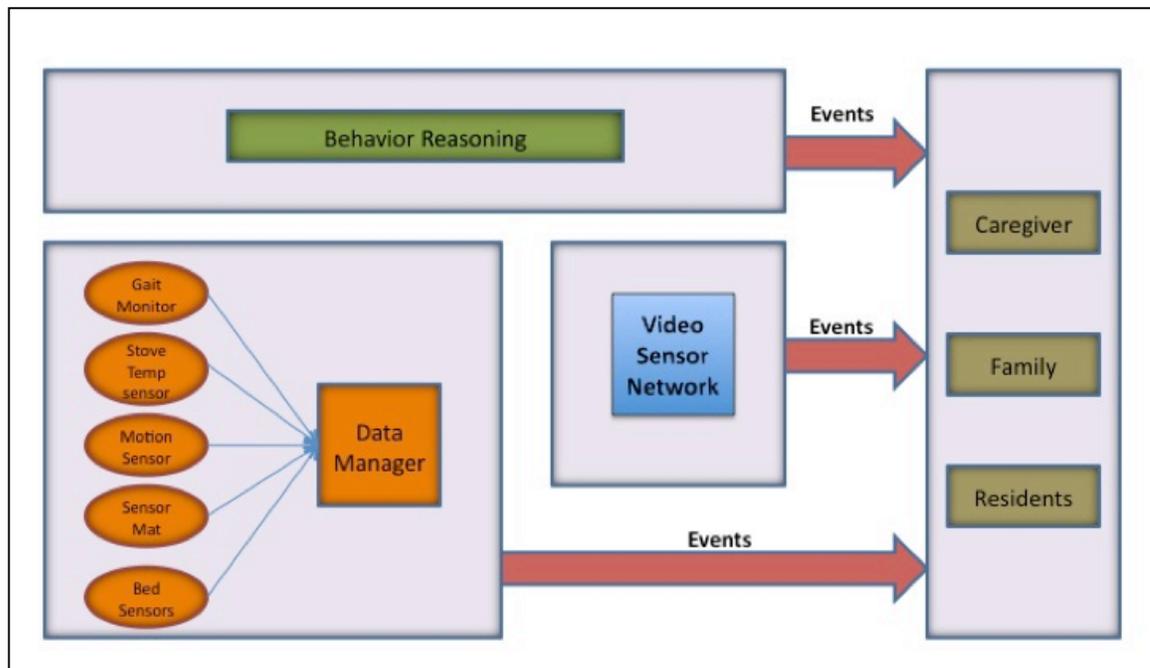


Figure1: Data Sources for a Human-Centered Integrated Health Data

Display at TigerPlace

(Adapted from (Yang Gong & Chandra, 2011a, 2011b))

3. Objectives

Our preliminary study about LTC settings started with TigerPlace, an Aging in Place care model aiming at independent living for the elderly residents. The overall goal of our research is to explore the design consideration for LTC EHR and how some of the ideas at TigerPlace can fit into other LTC setting needs. The research findings are aimed at meeting the information needs of the care providers and providing them enhanced design features for clinical decision-support, (Chandra & Gong, 2012) which would eventually enable better-informed clinical decision-making for the elderly (Chandra & Gong, 2012; Chandra & Yang, 2012).

We initially aimed at understanding the information needs of providers at TigerPlace (Chandra & Gong, 2012). We designed a prototype based on our findings to represent a holistic display of all health information available at TigerPlace. This design framework can enable residents live independently and improve their functional ability with the availability of relevant health information in the form of a holistic view. Our design concept was aimed at providing an enhanced feature for detecting and alerting preventable risks that may arise due to the presence of identified health problems of the residents, and information that are highly relevant to their co-morbidities and disease outcomes (Chandra & Yang, 2012). The design prototype additionally supports understandability and usability of the end user (Chandra & Gong, 2012).

At a later stage, our research focused in finding the information needs of general LTC facilities. We conducted interviews with a few LTC care providers to

understand their information needs and recorded their recommendations related to the design goals of a LTC EHRs. After conducting the tasks, design and analysis for the collected information, we attempted to generalize the ideas about TigerPlace to other LTC facilities and we are interested to see how LTC facilities can be enhanced using combination of tools and recommended design features of LTC EHRs to address the information needs (Chandra & Yang, 2012). The design framework along with the recommendation from the interviews conducted should enable the providers to tailor health information according to the disease condition and personalize it according to the needs of the elderly patients (Chandra & Yang, 2012).

4. Methods

Information related to the system was obtained by doing a thorough literature review of the research papers that published detailed overview about TigerPlace and the technology employed there related to assistive living for the senior residents. The literature review goal was to take into account all the clinical and research data to a maximum level and collect all the information and findings from all previous projects. The design requirements, needed data, and the flow of information were derived from the literature review process and combined with an unstructured interview with nurses, data managers, and observations done by field trips at TigerPlace (Yang Gong & Chandra, 2011a, 2011b).

Information related the various kinds of data present in the system were collected from the data managers who work with the information collected at intervention levels from the residents at TigerPlace. A field trip to TigerPlace was done to observation to get important insight about the clinical flow of information, understand the problems they face with the health condition of the residents and the shortcomings of the system at TigerPlace as a whole. The interaction provided some ideas for future design approaches that would help make the system user-friendly.

4.1. Design Prototype

The UFuRT framework was used to design and develop the user-centered single interface. The UFuRT process guided the analyses and design to be a

human-centered information system (Zhang & Butler, 2007). The four rigorous analysis steps done were: user analysis, functional analysis, task analysis, and representational analysis (Yang Gong & Chandra, 2011a, 2011b).

4.1.1. User Analysis

User analysis was conducted to identify the characteristics of stakeholders who would use the human-centered integrated interface, i.e., expertise, skills, knowledge, educational background, cognitive capacities and its limitations, perceptual variations, age-related skills, and available RIDs time for learning (Yang Gong & Chandra, 2011a, 2011b).

4.1.2. Functional Analysis

The process of functional analysis identifies critical top-level domain structures, goals, and inherent properties of the work domain that are independent of implementation. Task and representational analyses are less abstract than functional analysis it does not involve details of task processes and representation. As the stakeholders are required to seek information for decision-making, the human-centered integrated interface comprise of a distributed information system (Yang Gong & Chandra, 2011a, 2011b).

4.1.3. Task Analysis

Task analysis was conducted to identify the procedures and actions that need to be carried out, and the information that need to be processed to achieve task goals for the congestive heart failure (CHF) user-centered interface. CHF was considered because it is a very common health condition of the elderly. One

of the important functions of task analysis is ensuring that only the features matching users' capacities and required by the task would be included in the system specifications. Sophisticated features will not be included in the system specification not matching the capacity of the users or not required by the task, as they would generate additional processing demands for the users and make the system difficult to use. This analytical approach helped in identifying how different stakeholders interacted with the displays having the same (Yang Gong & Chandra, 2011a, 2011b).

4.1.4. Representational Analysis

Representational analysis was conducted to identify appropriate format for information display for a task performed by a specific type of user such that there is a direct interaction mode for the interactions between the users and the systems. Users can directly interact through direct interfaces, and perform the primary tasks they intend to more efficiently. This representation form can influence and sometimes determine information that can be perceived easily, processes that can be activated, and derivation from the representation (Yang Gong & Chandra, 2011a, 2011b).

4.2. Design Considerations to Aide Users

We analyzed the information needs at TigerPlace to understand the overall information needs at LTC settings. Information related to the systems available at TigerPlace was obtained from thorough literature review of the

research publications available. Information was also obtained from existing literature about the needs of LTC facilities, which provides the potential to borrow some of the ideas from TigerPlace to fulfill the LTC needs (Chandra & Gong, 2012).

The interaction with nurses and data managers enabled understanding and evaluation of the current shortcomings of the system. The research also focused in identifying relationship among the telemedicine data and sensor data for certain medical conditions taking CHF into consideration, which is a common health condition for the elderly residents. It supported exploring an effective holistic health data integrated display for the care providers, interested in monitoring the residents' health status. The analysis of the information needs of care providers at TigerPlace helped in understanding similar needs in other LTC setting and what could be borrowed from the technological perspective and extended to LTC facilities e.g. EMR requirements focused for LTC settings (Chandra & Gong, 2012; Chandra & Yang, 2012).

4.3. Interviewing Process

After the prototype was developed, further research was done to understand the information needs of LTC facilities. From the findings it was derived that the best way to understand the needs of LTC facilities is by conducting interviews with care providers engaged with LTC facilities. An Institutional Review Board (IRB) approval was taken to interview care providers at LTC facilities, refer Appendix section. A convenient sample of ten care

providers was approached for the interviews within the University of Missouri healthcare system, among which seven of them accepted the invitation for the interview (Chandra & Yang, 2012).

During the interviews conducted with the care providers two sets of questions were asked, as seen in Table 1 and Table 2. The first set of questions focused on understanding their expertise in LTC, their views about the current status of EMRs in LTC, the information needs at LTC facilities from providers perspective and what features or functionalities are ideally needed by them to work more efficiently. Before asking the second set of questions, the designed prototype was shown to them with explanation and background information related to our research. The second set of questions was related to collecting suggestions for modification from the care providers to enhance the prototype, and how the prototype could be made useful and could fit into their workflow and real information needs. Recommendations' were taken from them to understand how the design could be enhanced, which also provided insight about the real requirements of information of users at LTC facilities (Chandra & Yang, 2012).

Table 1. The General Questions Asked Related to LTC Needs

General Questions:
<i>What is your area in long-term care?</i>
<i>What are the technological needs and challenges you face while providing care?</i>
<i>Do you use any EMR/EHR in LTC? How do EMRs or EHRs help you in your care-giving process?</i>

<i>What is the current status of the EMR's in LTC? What are the Long-Term care EMR requirements?</i>
<i>What features of the applications/software within the EMR, makes your work more efficient?</i>

Table 2. Specific Questions Asked Related to Providers' Clinical and/or Administrative Needs

Specific Questions:
<i>What is your opinion about my prototyped design, what is missing in it from the perspective of your information needs?</i>
<i>How personalized can the prototype be made in relation to your work and to make better clinical decisions?</i>
<i>What are the features you need that would make it look more usable or user-friendly, fit into your workflow, improve integration and interoperability?</i>
<i>What are the data that you would want to enter for documentation/ quality etc., while you are working with this dashboard (in case you have a CHF patient)?</i>
<i>How do you want to use this prototype together with the EMRs and EHRs that are in practice? Does it help you in clinical decision support or quickly assessing the status of the resident?</i>
<i>How the improvements might benefit care-giving process (specific to role)?</i>

After the interviewing process, the data collected from the interview was transcribed and combined with the notes taken during the interview together. It provides the requirement specification for the enhancement of the design. The collected data was analyzed and the information was categorized find the results from the interview that will aide in understanding the provider requirements in LTC (Chandra & Gong, 2012).

