

# Don't They do That?

## Interdisciplinary Iterative Design of a Personal Health Application for Older Adults

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### 1. INTRODUCTION

Older adults during transitions of care find it difficult to manage and share their complex medication regimes [Coleman 2003]. Research shows that older adults take an average of five medications per day [Kaufman et al. 2002]. In addition, medication regimes are complicated because older adults, with declining cognitive abilities, may receive prescriptions from different doctors with different dosing frequencies [Ruscin and Semla 1996]. If older adults cannot manage their medication regimes, they can have serious health consequences, such as worsened conditions and higher mortality risks [Ho et al. 2006; Kettani et al. 2009; McDermott et al. 1997]. It is estimated that medication management errors cost over \$100 billion per year to the United States populace [Gibaldi 1996].

The design community has responded to these problems by assessing user needs for medication management [Palen and Aalø kke 2006] and developing medication management technologies [Hayes et al. 2006; Kaushik et al. 2008; Wan 1999]. These efforts have been piecemeal with little collaboration between the user needs, medical experts, and technology researchers. In addition, with the exception of work by Eric Coleman and colleagues [2004], the aforementioned systems would not meet the needs of older adults during transitions of care because they do not provide older adults with the functionality necessary to manage and share medication regimes. In this paper, we present a comprehensive case study tracing the iterative design process to create a functional Personal Health Application (PHA) - the Colorado Care Tablet (CCT) for older adults and caregivers in transitions of care that was informed by a user needs assessment [Haverhals et al. ], doctors, and interaction

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designers.

The CCT evolved from multiple paper-based low-fidelity prototypes to a high-fidelity functional prototype over the course of six user studies. In this case study, we discuss the challenges that we faced while designing the CCT and provide the community with a set of guidelines to help design future PHAs. Specific to our target population of older adults and caregivers, we recommend participatory design to find the right balance between metaphor and textual information on interfaces. More generalizable recommendations include designing PHAs with interdisciplinary and transdisciplinary collaborations to ensure all stakeholders have a voice in the design process.

## 2. CCT BACKGROUND

The CCT is a tablet PC-based PHA that was developed over a two year period concurrently with eight other PHAs as part of the Robert Wood Johnson Foundation Project HealthDesign. We designed CCT for a tablet PC because it provides portability along with a large interface. In addition, patients can use CCT wherever they feel comfortable using a tablet PC and have Internet accessibility. We broke up our development into four design cycle components: user needs assessment, low fidelity prototyping, high fidelity prototyping, and functional prototyping. Deliverables from each design cycle component were reviewed by the target user group and a panel of experts as shown in Figure 1.

### 2.1 User Review

During the first six months of the CCT project, we conducted a user needs assessment with four focus groups (2 exploratory and 2 confirmatory) and twenty-one *in situ* interviews to explore the issues older adults and caregivers experience when managing medications during transitions of care and Personal Health Information (PHI). We found that older adults and caregivers sought: (1) medication information from multiple sources depending on the urgency of their informational needs; (2) autonomy of their medication regime; (3) a better way to integrate conventional and alternative medications into their regimes; and (4) reasons for taking too many medications [Haverhals et al. ]. The findings from this needs assessment and recommendations from the expert review informed the design of CCT. The comprehensive findings of needs assessment are out of scope of this paper and are presented in detail in [Haverhals et al. ]. In this paper, we detail the results of the six subsequent user studies that iteratively designed the PHA.

### 2.2 Expert Review

The main research team was composed of human computer interaction researchers, medical informaticians, and social scientists. In addition, we had an expert review panel that consisted of an older adult patient and four experts in the areas of transitions of care, health information technology (HIT) interoperability, behavioral science, and patient-centered HIT. Initially, the expert review provided us insights into what older adults and caregivers experience during transitions of care and assisted us in the design of the user needs assessment. We reviewed findings with the expert review from each design cycle and discussed next steps in the prototype development. During the low fidelity prototype stage, we conducted a design