5. Results

5.1. Preliminary Design Prototypes

After collecting information about TigerPlace, the findings showed that the EMR system contained the medical summary of health conditions of residents, the telemedicine system is used to the daily/weekly progress of the residents' health status, and contains vital signs, chief complaints, etc. on a daily basis, and the sensor system contains information related to the residents' activities of daily living (ADLs) (M. Aud, et al., 2010). The patient data stored in the EMR and telemedicine system, may serve as a foundation for reasoning the behavior of a resident related to his medical history and chief complaints on a high-level data display. This information can trigger further health investigation by decision-makers on the next screen. The need for this investigation can be brought up by setting up reminders or alerts for clinical decision makers and can be used while interacting with their patients, as shown in Figure 2. The sensors at TigerPlace monitor the residents' activities, gait, stove temperature, motion, sleeping time, restlessness, etc. at frequent time interval. The human-centered integrated health data display framework can be tailored and personalized to meet the information needs of all caregivers, family members, or residents at TigerPlace (Yang Gong & Chandra, 2011a, 2011b).

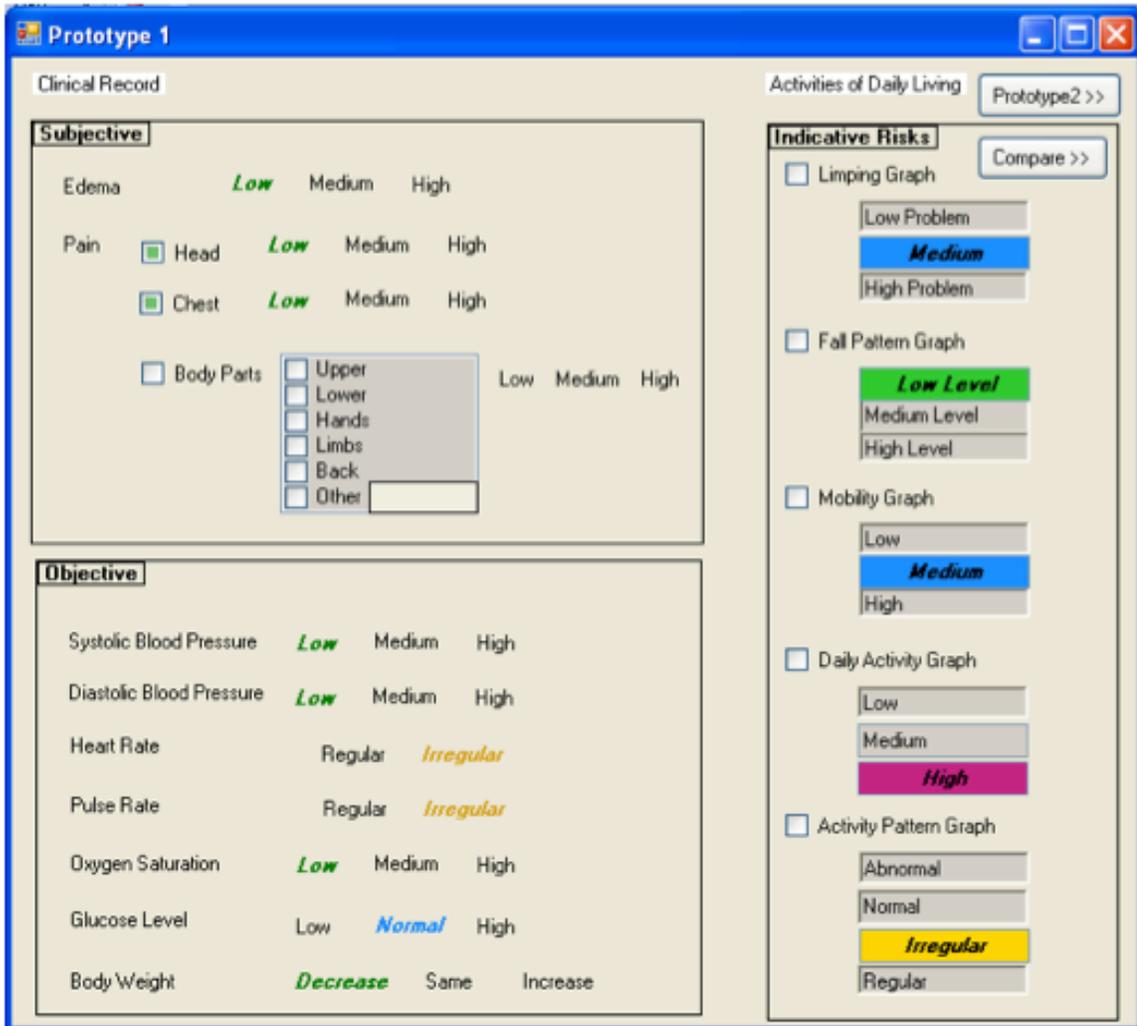


Figure 2: Interface for Congestive Heart Failure Patients

(Adapted from (Yang Gong & Chandra, 2011a, 2011b))

5.1.1. Static Design or Design Level 1: Prototype1 and Prototype2

In the preliminary design, hypothetical vital sign data available at the telemedicine system was used and the original ratio scale was transformed to an ordinal scale. Through user and task analysis, we got an understanding about the available data and its format present. We considered the CHF scenario to be a feasible medical condition that can be used for simplification and summarization of the data review process (Yang Gong & Chandra, 2011a,

2011b). Two prototypes (Figures 2 and Figure 3) were developed to demonstrate the different health status of CHF patients. For easy understandability and better user interpretation, the CHF associated clinical and sensor data were converted to ordinal scale. All pertinent data on CHF were integrated into a holistic interface so that it represents subjective and objective sections of a typical EMR. Color-coding scheme was also employed to represent the levels of actual values in the EMR and the sensor data system (Yang Gong & Chandra, 2011a, 2011b).

Initially the resident/patient information was selectively extracted from the telemedicine system and the EMR according to the needs of CHF condition. The left column in both the prototypes displays the vital sign information and associated CHF symptoms. The original ratio data was transformed into an ordinal comparative scale (low, medium, high). Other associated health information also can be accommodated in the interface i.e., medical history, earlier and current diagnosis, procedures, diagnostic tests, active and inactive medications, etc. In the right hand column, the information from the sensor data has been displayed based on color-coding scheme indicating abnormalities and severity of ADLs. The availability of vital signs, symptoms and associated ADLs on a single interface provides convenient holistic view of all the clinical information of the residents (Yang Gong & Chandra, 2011a, 2011b).

Static Design

Initially, we incorporated a static prototype that showcased the ability of the system to display information from two different systems (vitals signs from the telemedicine system and different ADL functionalities) on a single frame. This

dashboard can help in easier interpretation and understanding of a disease condition since one can see both the vital signs information and the ADL functionalities of a resident, which is considered critical for early diagnosis. To employ the static dashboard interface we chose to demonstrate two important CHF scenarios to consider how effective it may be to the care providers who are the major users in our design consideration. The static dashboard will help them in seeing information together rather than logging in to different system to see each information individually saving them time and effort.

Description of Static Design

Vital signs information has been fetched from the telemedicine system presented in the left hand side of Prototype1 and Prototype2, and the ADL functionality is presented in the right hand side, fetched from the sensor system. Monitoring the daily activity of the residents while inside TigerPlace collects the ADLs. The vital sign information that is related to CHF has been considered for our prototypes. Edema, pain in different parts of the body e.g., head, chest, other parts of the body etc., breathing problems e.g., shortness of breath, orthopnea, palpitation, etc. are more related to the subjective information present in a typical EMR. It is related to the general feeling of the resident indicating his signs and symptoms of an ailment. The other vitals information that have been included in the designed prototype are systolic blood pressure, diastolic blood pressure, heart rate, pulse rate, respiration rate, oxygen saturation level, glucose level, body weight and temperature. These are real observation values recorded in the telemedicine system and an important data recorded in any EMR system. The

ADLs that have been considered are falling pattern, limping, mobility, daily activities that include patterns of daily activity, bed restlessness and sleep time.

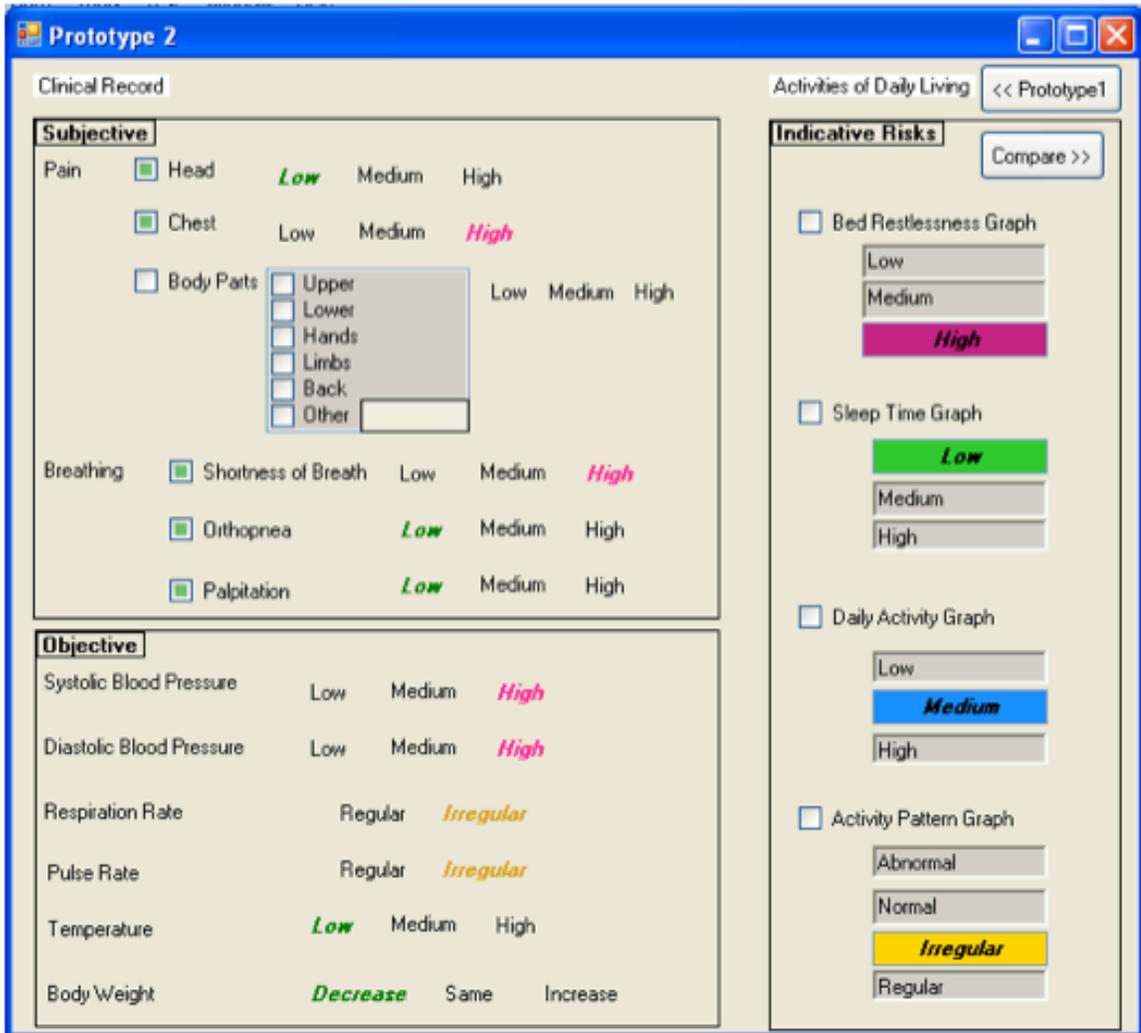


Figure 3: Interface for Congestive Health Failure Patient with Mobility Constraints

(Adapted from (Yang Gong & Chandra, 2011a, 2011b))

Falling pattern refers to the pattern of falling that happens to residents while trying to do regular daily activities or while trying to move from one place to

the other, or exercising etc. within TigerPlace, and this is monitored through the sensor system placed in different locations inside TigerPlace. Limping is captured by interpreting the gait pattern that is monitored via the sensors provided by the evidence if the gait shows deviation from the normal angle of inclination of a person while walking. Mobility refers to the activity of a person related to his movement, which combines walking, exercising, moving from one place or other, movement within the room etc. Daily activity that is captured by the sensors refers to cooking, bathing, moving within the room, going to the bathroom or outside ones room, going to bed and up etc. Activity pattern refers to pattern of daily activity like going for exercising or a walk on a regular basis, going to eat breakfast, lunch and dinner at regular interval of time during the day, skipping meals, skipping sleep, randomly visiting the bathroom etc. Bed restlessness refers to body movement in bed while in bed either while sleeping or due to sleeplessness or due to frequent visit to the bathroom. Sleep time refers to the actual sleep time of a person during the night without restless movement or frequent visits to the bathroom. Two cases have been considered to understand the relationship better by using Prototype1 and Prototype2. Refer to Figure 2 and Figure 3.

In Prototype 1 (Figure 2), the relationship between edema and pain in different parts of the body along with variations in values of blood pressure, glucose level, heart rate, pulse rate and body weight can be associated to limping, falling and mobility of a resident. These variations can also affect the daily low to high general activity of a person and show irregular or abnormal

activity pattern of a resident recorded over a time range of weeks or months.

In Prototype 2 (Figure 3), the relationship between different problems in breathing related to shortness of breath, orthopnea or palpitation in conjugation with respiration rate, temperature, pulse rate, and varying blood pressure can affect the resident's bed restlessness and sleep time. Breathing trouble in conjugation with pain in head or other body parts can also affect the daily activities and pattern of daily activity of a resident recorded over a time range of weeks or months.

In Prototype 1 and Prototype 2, the clinical record contains the signs and symptoms and vitals signs information in the left side and the ADLs in the right hand side. This has been facilitated so that information related to each other can be seen on a single screen. The symptoms and vital signs information has been transformed into a comparison (ordinal) scale of low, medium and high. Vitals signs like glucose level and temperature have been transformed into a comparison scale of low, normal and high. Heart rate, pulse rate and respiration rate has been transformed into irregular and regular pattern in the prototypes. For the ADLs, the information has been color coded as green for low severity, blue for medium severity and red for high severity respectively. For one of the ADLs i.e. the activity pattern graph has been color-coded as green for regular, yellow for irregular, blue for normal pattern and red for high activity pattern.

The major focus of designing these prototypes is to provide care providers a way to see related information in a single view for easy interpretation and helping them compare between the variations of vitals and their relationship with

associated ADL that are very important for the residents daily living and monitoring the progress of any present disease.

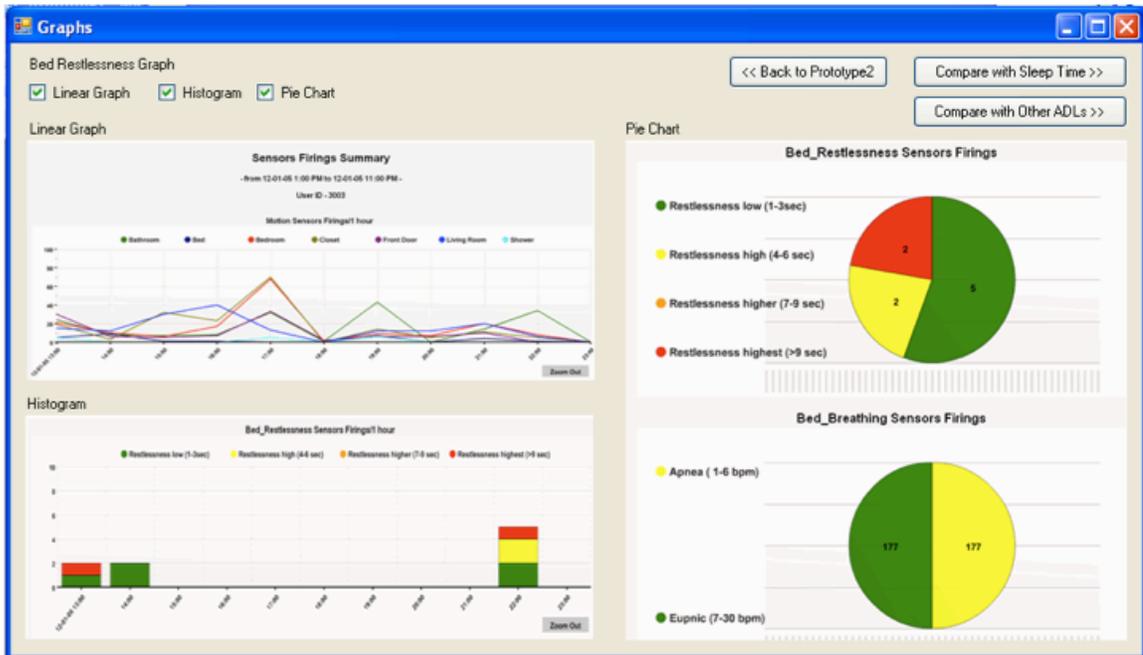


Figure 4: Different Kinds of Graphs Showing Same Functionality

(Adapted from (Florea, 2009))

5.1.2. Dynamic Design or Design Level 2 and Level 3

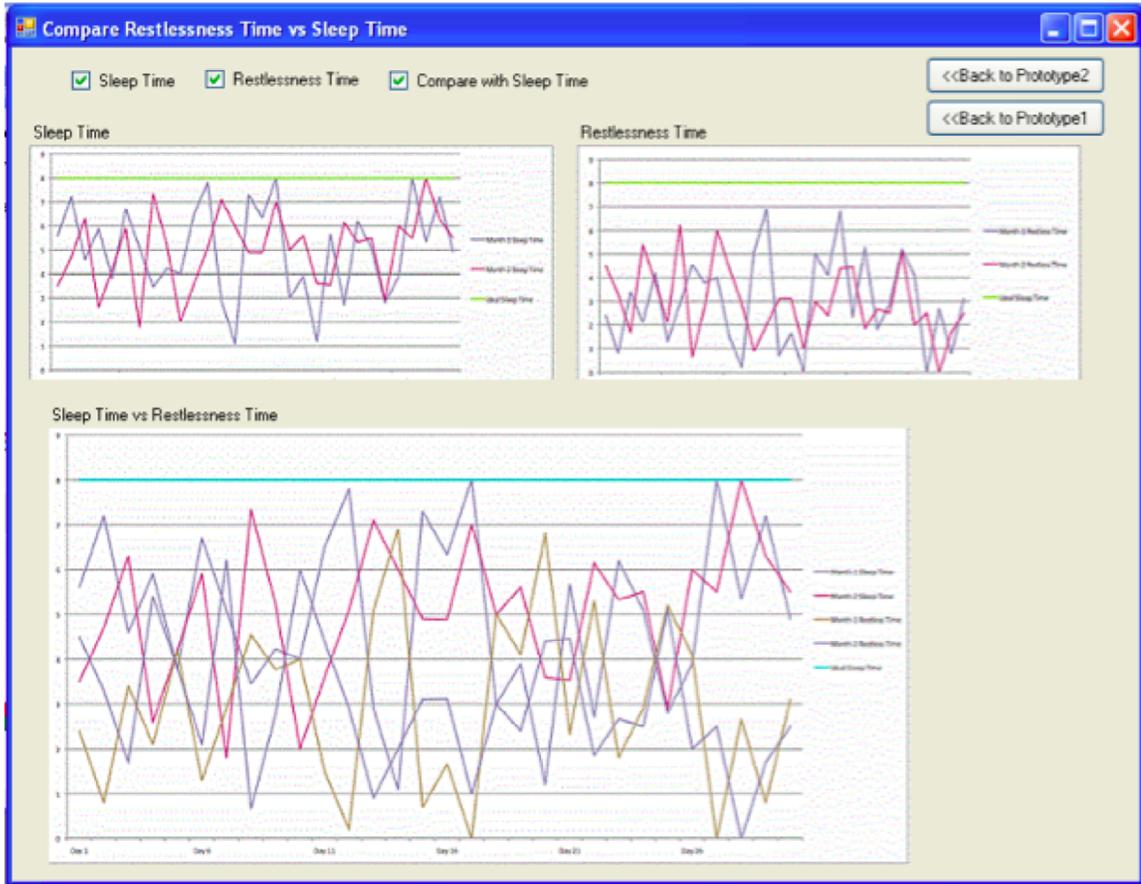


Figure 5: Comparison of Sleep Time & Restlessness Time ADLs

Design Level 2

The goal of the dynamic design can be achieved by adding views that additionally support different form of graphs embedded in the workflow and can be displayed in the same screen. This design can also be better enumerated if we create a view in which the care providers can see multiple views of the same information in different formats and can view old data for comparison in a graphical format with the new data that may help easy interpretation of results and understanding changes in trends and values. We illustrated this design with

interpretation of one of the ADL functionalities taken from CHF, which is bed restlessness time. The graphs related to restlessness were presented in three formats: pie chart, bar chart and histogram. It aids the clinical decision-maker to interpret the patient condition related to bed restlessness from different viewpoints as shown in Figure 4.

Description of Design Level 2

The line chart for bed restlessness provides information related to restlessness related to different activities i.e. visiting the bathroom, movement on the bed while sleeping and its frequency etc. This will help care providers understand the pattern of activity which may be responsible for restlessness enabling the reason behind that is causing it. The restlessness can be due to breathing trouble associated with sleeping in bed i.e. orthopnea or shortness of breath, or due to pain in any part of the body. The histogram helps determine the level of restlessness depending on time in seconds categorizing it low, medium or high. The pie chart helps determine the level of bed restlessness and additionally the frequency of its occurrence over the night. The granularity of the information helps find the gravity of the problem related to the observation in the form of graphs. The information now which can be used to be interpreted majorly by care providers, can be used in a portal for other users i.e. family member and other staff of the hospital, to view by transforming the information to other ordinal scale depending on the user needs.