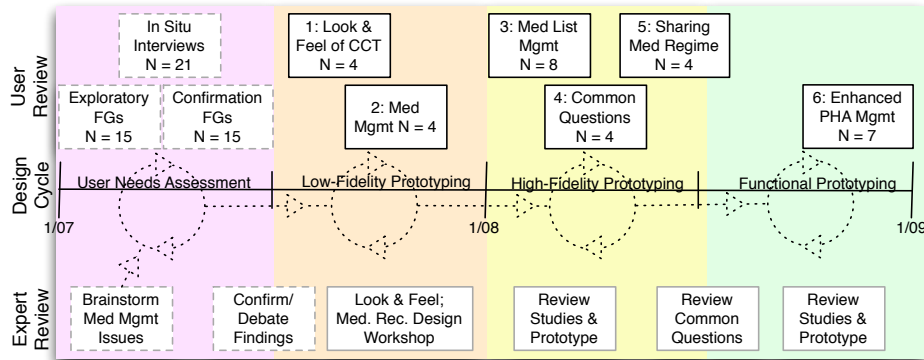


Fig. 1. CCT Iterative Development Timeline

workshop with the expert review panel to brainstorm ideas on *medication reconciliation*, the act of comparing a patient’s medication list with her doctors’ medication lists to identify inconsistencies. Pairing expert review with user studies provided us with the opportunity to develop a PHA that would help older adults with their medication management and provide healthcare providers enough information to help older adults make informed decisions.

### 3. RELATED WORK

In this section we briefly differentiate between Electronic Medical Records (EMRs) and Personal Health Records (PHRs). Furthermore, we examine the reasons for older adults’ inability to follow medication regimes and how CCT can help them in addressing these challenges. Finally, we explore current medication management technologies and describe their shortcomings.

### 3.1 EMR vs PHR

EMRs are digital patient medical records that are intended for doctors and generally owned by healthcare institutions. Patients may get paper copies of the information in their EMRs, but cannot alter them. In addition, in the United States, EMRs are typically not interoperable among healthcare institutions. Conversely, PHRs are intended for patients. Electronic PHAs connect to PHRs to provide patients the ability to access, manage, and share their health information with trusted parties who may include doctors, nurses, or caregivers [Markle 2003].

### 3.2 Medication Regimes and Adherence

Research suggests that patients have difficulty taking intended medication regimes because they: (1) find medication regimes are too complex; (2) forget to take medications; (3) do not have sufficient medication information; and (4) feel they cannot communicate effectively with doctors [Leirer et al. 1991; Osterberg and Blaschke 2005; Parkin et al. 1976; Stewart and Pearson 1999].

*3.2.1 Complexity of Medication Regime.* Older adults with multimorbidity often visit multiple doctors for treatment. Each doctor can potentially provide multiple medications that vary in dosage and frequency which can often result in a complex medication regime. In order to address the complexity of medication regime, we designed a single consolidated medication list in CCT that provides older adults the ability to easily view, add and delete the medications prescribed by various doctors.

*3.2.2 Forgetting Medication Dose.* Older adults who take multiple medications often miss a medication dose due to forgetfulness [Leirer et al. 1991]. Forgetfulness can take two forms: (1) Forgetting the correct way of taking the medication dose resulting in over-dosing or under-dosing; and (2) forgetting the medication dose all together. Hence, the problem of forgetfulness raises the need for a reminder system that prompts older adults whenever a medication dose is due. Through a common PHR platform developed by Project HealthDesign, the CCT was able to incorporate a mobile phone application developed by fellow grantees in the Vanderbilt University Department of Biomedical Informatics that allowed users to set up reminders, doses taken, and send alerts when medications are missed.

*3.2.3 Lack of Medication Information.* Lack of medication information contributes to nonadherence of medication in older adults since they are unaware about the purpose of a medicine or the consequences if they miss a medication dose. Prior to designing CCT, we conducted in-home interviews and found that older adults desired easily-accessible authoritative-information about medications. We further found that older adults had medication management areas in their house where they kept file cabinets containing binders and booklets about medication information. However, searching for particular medication information in these medication management areas was a tedious task and therefore older adults used them infrequently. We designed an interface in CCT that provides a convenient way to obtain authoritative medication information.