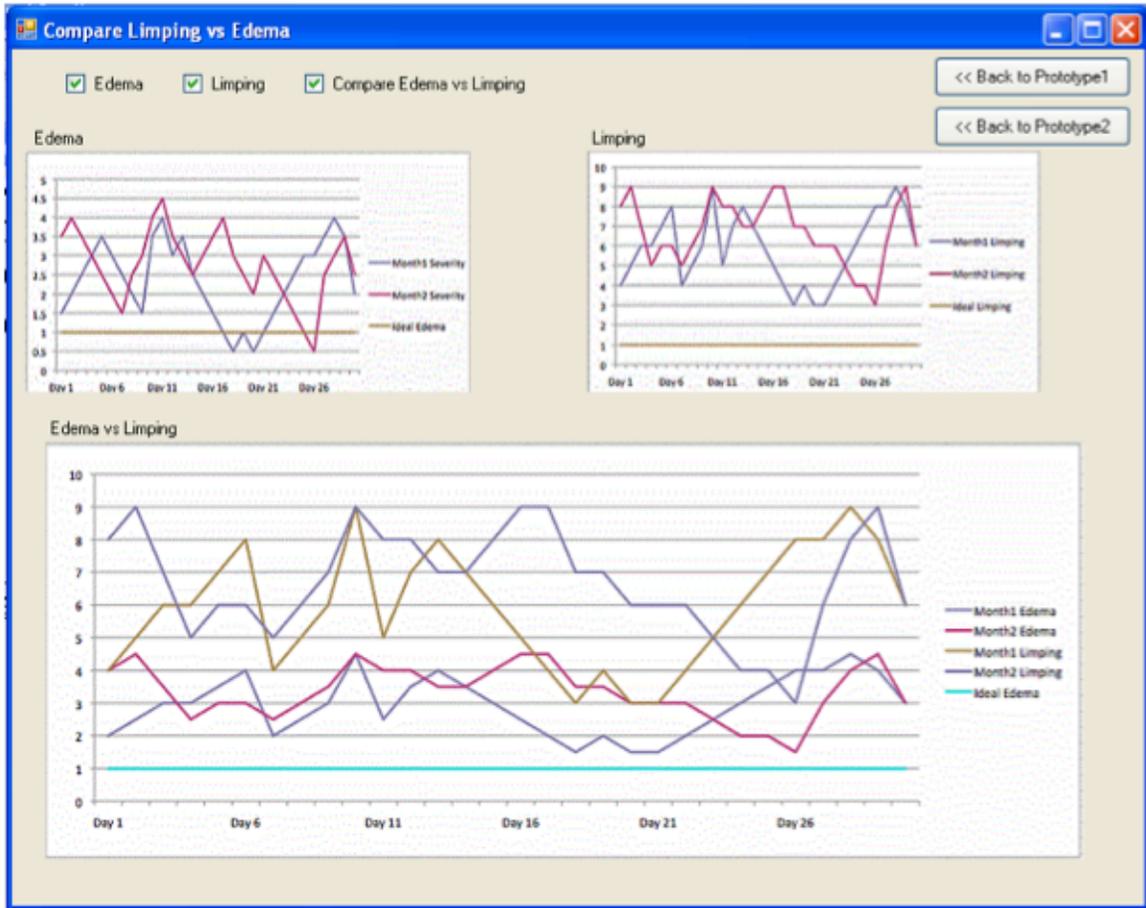


Figure 6: Comparison of Sensor Data of Edema and Limping ADLs

Design Level 3

In the next level, upgrading the prototype interface from static to dynamic may provide a higher level of effective clinical decision-making using a human-centered framework. The next design objective is to make the design to be able to provide the next level of support that will help in the better interpretation of the information represented in the designed prototype interface. Care providers will have access to the ADL functionality but do not have the privilege to compare the information to see how effectiveness the treatment or to find out the changes in

the outcomes within different time intervals. In this level of design we have employed the prototype to be able to compare the same functionality over two different time periods and making comparison between two different functionalities over a time interval. The design has been employed by using 2 scenarios from the CHF related ADL functionalities. This design will enable the care provider to use the compared information to match it with the general trends to identify abnormalities or quantify how far the difference is from the ideal scenario.

Description of Design Level 3

To illustrate the dynamic design or design level 3 with examples:

Comparison of graphs of same functionality has been explained by using comparative ideal trend: Comparing graphs for two different time period or months/weeks compared to the general trend. This will enable the care providers to observe the abnormality when compared to the actual trend, effective in decision-making. For examples, if the general trend of old people is to sleep for 8 hours regularly, we can plot a graph for a resident with his regular sleep time, we can find if he is sleeping properly or not and if it is due to shortness of breath or orthopnea or pain related to head, chest or other body parts.

Comparing graphs like the current trend vs. the threshold values. This can be used to see how technology or medicine/therapy can be used to measure the changes.

Comparison of graphs of two different functionalities has been elaborated

using two scenarios:

Scenario1: Subjective section in EMR, derived from the vital sign information: shortness of breath (SOB), orthopnea. Two corresponding ADLs related to CHF used are bed restlessness time and sleep time.

In this relationship we can see that more the resident is restless in bed, lesser is his sleep time. And we could compare this trend with the ideal sleeping time and further compare restlessness time with the resident's actual sleeping time. These conditions i.e., SOB, orthopnea, pain related to head, chest or other parts of the body, can be analyzed by using the comparison of the two ADL functionality comparison graph. In Scenario1, the data for restlessness time and sleep time has been transformed into a scale of 1-10 corresponding to the number of hours, keeping 8 hours as the ideal sleep time. We have limited our comparison of both sleep time and restlessness time in bed to 8 hours a day, as shown in Figure 5.

Scenario2: Subjective section in the EMR, derived from the vital sign information, i.e., edema, pain in head, chest, other parts of the body etc. Corresponding ADLs related to CHF used are mobility, fall-pattern and limping.

The ADL functionalities i.e. limping and mobility can have high probability of patient falls. Falling can further decrease mobility and deteriorate patient conditions i.e. edema, body pain etc. related to falling. When we are able to compare the trends in relation to how mobility due to limping of a patient can be affected by edema or body pain over time, care providers correspondingly will be able to determine the problems related to the outcomes and how they can

improve the patient condition related to pain and edema. In Scenario 2, the condition of edema has been transformed to a scale of 5 levels representing from the lowest to the most severe condition. The ADL for the severity of limping has been transformed to a scale of 1-10 depending on the severity. We have considered 1 to be the ideal scale for both to complexity in mapping the scales and to make the graph easy for interpretation, as shown in Figure 6.

5.2. Needs of Current LTC Facilities

The designed prototype enables a quick synopsis of a CHF resident at TigerPlace, presented in Figure1. The designed prototype alone cannot assist clinicians with effective care coordination among themselves by just having a view of the prototype. It is essential to provide additional tools that will enable care providers to do easy documentation, care coordination and communication among themselves. These tools should have embedded usability features and adopting providers to use the new system and visualize changes in the health status of the residents. Figure 7 represents the relation of nursing documentation along with the nursing assessment needs (Kane & Kane, 2000). It's a high level view of the different nursing assessments at LTC settings and how LTC EMRs can support them (Chandra & Gong, 2012).

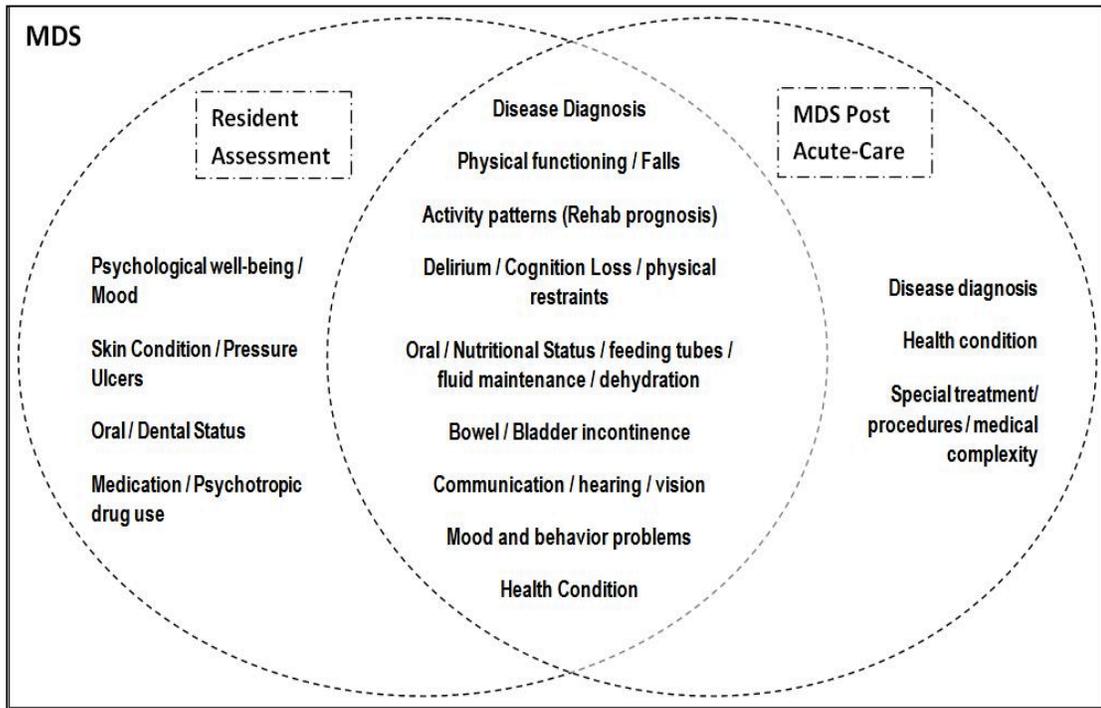


Figure 7: Relation between Different Resident Assessment Needs in a Minimum Data Set (MDS)

(Adapted from unpublished paper by (Chandra & Gong, 2012; Florea, 2009)

Table 3 shows the first consideration for the interview that goes to the ability of the tool to be used or embedded with the current EMR/EHR system.

Table 3. First Design Considerations

Purpose	Approach	Explanation
Visibility of all health related information	Holistic representation of ADL functions & graphs, nursing notes, progress trends of residents' multiple chronic conditions	Prediction of emergent problems of residents earlier than the actual appearance of the symptoms
Better disease prediction	Availability of ADL functions, vital signs, nursing notes and evidence-based medicine	Aid for better clinical and nursing assessment
User-friendly	Using minimal number of screens and fitting into the workflow of the care provider	Visualizing change of care plans with advent of time for accuracy and quality
More efficient clinical decision-making	Reconciliation of nursing documentation in a single note section	Nursing documentation can be done from any available screens in the prototype
Avoiding information overloaded	Personalization of the resident information according to individual resident needs	Tailoring appropriate health information based on providers' and residents' needs

The tools cannot function efficiently without the help of holistic designed prototypes similar to the ones designed for CHF scenario. Table 4 shows the second consideration for the capability of the tool along with the prototypes.

Table 4. Second Design Considerations

Purpose	Approach	Explanation
Taking nursing documentation while viewing relevant health information	Documenting process and clinical workflow to be structured with the relevant health information e.g. list of problems, vitals & ADLs, etc.	Nursing documentation to be analogous to the information displayed on the screen and once notes saved from any screen should display on the main nursing notes
Features to review documentation	Individual electronic signatures with date and timestamp on notes	Button and additional comment section for amendments on notes by peers
Usability: less is more	Limiting number of screens from 3-5	Easy printing of notes sections
Prioritizing visibility of information	Sort historical health information based on date range, visit, priority etc.	Examples are latest hospitalization report, discharge summary, etc.
Easy visualization	Using colors or numbers for visual effect	Flagging data with colors for prioritization
Easy comparison of information	Prediction of trends and thresholds for ADL functions and vitals	Comparing 2-3 trend graphs over a date range
Information security	Access to health information of users governed by levels of security and confidentiality	Registered nurse getting access to more confidential information compared to physical therapist

5.3. Interview Results

Table 5 illustrates the top five findings from interviews with providers in

long-term care (Chandra & Yang, 2012).

Table 5. Findings from Interviews with Care Providers in LTC

Lack of Technology
Inadequate or Absence of Technology – Interviewees showed concerns related to lack of adequate technology in nursing homes, <i>“basic ones lack the proper IT infrastructure, Internet connection, use of computer and the knowledge to use it”</i> . Another provider quoted <i>“non-availability of good support system to help develop those technologies in long-term care, very few people trained in doing it in long-term care. There are people trying to implement things which they are not educated or trained to do.”</i>
Problems with Technology
Non-availability of dedicated system for LTC needs – The biggest challenge for providers was <i>“there are no systems having a dedicated system for long-term care. It was within the context of the hospital information system. No unique features for LTC were available”</i> .
Systems not-integrated – There were concerns integrated systems. <i>“Presently, everyone doesn’t have a fully integrated EMR. First paper collection and then it is put into EMR.”</i> One provider quoted <i>“Most of them are stand-alone systems. There is little integration across systems or even within the system for different nurses.”</i>
Scattered Information – The collected data is often cluttered and not organized properly. One quoted that <i>“Present records are scattered and not together.”</i> Also, mentioned that <i>“they had a health record and all the reports of the patients is available somewhere else.”</i>
Unavailable Holistic View – Providers expressed that they are <i>“not able to see the big picture of a patient in the clinical setting”, “like patterns and trends, change in health status”</i> to track real patients needs. They also quoted, <i>“there is great deal of duplication in work... varies in documentation, insufficient completion of documentation... difficulty to check that.”</i>
Interoperability – Providers <i>“require interoperability between homes and hospitals, connect</i>

<p><i>long-term care, physician offices and patient. All should be connected.” They require “one secure access point to see the data at one place”.</i></p>
<p>Inter-professional Communication – Providers expressed that there was <i>“No two-way communication, within disciplines and between healthcare systems”, and “very few technologies that support communication between different providers like nurses, nursing-aids, physical therapist, administrator, etc.” and “lot of that is on paper and not electronic.”</i> They require <i>“Capability of communicating with other EHRs... in the same service area”.</i></p>
<p>Clinical Decision Support – Providers stated that there is <i>“Not much clinical decision support inbuilt... if the weight has increased, it should be sent to a queue for nurses to look at the history. Parameters needs to be set so that for changes one can see the history or flag it with alerts... showing average weight”.</i></p>
<p>Portability – Providers require <i>“One secure access - point to see the data at one place... they had a health record and all the reports of the patients in available somewhere else.”</i></p>
<p>Information Needs</p>
<p>Data Capture – Providers should be <i>“able to capture real-time with timestamp”, “maximizing the usability, user-friendly for the staff, sophisticated enough to see the high-level clinical picture, analyze and make decisions based on it”.</i> They want it to be intuitive, <i>“information should come to them”.</i></p>
<p>Point of Care – The nurses concern is <i>“nursing chart should be at the point of care... are mobile enough to be at the bedside. It just makes the work easier”, “bed-side point of care is a different delivery method, it is just helpful for the users... depends of the system... laptop on a cart is cumbersome versus using a small pda...”</i></p>
<p>Integrated Information – <i>“Nurses should be able to pull the history in another format for viewing and look back over time”, “ability to see the visits and trends over time”, “able to analyze the data they collect from patients. Able to do interventions much faster by looking at the assessment trends revealed”.</i> Another provider stated that they need to <i>“pull information</i></p>

<p><i>related to nutrition, supplements, mobility, high-grade... de-hydration has higher skin breakdown... input output... stopped drinking</i></p>
<p>Alerts – <i>“EMR to generate alert trigger for nurses for risk assessment...” “They require alerts for understanding what needs to be completed... color-coded pink/grey, alerted, tracking...”</i></p> <p><i>Another provider stated, “require ‘i-alerts’ as weight may change, and documentation may be missed as ‘LPNs’ are more focused on the task in hand. The vital signs change from resident baseline, when out of range...” and “alert fatigue should be avoided... opportunity to ignore alerts”.</i></p>
<p>Suggestions and Concerns</p>
<p>Risk Evaluation – <i>“Future goal is to help design the system that can be prevented”, “Incident report for medicines, error, falls... Fall trends, medication error trends... increase or decrease over a period of time”. “Graphical display to notify which residents may have change in status over time... more urgent ones”.</i></p>
<p>Nursing Assessments – <i>“Not all assessments can be done through an EMR but they should receive certain alerts, pathways for assessments” and “Building assessment pre-formulated templates electronically for nurses to capture the information quickly.”</i> The <i>“major ones are ADL, IADLs, fall risks, skin risks, memory scales, gait and balance scales, nutritional, continence, psychiatry assessments, caregiver burden scales, rehabilitation, maintenance therapy assessments, medication therapy monitoring assessments.”</i></p>
<p>Nursing Documentation – <i>“Documentation for long-term system... its more appropriate to have dedicated, designated or tailored EHR, rather than just the generic system that serves everybody”.</i> Another provider stated <i>“documentation which has all forms together, for charting vital signs, date, period of time, what they have done... makes it easier, time efficient... increases productivity.”</i> <i>“EHR documentation for care-planning and coordination of care... longitudinal care plan and transmit them between people who are using the same information system... helps track patient care, understand patient needs at specific times, not loose time or</i></p>

<p><i>information over time”.</i></p>
<p>Need Clinical Decision Support – <i>“Some have forms with clinical decision support... have intervention list created by the nurses electronically, which allows... to know which things have to be done and it pins out for alerting the nurses... track real needs of the patient...”</i> Another provider stated <i>“features and frequency parameters for care plan to direct the nurse... inbuilt rules and active clinical decision support... like queue-based... everyday or regular ability to modify assessments and the record should have the capability to do such changes”.</i></p>
<p>Maximizing Usability – Concerns related to <i>“maximizing the usability, user-friendly for the staff... intuitive... Information should come to them”.</i> Another provider stated, <i>“Usability of the user-interfaces are major concerns”.</i> They suggested, <i>“Alert fatigue should be avoided... opportunity to ignore alerts”.</i></p>
<p>Provider Preferences</p>
<p>Security and Privacy – Providers need <i>“access control of who can tailor the plan of care. Consolidate the parameters to make clinical decision; only the ‘RN’s’ or nursing directors should have the ability modify it”, “manager administrative rights... setting new one or change it... control who sees what”.</i></p>
<p>Tailoring - <i>“Tailor it facility wise... nursing unit based... like sub-acute stays, more frequent assessments and very specific parameters each time”</i> <i>“Tailor it by user and by discipline like nurses, physicians, social worker, pastor...”</i> <i>“Individualized... resident basis... based on parameter, tailor it as per resident need”</i></p>
<p>Personalize – <i>“Nurses should have a wish list... co-morbidities, potential high risk patients, more frail adults, tailor the dashboard for the resident and also it should be flexible... change over time depending on the resident need”</i> <i>“Dig into individual information to understand the individual better”</i></p>

Pathways for Nursing Assessment – The nurses are concerned that *“in the system, data to flow to the quality reports... to avoid double documentation, duplications... also alert staff members for things that need to be done... inform the nurses... like skin assessment form focused on the problem, and that should prompt a changed... plan of care changes and also specify... dry wound protocol and wet wound has different protocol... has type, location, site...”*
“Nursing assessment, evidence based data, and how they can be systemically arranged, skin, cardio, neurology for nurses or providers... needs to know”

Enhancing Nursing Assessments – *“Nurses use different documentation, different timelines, different data for assessment and compliance... certain assessments can be enhanced on parameters for high risks.” “Different assessments that are most frequent or most important... is different across individuals and facilities”*

Quick Checklist – Providers want to avail *“dropdown menus, limited free-text to decrease workarounds... flags when certain things to be filled-in are missing... types of data... need lots of details that need to be included in the nursing assessment forms”*.

Quality – Providers need information related to *“rate of hospitalization related to the diagnosis”*. Providers to ensure *“medication changes or orders... not too many medicines”*.

Viewing Information – Providers have *“different capabilities for caregivers - different user views for them”*. *“Enable compare to functions over time... IT will help in continuity and shift handovers...”*

6. Conclusions

Based on the UFuRT framework (Y. Gong & Zhang, 2005; Zhang, Patel, Johnson, & Smith, 2002) we planned to prototype a human-centered health data display interface to facilitate clinical decision-making process and meet the information needs majorly of care providers. To achieve this purpose, the data collected from the telemedicine system to the sensors needed to be mapped with significant relevance and data categorization (M. P. Aud, M; Rantz, MJ; Skubic, M; Alexander, G; Koopman, R; Miller, S, 2010).

The process of developing a couple of prototypes based on scenarios of CHF, a chronic disease was reported. Many other chronic diseases or conditions of the residents in TigerPlace can have potential benefit from the effort. TigerPlace, however, does not have a holistic display in use for the decision makers to be able to see the vital signs, current symptoms, diagnosis and the collected sensor data i.e., daily activity, mobility, falls, etc. (Rantz, Aud et al., 2008). For ensuring quality of care, especially for the frail elderly who suffer from multiple chronic diseases or conditions, it is necessary that all relevant clinical information is available to care providers for effective decision-making. With the help of technologies, the elderly can live more independent life at old age and take limited support from others (Skubic, et al., 2009). The elderly can also live longer life with the help of technologies that can potentially decrease their risks of accidents, which otherwise can be fatal or can disable them permanently (Yang Gong & Chandra, 2011a, 2011b).

Efforts were made to design a single interface to see all staggered health information present at TigerPlace, which helps in critical clinical decision-making to mitigate potential risks of the elderly are the primary concerns of patient care and patient safety. The interface needs to be made more usable, natural and simple in order to externalize internal information requirements to the maximum. The tool also needs to be made more transparent for users to increase efficiency and optimal performance.

This research exploring the human-centered interface to support aging in place using hypothetical residents' health data extracted from the three systems at TigerPlace, has more practical implications than theoretical. It practically contributes in identifying variables in relational search tasks, distribution of data at data scale level, distributed information analysis. It also helps in advancing the UFuRT concept in the aging research. URuRT framework has a variety of application in many healthcare activities, but this study provides the evidence its use in designing healthcare information systems used by care providers, nurses etc.

Our design on the integrated display of health data has the capability of viewing information from the telemedicine and the sensor system in conjugation taking into considering only CHF. Through the single interface, the design has been slightly advanced to enable the care providers to see more relevant health information using dynamic design. The dynamic display designed so far can be extended by more functionality to the holistic view. It can be advanced to provide support to care providers as well as other users of the system in the form of

reminders and alerts. The present design is more focused on care providers, but eventually the same design principles it can serve as a patient portal and can be extended to different user groups i.e. other hospital staff, residents, family members etc. by transforming the available data scales to a lower data scale depending on the viewer needs. Residents and their family members could have access to more reliable information through the integrated display, which potentially can increase the credibility of consumer-reported healthcare information (Yang Gong & Chandra, 2011a, 2011b). For the system to be able to acquire higher level of clinical knowledge and to be able to retrieve stored information when needed, the system requires to attain a higher level of clinical knowledge transformation.