3.2.4 *Poor Patient/Doctor Communication.* Another factor that contributes to nonadherence of medication is poor patient/doctor communication. Researchers have found that patients receive inadequate information on the benefits and side effects of medications from their doctors [Osterberg and Blaschke 2005]. This was confirmed in the focus groups that we carried out for needs analysis of CCT.

### 3.3 Older Adult Medication Management Systems

Older adults with multiple chronic conditions must manage their medications in a multitude of ways. We found that older adults employed several methods to manage their medications, including pillboxes and paper-based medication lists. Although current paper based systems are inexpensive, they are often illegible, out-of-date, difficult to share with multiple providers or remote caregivers, and cumbersome to transport. Indeed, one couple in [Haverhals et al. ] discussed moving file cabinets between their two homes to share medical information with providers. Patients also use computer-based stand-alone medication lists using software such as Microsoft Notepad and Excel [Haverhals et al. ]. Other researchers have created electronic pillboxes [Hayes et al. 2006] and medicine cabinets [Wan 1999] that automatically monitor nonadherence and medication errors. Although these devices may assist in medication management, they do not provide the ability to create, manage, and share medication lists. In addition, a medicine cabinet is not portable - an attribute the target population mentioned in our early work.

Web-based PHAs have the potential to address all of the preferred functions of the target user group. One such PHA, that is recommended by the surgeon general of the United States, is My Family Health Portrait (<https://familyhistory.hhs.gov/>). This PHA, however is not interoperable and does not provide an online repository to store patient data. Rather, it is the user's responsibility to manually save a XML file to his computer that contains all the patient information. More recently though, there has been a rise in web-based, interoperable PHAs including Google Health, Microsoft HealthVault, and Dossia. CCT is different because we provide a unified personal health information management system informed by older adults and health professionals, whereas other PHAs do not [Siek et al. 2009]. Here, we would like to mention that this paper emphasizes on how and why we designed CCT interfaces while our earlier paper [Siek et al. 2009] was a cognitive walkthrough comparison of three different PHAs.

## 4. STUDY OVERVIEW

We were motivated to use user-centered, participatory design because researchers [Czaja and Lee 2003; Siek 2008] have successfully used these methods to create applications for older adults. In addition, healthcare technology is mostly designed from a doctor's perspective - designers must *integrate the citizens' perspective* into healthcare technologies [Ballegaard et al. 2008].

### 4.1 Participant Recruitment

After we received Human Research Committee approval, we recruited participants for the user studies. A co-author is a social scientist who purposefully recruited participants and ensured similar make-up. We did a brief cognitive screen to ensure participants were able to participate. The participants were selected from a large

urban area for the first four user studies (studies 1-4). The first site was a residential facility for older adults in a medium sized city that was a combination assisted living and independent living facility. The site housed predominantly highly educated older adults, many who were past university professors or medical doctors. The second site was a senior citizen center in a large metropolitan city that catered mainly to the surrounding working class community. The third site was a hospital clinic that predominantly served patients from a highly educated community in the large metropolitan city. The fourth recruitment site was a smaller, independent living residential facility for older adults in a suburb of the large metropolitan city.

While conducting the first four studies, we learned that caregivers were more likely to use the proposed technology and assist older adults with using the PHA. Thus, we recruited caregiver participants for the latter two studies by emailing recruiting notices to a university mailing list.

For each study, participants had to be at least 65 years old, or caregivers of such individuals to be eligible to take part in the research. Furthermore, the participants were required to be or care for someone who: (1) was hospitalized at least once in the past three years; (2) regularly sees two or more medical providers; and (3) takes three or more prescription medicines. In addition, participants had to be willing to use a computer application to manage health information. All participants were able to write and speak in English.

## 4.2 Participants' Demographics

The 6 user studies involved a total of 31 participants. Nine participants self-defined themselves as caregivers and 18 participants self-defined themselves as older adults. Four participants were older adults and caregivers. Since these four participants cared for themselves and a loved one and mostly discussed their own experiences with us, we categorized them as older adults.