On further analysis, we look at design considerations listed in Table 3 and Table 4, which is not limited to our findings. The elderly residents keep moving to and from acute care to LTC, care providers require information to be exchanged between the two care settings. Health information needs to be made available to providers for better treatment decisions and facilitating interoperability of the same plays a pivotal role in effective clinical decision-making. It is necessary that the health status and related health information of the residents are available to the care providers at the point of service (POS) using mobile technologies. The LTC EMR should facilitate embedding nursing assessment templates for easy clinical documentation. The minimum data-set (MDS) documentation is necessary for the nursing assessments for quality and payments (Resnick, Manard, Stone, & Alwan, 2009). The documentation of quality of life (QOL)

indicators also needs to be supported by the nursing assessments embedded in the LTC EMR (Kane & Kane, 2000). The healthcare needs and assessments of residents at LTC are very different and our design considerations focuses distinctly on these needs. Residents at LTC are typically monitored round the clock and even a small decline in their health status may become an emergent condition, as the elderly are frail and more vulnerable to health deterioration compared younger adults. LTC settings also have different quality goals related to patient safety and care providers have to look at different assessments and intervention outcomes for quality reporting and payment for health services. Evaluation is further required on how our design analysis and prototyping can be extended to different kinds of LTC settings e.g., semi-skilled nursing and assistive living. Research is also required to find the information needs of home health and rehabilitation for the senior residents. The design also needs considerations related to the needs of different caregiver user groups at LTC facilities (Chandra & Gong, 2012).

7. Discussion from Designed Prototype and Interviews

The prototype built on the design framework; UFuRT through a single interface provides an advanced feature or tool to support a higher level of decision support. The system will have the ability to compare similar problems, diseases and treatment options available from other individual residents or the old population as a whole. To establish this we need to develop a knowledge base, which has the complete health information from other patients, trends of a

disease etc. more toward evidence based medicine (EBM). This information can be stored and eventually we would require designing an inference engine where certain set of rules can be built to aid in the clinical diagnosis process i.e., using rule-based and case-based inference engines, to alert potential risky or emergent conditions. The objective of the system can be extended to designing a system that would assist clinicians to avoid adverse situations i.e. emergency and improve patient safety, with the timely triggering of the designed clinical decision support system.

From interviews and information collected from the care providers, it is clear from Table 5 that they expressed concerns related to the present status of EMR and EHR in LTC settings. It is evident from the interview findings that the adoption of technology and EMR or EHR is slow in LTC. TigerPlace, is an unique LTC independent living facility providing the elderly residents a very different and enhanced model of care. Typical nursing homes are still in the adoption process, and the care providers are concerned because it is a mandate for nursing homes under the criteria for meeting “Meaningful Use Stage2”. One of the providers quoted “at present, Meaningful Use is driving the nursing homes - transition from to electronic, implement ‘CPOE’, ‘eMAR’...” Providers also clearly expressed their concerns related to the usability for the electronic systems they use, which are not fully integrated and they still have to use a lot of paper for providing care, taking notes, communication and charting. Some of the paper gets scanned into the EMRs, but the information is scattered and disintegrated either within or outside the information system they use at a facility. There is a lot of data

duplication, which makes it inconvenient to report correct information. Communication within disciplines and facilities is a big challenge, especially during hand-offs or shift changes. One of the providers stated the need as “In a perfect world, the EHR's should be shared and be able to communicate through it. Having a centralized database to do it.” Another provider quoted “we are data rich, and information poor”. The available information of the residents from LTC homes should be available with the physicians they visit or incidents when they need to go to emergency care or become inpatients. The variation in the adoption of technology across healthcare systems also poses a challenge for interoperability and exchange of information (Chandra & Yang, 2012).

In addition to that, clinical decision support is almost not available for them to check or predict risks. They need data to be portable and available at the point of care (POC). The providers want the system to be intuitive, so that it can guide them what to do. At present the systems are more used as repositories rather than a tool for meeting their information needs. The providers who use the EMR or EHR system often lack training to explore and utilize the full capabilities of the system. The providers require alerts that will be intuitive and will correct them when things go wrong or will guide them towards a correct protocol, depending on the situation. The alerts for individual residents need to be adjusted to the resident baseline for predicting risks for the individual, as the normal range for residents vary depending on their health status. Risk evaluation and predicting what may go wrong was one of the biggest concerns among the care providers in LTC. They want to see the trends of health decline over time, and have ability to

compare historical data of a resident. The information is often so cluttered, that they are unable to get the “big picture” of the residents’ health status. Nursing assessment and documentation is an integral part of the care giving process in LTC. The present documentation systems are often not user friendly and are free text based. Nursing assessments and evaluations also need lot of attention. They want it to be intuitive and “quick” and since it involves lot of different kinds of data, they don’t want it to be “cumbersome”. The LTC providers need enhanced tool for doing nursing assessments by using pre-formulated templates that are user-friendly. These templates are often not available in the electronic system they use (Chandra & Yang, 2012).

The providers are looking at using the systems to their full capabilities, but they also need lot of personalization depending on their user roles, to complete their task easily. They require a tailored system that gives them the most important information, and have control over the information they see or they intend to see. They also want the electronic system to be individualized based on the resident needs and have the ability change it as the plan of care of the resident changes. The providers want to see information in a certain format depending on their role. So the system should display information in a variety of ways for easy visibility. Ultimately, quality of resident care and their safety are of a major concern to the care providers. Preventable risks from incidents i.e. fall, medication errors, etc. needs to be averted in every possible way and ensure the residents’ wellbeing (Chandra & Yang, 2012).

8. Limitations of the Study and Future Work

In this project we have made an attempt to demonstrate our efforts in analyzing the clinical data currently scattered in the complex health information systems. We initially analyzed two CHF scenarios to design two prototypes, but it was realized that other common chronic diseases might have very different data elements, measures and occurrences. These measures may have higher frequency of occurrences within a health information system that cannot be demonstrated within the designed prototypes. Therefore, continuous efforts are needed to develop interfaces that are more practical and can accommodate more data sets for complex disease conditions. Though the UFuRT framework theoretically ensures a human-centered design, further usability evaluation is required to fully evaluate its capabilities and limitations. We anticipate that a validated theoretical framework can be developed with further research and data collection (Yang Gong & Chandra, 2011a, 2011b).

Our study also focused a lot on the present literature review of the aging in place model e.g., TigerPlace, and current state of LTC EMR collected through the interview findings from a convenient sample of only seven care providers in LTC. The prototype design and the design considerations for LTC EMR need to be enhanced by detailed interviewing with care providers, which are iterative in nature, and may require detailed interviewing process with different kind of care providers in the LTC setting. The study was limited to providers available at Missouri State, who are related to the Sinclair School of Nursing or University of Missouri Healthcare system. Our study was also limited to providers available

locally and the findings presented in this paper are also limited to their experience and background. The interview certain important insights to the present status of EMR and EHR adoption in LTC, but findings may vary from different geographical regions (Chandra & Gong, 2012; Chandra & Yang, 2012).

Evaluation of the needs on LTC setup is in a very preliminary stage for understanding the reasons why the adoption of EHRs is slow in LTC facilities. The present study also requires insights from different type of LTC homes, which may vary in size, to capture the actual requirements of different sized facilities. It was also realized during the conversation that certain homes may be specialists in housing residents having special or critical needs e.g. dementia, cognitive disability etc. Our study does not focus on any such special needs and we understand that a detailed data collection is required to understand the requirements of residents with certain chronic and terminal illnesses. This study also does not cover their social needs related to quality of life QOL as well (Chandra & Yang, 2012). Apart from just elaborating the high-level design requirements of LTC EMR, the threats also need to be evaluated and discussed (Chandra & Gong, 2012).

9. Appendix

9.1. IRB Approval Form

HS IRB Exempt Application

Project Number: 1198504

Review Number: 98940

SECTION A - Investigators

(1) Study Staff (students, fellows & residents must have a faculty member as a co-investigator)

Name	Role	Training Date	Primary Contact	Consent Personnel	VA Personnel
Arpita Chandra	Pri-Investigator	10-02-2011	X		
Yang Gong	Advisor	10-31-2011			

All training must be complete before you can submit

(2) Contact Information

Principal Investigator: Arpita Chandra
Department/Division: HMI
Telephone #: [REDACTED]
Address: [REDACTED]
E-Mail: acv47@mail.missouri.edu

Contact Person: Arpita Chandra
Department/Divisions: HMI
Telephone #: [REDACTED]
Address: [REDACTED]
E-Mail: acv47@mail.missouri.edu

(3) Do all study team members have a current, up-to-date MU Conflict of Interest Disclosure on file with the Office of Research that describes any conflict of interest? *

Yes No

(4) Describe any Conflicts of Interest with this study. *

Example: Financial, Personal, Institutional, or Other for any study team member.

None

(5) Does this study involve the VA subjects, investigators or resources?

Yes No

Figure 8: Page 1 of IRB Application Form

SECTION B - Project Information

(1) Project Title *

Designing a holistic dashboard for elders that helps them in a true 'aging in place'.

(2) Objectives: Research question (what are you hoping to learn)

Improving the design of Electronic Medical Records used in Long-Term Care by understanding their information needs and providing them a holistic solution that goes with their workflow and helps them in making better decisions.

(3) Please provide a description of your project. *

I intend to interview long-term care providers (nurses, physicians etc.) who can provide the insight around the problems they face with technology. Their feedback will help in advancing my design according to their needs. It will also enable a better understanding on how different EMR's and EHR's required in the long-term care settings.

(4) Where will the research take place? *

University of Missouri

(5) Describe the recruitment and collection procedures. *

Include criteria for inclusion and exclusion, if applicable.

I am going to get references of long-term care providers from the nurses and faculty I already know in the University of Missouri. I will first request a meeting request for an interview with them.

For inviting them for the interview I am going to use a cover letter to introduce myself and my research, which will also include a

simple consent from them in the form of e-mail or phone. Their participation is completely voluntary.

During the interview process, I am going to audiotape the conversation and later transcribe it that can be used for my research.

(6) What is your proposed start date for subject recruitment? *

You cannot recruit until after IRB approval is obtained.

10-24-2011

(7) What methods will be used to ensure the privacy of participants? *

For example, if asking a subject to complete a survey consider the surroundings and timing of asking them to participate. Is the location public or private, is there an alternate time that may be better to ensure the subject's privacy.

I intend to interview the care providers in their private office or workspace for confidentiality of the information I receive from them and to ensure that they are comfortable with their timing, I will schedule a time with them when they are located in their private offices. I am sure that during the interview process, we are not going to look at any patient specific data, but rather talk around EMRs and EHRs and the features that helps them in better decision-making.

(8) Please identify the number of subjects that will be recruited to participate in your project and the rationale. *

Note: Summarize briefly the statistical consideration or other considerations which determine the total number of subjects.

30

Figure 9: Page 2 of IRB Application Form

(9) Describe the subject population. *
(e.g. high school or college students, cognitively impaired persons, etc.)
 health care providers e.g., nurses, clinicians, physicians etc.

(10) Will children be included in the study? *
 Yes No

(11) Describe the nature of the involvement of human subjects. *
Please include duration of subject participation.
 I am going to have face-to-face interview with them.

(12) Are you offering subject compensation that is subject to MU Accounting Services approval? *
If yes, please upload the approval documentation.

Note: If you are using external or internal funds to pay subjects (cash or non-cash items), you will need to secure approval through accounting services. Please contact Jennifer Walker at 882-4652
 Yes No

(13) Are you offering extra or course credit? *
 Yes No

(14) If you are offering extra or course credit, please describe the alternative assignment.
If extra or course credit is offered for participation, students must be provided with and informed of non-research alternatives involving comparable time and effort to obtain the extra credit in order for the possibility of undue influence to be minimized.

(15) The IRB will need to review all questionnaires, interview questions, etc. to make an accurate Exempt determination. Did you upload these to the application? (Please do not upload URL addresses - upload the content of the survey as a document) *
Mark "no" if not applicable. If this is a non-English speaking population and translated documents are required, please obtain IRB approval for the English version first.
 Yes No

SECTION C - Exclusions from Exemption

If you answer YES to any question in Section C, the project cannot be Exempt.

(1) Does the project pose greater than minimal risk? (45 CFR 46.102(i)) *
Minimal risk means that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.

Yes No

Figure 10: Page 3 of IRB Application Form

(2) Does the research involve prisoners? (45 CFR 46.301) *

Yes No

(3) Does the study include fetuses, pregnant women or human in vitro fertilization? (45 CFR 46.201) *

Yes No

(4) Does the study involve deception? *

Deception is defined as 1) intentionally misleading participants about their status; 2) giving false information about the investigators or research purpose; or 3) omitting information about the real purpose of the research.

Yes No

(5) Is this study subject to FDA regulation?

Clinical investigations that support applications for research or marketing permits for products regulated by the Food and Drug Administration, including foods, including dietary supplements, that bear a nutrient content or claim or a health claim, infant formulas, food and color additives, drugs for human use, medical devices for human use, biological products for human use and electronic products.

Yes No

SECTION D - Funding Information

(1) Is this study sponsored? *

Yes No

(2) How is this project funded? *

Internal Grant (ex. Research council, etc)

(3) Sponsor or Funding Source Information

Agency/Sponsor	Contact Name	Phone Number	Email Address	Funding Mechanism
University of Missouri - Columbia	██████████	██████████ ██████████	██████████	<input checked="" type="checkbox"/> Grant <input type="checkbox"/> Contract

(4) If this study is sponsored please provide the MU Sponsored Program Grant Proposal Number (OSPA)

Internal from MU Interdisciplinary Center on Aging -Research Enrichment & Dissemination (READ) Award

(5) If this study is sponsored please provide the MU PeopleSoft Number

If you receive funding after IRB approval, please update this information using the Identification Form.

MoCode: ██████████

Figure 11: Page 4 of IRB Application Form

(6) Is this research conducted or supported by a federal agency, DHHS, NIH, or CDC? *

Yes No

SECTION E - Risks to Subjects

(1) Risks

A. Does the study involve any potential physical, psychological, legal, social, or economic risks for subjects? *

Yes No

B. Does the study use private records including: educational records or medical charts? *

Yes No

C. Does the study manipulate physical, psychological, or social variables, such as: sensory deprivation, physical stimuli, social isolation, or psychological stress? *

Yes No

D. Does the study probe for or present any materials which subjects might consider sensitive, offensive, threatening, or degrading? *

Yes No

E. Does the study involve collection of information that would be reportable to authorities or collection of information that might render the subject prosecutable under the law (e.g. child abuse, alcohol abuse by a pregnant woman, danger to self or others?) *

Yes No

F. Does the study involve major changes in diet, exercise or sleep? *

Yes No

G. Does the study use voice, video, digital, or image recordings for data collection? (45 CFR 46.110) *

Yes No

H. If yes, does the audio or videotaping place subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation? *

Yes No N/A

I. Describe any potential risks for subjects associated with the research. *

If you checked any YES to any of the items above, describe the nature of the risk of harm for each. Describe how these risks will be presented in the informed consent or cover letter.

None

Figure 12: Page 5 of IRB Application Form

SECTION F - Confidentiality

(1) Confidentiality

A. Describe the specific methods by which confidentiality will be protected. *

The information will be saved with my adviser, Dr. Yang Gong for 7 years in his locked office. The information saved will have no identifiers of patients or providers from whom I am going to get the information.

B. When you collect and store the data, will it be: *

- Anonymous
- Coded (with link to identity)
- Identified

(2) Data Security

A. Mark all protections that apply for Electronic Data:

- Secure Network
- Password Access
- Coded (master list kept and secured separately)
- Other

B. Mark all protections that apply for Hardcopy Data:

- Locked Suite
- Locked Office
- Locked File Cabinet
- Coded (master list kept and secured separately)
- Data de-identified by PI or Research Team
- 24 Hour Personnel Supervision
- Other

C. If OTHER, please explain

(3) Data Sharing

A. Indicate positions, other than members of the research team, who will have access to study data: *

- No one/ Not applicable
- Sponsor
- Colleagues
- Colleagues through NIH data sharing requirement
- Data, Tissue, Specimen Registry(s)
- Other Research Laboratory(s)
- Coordinating Center

Figure 13: Page 6 of IRB Application Form

Other

B. If OTHER, please explain

C. Indicate how the data will be shared *

Without any Identifiers

With Identifiers

With a Linked Code

As a Limited Data Set

Other

SECTION G - Exempt Categories

Depending on which category you select, a sub-form will be generated at the end of the IRB application for your completion. Your project may fall under more than one category.

(1) Is the research being conducted in established or commonly accepted educational settings involving normal educational practices? *

Yes No

(2) Does the research involve educational tests, surveys, interviews, or observations of public behavior? *

Please note: children cannot be included unless it is only for observation.

Yes No

(3) Does the research involve elected or appointed public officials completing educational tests, surveys, interviews, or observations of their public behavior? *

Yes No

(4) Does the research involve the study of existing data or tissue samples? *

Yes No

(5) Is this a research or demonstration project conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine public benefit or service programs? *

Yes No

(6) Does the research involve a taste and food quality evaluation and consumer acceptance study? *

Yes No

Exempt Category 2

Figure 14: Page 7 of IRB Application Form

SECTION A - 45 CFR 46.101(b)(2)

(1) Does this research involve educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior? *

Yes No

(2) Does the research involve children as participants? *

Yes No

(3) If children are involved, are their activities limited to educational tests or observations of public behavior when the investigator(s) does not participate in the activities being observed? *

Yes No N/A

(4) Can participants be identified, directly or through identifiers linked to the participants? *

Yes No

(5) Could any disclosure of the participants' responses outside the research reasonably place them at risk of criminal or civil liability or be damaging to their financial standing, employability, or reputation? *

Yes No

Figure 15: Page 8 of IRB Application Form

9.2. IRB Approved Question

Questionnaires or Interview Questions

I have two prototyped designs with me, which is based on my preliminary study of the technology, EMR, telemedicine and sensor system at TigerPlace, an aging community near the University of Missouri.

As a part of introducing the interviewees to my research, I am going to first demonstrate them my prototyped design either in the form of power-point presentation or color printed copies. It should enable the interviewees to understand my research and my goals that I want to achieve by interviewing them.

After showing them the demo, I am going to ask them some general and some specific questions related to long-term care needs and the use of EMRs and EHRs and how my prototypes design can be enhanced.

They are the following:

- 1) What is your area in long-term care and what are some of the technological needs and challenges?
- 2) How does EMRs or EHRs help you in your care-giving process?
- 3) How efficient are the applications or software you are using now and how do you think they could be made better?
- 4) What is your opinion about my prototyped design? What is missing in it?
- 5) What additionally should be added to it for it to be more useful for your information needs?
- 6) How to improve it so that it can fit into your workflow?
- 7) How do you want to use it in conjunction with the EMR's and EHR's that are in practice?
- 8) How personalized do you think my prototype can be made in relation to what you do?
- 9) What is that you want to see in my design that will help you in making better clinical decisions?
- 10) Your suggestions in relation as how to improve my present design from any perspective e.g., patients, physicians, nurses etc.

In order to answer questions as may arise out of our conversation can be addressed to me via e-mail or phone. The detailed information to that will be provided to the interviewees in my cover letter that will be sent to them when getting their initial consent for conducting the interview.

Figure 16: IRB Approved Interview Questions

9.3. IRB Approved Cover Letter

Cover Letter

I am presently a second year masters student in Health Informatics. I am a researcher in the area of the use of technology in eldercare and long-term care and how it can contribute to 'aging in place'. My present work focuses in finding a dashboard that can help elders and care-providers to see health information in a single screen. The dashboard can help clinicians and care providers to better understanding the health status of the elderly.

The main objective of my project is to integrate the health data available at 'TigerPlace' and provide a holistic representation of the information for the users. It should help in exploring feasibility of clinical decision support based on the available data and the proposed design framework can facilitate better communication between providers and senior residents. Based on my preliminary studies and existing literature available in eldercare, I have prototyped a design framework based on two congestive heart failure (CHF) scenarios.

To gather more proof for the dissemination of my idea, I need to interview care providers who work closely with patients in long-term care settings. I intend to interview them related to the long-term care EMR needs and their information needs. My goal is to find out design considerations that would help enhancing my prototype and how it can be used along with an EMR/EHR in long-term care.

As a part of the process, I need to identify care providers (clinicians, physicians, nurses) who can provide insight on the long-term care needs. From the collected information I have to see how their viewpoint can help me in enhancing my prototype.

I require the care-providers valuable inputs for my research work. I need your permission for an interview. If you grant permission for the interview, please let me know a time and convenient location when we can meet.

Thanks & Regards,
Arpita Chandra

Figure 17: IRB Approved Cover Letter

9.4. IRB Approval Letter

	Health Sciences IRB University of Missouri-Columbia	190 Galena Hall; Dc074.00 905 Hitt Street Columbia, MO 65212 PHONE: (573) 882-3181 FAX: (573) 884-4401
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October 27, 2011

This project was reviewed and approved by the University of Missouri – Columbia Health Sciences Institutional Review Board (HSIRB) according to the terms and conditions described below:

Project Number	1198504
Project Title	Designing a holistic dashboard for elders that helps them in a true 'aging in place'.
Principle Investigator	Chandra, Arpita
Primary Contact	Chandra, Arpita
Approval Date	Oct 27, 2011
Expiration Date	Oct 27, 2012
Approval Category	Exempt 45 CFR 46.101(b) 2
Level of Review	Exempt

All documents reviewed and approved can be found in digital documents and are highlighted green.

You are expected to comply with the requirements outlined in the MU HSIRB Policies (<http://research.missouri.edu/hsirb/policies.htm>). This includes reporting any unanticipated problems involving risk to research participants or others.

Changes in the conduct of the study, including consent process or materials, require submission of an amendment form which must be approved by the HSIRB *prior* to implementation of the changes. Changes in the source of study funding must also be reported.

According to federal regulations, this project requires IRB continuing review. As such, prior to the expiration date above, you must submit either an Exempt Annual Update (EAU) or the Completion/Withdrawal Form. If you have questions or require additional information, please contact us at (573) 882-3181 or irb@missouri.edu

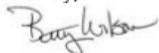
Sincerely,

Betty Wilson
Compliance Officer, HS IRB

Figure 18: IRB Approval Letter

10. References

- Asteljoki, S., Kesanen, J., Pykalamaki, H., Korpela, S.-V., & Montin, L. (2009). Documentation of pain management with TT- 2000+ in May 2008 viewed from clinical nursing practice. *Studies in Health Technology & Informatics*, 146, 503-505.
- Aud, M., Popescu, M., Rantz, M. J., Skubic, M., Alexander, G., Koopman, R., et al. (2010). Developing a Comprehensive Electronic Health Record to Enhance Nursing Care Coordination, Use of Technology, and Research. *Journal of Gerontological Nursing*, 36(1), 13-17.
- Aud, M. P., M; Rantz, MJ; Skubic, M; Alexander, G; Koopman, R; Miller, S. (2010). Developing a Comprehensive Electronic Health Record to Enhance Nursing Care Coordination, Use of Technology, and Research. *Journal of Gerontological Nursing*, 36(1), 13-17.
- Chandra, A., & Gong, Y. (2012). A Human-Centered Design for Supporting Long Term Care Management. Unpublished Conference Paper.
- Chandra, A., & Yang, G. (2012). Practitioners Needs and Views about the Enhancement of Long-Term Care EHRs. Unpublished Symposium Paper.
- Cowan, D., & Turner-Smith, A. (1999). The Role of Assistive Technology in Alternative Models of Care for Older People. In A. Tinker (Ed.), *Royal Commission on Long Term Care* (Vol. 2, pp. 325-346).
- Demiris, G., Oliver, D. P., Dickey, G., Skubic, M., & Rantz, M. (2008). Findings from a participatory evaluation of a smart home application for older adults. *Technology & Health Care*, 16(2), 111-118.
- Demiris, G., Rantz, M., Aud, M., Alexander, G., Oliver, D., De, M., et al. (2006). *TigerPlace: An Innovative Educational and Research Environment*: University of Missouri Health Management and Informatics.
- Elting, L. S., Martin, C. G., Cantor, S. B., & Rubenstein, E. B. (1999). Influence of data display formats on physician investigators' decisions to stop clinical trials: prospective trial with repeated measures. *BMJ*, 318(7197), 1527-1531.
- Florea, E. (2009). *Prediction of Clinical Events in Elderly using Sensor Data : A Case Study on Pulse Pressure*. University of Missouri - Columbia, Columbia.
- Gong, Y., & Chandra, A. (2011a, 13-15 June 2011). *Design of a holistic dashboard for technologies enhancing aging in place*. Paper presented at the e-Health Networking Applications and Services (Healthcom), 2011 13th IEEE International Conference.
- Gong, Y., & Chandra, A. (2011b). Developing an integrated display of health data for aging in place. *Human Factors and Ergonomics in Manufacturing & Service Industries*, 1-10.
- Gong, Y., & Zhang, J. (2005). A human-centered design and evaluation framework for information search. *AMIA Annu Symp Proc*, 281-285.
- Gorman, P. N. (1995). Information needs of physicians. *Journal of the American Society for Information Science*, 46(10), 729-736.

- Gorman, P. N. (2003). Excellent information is needed for excellent care, but so is good communication. *Western journal of medicine*, 172(2000), 319-320.
- Gunningberg, L., Dahm, M. F., & Ehrenberg, A. (2008). Accuracy in the recording of pressure ulcers and prevention after implementing an electronic health record in hospital care. *Quality & Safety in Health Care*, 17(4), 281-285.
- Gunningberg, L., Fogelberg-Dahm, M., & Ehrenberg, A. (2006). Nurses' perceptions of feed-back from the electronic patient record for the quality on pressure ulcer care. *Studies in Health Technology & Informatics*, 122, 850.
- Gunningberg, L., Fogelberg-Dahm, M., & Ehrenberg, A. (2009). Improved quality and comprehensiveness in nursing documentation of pressure ulcers after implementing an electronic health record in hospital care. *Journal of Clinical Nursing*, 18(11), 1557-1564.
- Hersh, W. R., & Hickam, D. H. (1998). How Well Do Physicians Use Electronic Information Retrieval Systems? A Framework for Investigation and Systematic Review. *JAMA: The Journal of the American Medical Association*, 280(15), 1347-1352.
- Hutchins, E. (1995). *Cognition in the wild*. Cambridge, Massachusetts: Massachusetts Institute of Technology.
- Hutchins, E. (2000, 5/18/00). Distributed Cognition. Retrieved Sep. 2. 2003, 2003, from eclectic.ss.uci.edu/~drwhite/Anthro179a/DistributedCognition.pdf
- Hutchins, E., & Klausen, T. (1996). Distributed cognition in an airline cockpit. In Y. Engestrom, Middleton, D. (Ed.), *Cognition and Communication at Work*: Cambridge University Press.
- Jimison, H., Gorman, P., Woods, S., Nygren, P., Walker, M., Norris, S., et al. (2008). Barriers and drivers of health information technology use for the elderly, chronically ill, and underserved. *Evidence Report/Technology Assessment*(175), 1-1422.
- Kane, R. L., & Kane, R. A. (2000). Assessment in long-term care. *Annu Rev Public Health*, 21, 659-686.
- Kesanen, J., Asteljoki, S., Pykalamaki, H., Korpela, S.-V., & Montin, L. (2009). The utilization of electronic patient record in pain management from the perspective of nursing management. *Studies in Health Technology & Informatics*, 146, 171-173.
- Knickman, J. R., & Snell, E. K. (2002). The 2030 problem: caring for aging baby boomers. *Health Serv Res*, 37(4), 849-884.
- Liao, H., & Chang, J.-L. (2011). Human performance in control rooms of nuclear power plants: A survey study. *Human Factors and Ergonomics in Manufacturing & Service Industries*, n/a-n/a.
- Malik, A. S., Giamouzis, G., Georgiopolou, V. V., Fike, L. V., Kalogeropoulos, A. P., Norton, C. R., et al. (2011). Patient perception versus medical record entry of health-related conditions among patients with heart failure. *American Journal of Cardiology*, 107(4), 569-572.

- Marceau, L. D., Link, C., Jamison, R. N., & Carolan, S. (2007). Electronic diaries as a tool to improve pain management: is there any evidence? *Pain Medicine, 8 Suppl 3*, S101-109.
- MedlinePlus. (2011, 26 January 2011). Heart Failure. Retrieved 30 January 2011, from <http://www.nlm.nih.gov/medlineplus/heartfailure.html#cat5>
- Mendonca, E., Cimino, J. J., Johnson, S. B., & Seol, Y.-H. (2001). Accessing heterogeneous sources of evidence to answer clinical questions. *Journal of Biomedical Informatics, 34*, 98-98.
- NIH. (2010). Heart Failure. from http://www.nhlbi.nih.gov/health/dci/Diseases/Hf/HF_WhatIs.html
- Petersen, J., & May, M. (2006). Scale transformations and information presentation in supervisory control. *Int. J. Hum.-Comput. Stud., 64*(5), 405-419.
- Rantz, M., Aud, M., Alexander, G., Oliver, D., Minner, D., Skubic, M., et al. (2008, November 7-9, 2008). *TigerPlace: An Innovative Educational and Research Environment*. Paper presented at the AAAI in Eldercare: New Solutions to Old Problems, Washington DC, .
- Rantz, M., Marek, K., Aud, M., Tyrer, H., Skubic, M., Demiris, G., et al. (2005). A technology and nursing collaboration to help older adults age in place. *Nursing Outlook, 53*(1), 40-45.
- Rantz, M., Skubic, M., Alexander, G., Aud, M. A., Wakefield, B., Galambos, C., et al. (2010). Improving nurse care coordination with technology. *Comput Inform Nurs, 28*(6), 325-332.
- Rantz, M., Skubic, M., Alexander, G., Popescu, M., Aud, M. A., Wakefield, B., et al. (2010). Developing a comprehensive electronic health record to enhance nursing care coordination, use of technology, and research. [Research Support, U.S. Gov't, Non-P.H.S.]. *Journal of Gerontological Nursing, 36*(1), 13-17.
- Rantz, M., Skubic, M., Miller, S., & Krampe, J. (2008). *Using technology to enhance aging in place*. Paper presented at the International conference on Smart Home and Health Telematics.
- Rantz, M. J., Marek, K. D., Aud, M., Tyrer, H. W., Skubic, M., Demiris, G., et al. (2005). A technology and nursing collaboration to help older adults age in place. *Nurs Outlook, 53*(1), 40-45.
- Resnick, H. E., Manard, B. B., Stone, R. I., & Alwan, M. (2009). Use of Electronic Information Systems in Nursing Homes: United States, 2004. *Journal of the American Medical Informatics Association, 16*(2), 179-186.
- Schulze, H., Brau, H., Haasis, S., Weyrich, M., & Rhatje, T. (2005). Human-Centered design of engineering applications: Success factors from a case study in the automotive industry. *Human Factors and Ergonomics in Manufacturing & Service Industries, 15*(4), 421-443.
- Skubic, M., Alexander, G., Popescu, M., Rantz, M., & Keller, J. (2009). A smart home application to eldercare: current status and lessons learned. *Technol Health Care, 17*(3), 183-201.

- Song, F., & Soukoreff, W. (1994). A Cognitive Model for the Implementation of Medical Problem Lists. *Proceedings of the First Congress on Computational Medicine, Public Health and Biotechnology*.
- Strawderman, L., & Koubek, R. (2008). Human factors and usability in service quality measurement. *Human Factors and Ergonomics in Manufacturing & Service Industries*, 18(4), 454-463.
- Wilson, V. (2004). The information needs of primary care physicians: digital reference service. Retrieved Jun 15, 2005, from http://www.slis.ualberta.ca/cap04/virginia/capping_exercise.htm
- Zhang, J. (1991). The Interaction of Internal and External Representations in a Problem Solving Task. *Proceedings of the Thirteenth Annual Conference of Cognitive Science Society*.
- Zhang, J. (1996). A representational analysis of relational information displays. *International Journal of Human-Computer Study*.
- Zhang, J., & Butler, K. (2007). *UFuRT: A work-centered framework and process for design and evaluation of information systems*. Paper presented at the Proceedings of HCI International 2007.
- Zhang, J., & Norman, D. A. (1995). A representational analysis of numeration systems. *Cognition*, 57, 271-295.
- Zhang, J., Patel, V. L., Johnson, K. A., & Smith, J. W. (2002). Designing human-centered distributed information systems. *Intelligent Systems, IEEE*, 17(5), 42-47.