The average age of the 22 older adults was 76.4 years old (s.d.= 7.3 years). We gathered information about older adults' computer usage. This information does not include data about 4 older adults from the second user study since that data was lost in transit. Out of the remaining 18 older adults, 14 had a computer in their house with Internet access. Two older adults did not have access to a computer, but had used a computer in the past. While 2 older adults neither had a computer, nor had they ever used one.

Out of the 14 older adults that had a computer, 10 older adults used it daily, 1 older adult used it 4 days a week while the remaining 3 mentioned they used it rarely. Eight older adults accessed health information on the Internet. Other primary uses of computers included email (N=10), word processing (N=9), and financial applications (N=5).

The average age of the 9 caregivers was 52.7 years old (s.d.= 6.9 years). Eight caregivers had a computer with an Internet connection that they used daily. While the remaining caregiver had used a computer in the past, but did not have access to a computer on a regular basis. The 8 caregivers frequently used a computer primarily for accessing health information on the Internet and emailing. Caregivers also used computers for word processing (N=5), photo editing (N=5), and shopping (N=3).

### 4.3 Method

We designed CCT using an iterative participatory design methodology informed by Rapid Iterative Testing and Evaluation (RITE) [Medlock et al. 2002; Wixon 2003] and Instant Data Analysis (IDA) [Kjeldskov et al. 2004]. Typically, researchers who use RITE methodology, discuss any problems the participant had during a study session and fix any major prototype deficiencies before the next participant study session. The IDA methodology is similar to RITE, however, it involves evaluation of data at the end of the user study day that could involve multiple user study sessions. We conducted RITE studies for the first two CCT user studies - since we were evaluating low fidelity, paper-based prototypes, it was easy to modify major prototype issues between participants if there was a definite need. During the high fidelity prototyping sessions (studies 3-5), we listed issues and possible changes in between the participants, but could not modify the prototype given the time constraints. The suggested modifications were reviewed by our expert review panel before any interface modifications were made.

We performed user studies with 4 - 8 participants per user study. Each participant session lasted about 1 hour. The interval between user studies varied between 2 to 6 months. We confirmed previous findings during each iterative user study to ensure the changes made between studies were appropriate for the target population.

### 4.4 User Study Protocol

The user study sessions were facilitated by two researchers: one from health sciences and another trained in user study techniques. The researchers obtained informed consent from each participant and explained what was going to be recorded during the study. Participants were briefed about CCT and the purpose of the user study. We used a think aloud protocol during the study and modeled a practice example of thinking aloud to show participants what was expected. From our needs assessment, we had identified the most common medication management tasks that older adults performed. We developed scenarios using these tasks and handed over the scenarios to the participants. The participants were asked to perform the tasks present in the scenarios and during this time we recorded their interaction with the prototypes. The health sciences researcher documented the study while the usability researcher facilitated the study. Participants were given a \$20 gift card to a supermarket for their participation in the study.

## 5. ITERATIVE DESIGN OF CCT

In this section we examine how an iterative participatory design approach helped us in transforming CCT from a needs assessment to paper-based prototypes to high-fidelity prototypes and finally to a functional application that older adults and caregivers found helpful in managing medications. We used paper-based prototypes for the the first two studies and designed touch-screen PC based prototypes for the rest of the studies. An overview of the study goals and findings is available in Table I.

Table I. Overview of Iterative Design Cycle Findings

Study	Goal	Outcomes
1	Identify what should the look and feel of CCT be based on our qualitative needs assessment.	<ul style="list-style-type: none"> <li>- Participants wanted interfaces to use metaphors from everyday life</li> <li>- Doctors and patients had different medication management expectations</li> </ul>
2	Refine the look of the prototype and define medication management interfaces.	<ul style="list-style-type: none"> <li>- Participants were confused about if they were editing their record or the EMR</li> <li>- Participants wanted easier input mechanisms</li> <li>- We found the balance between metaphor and text</li> </ul>
3	Refine medication list management viewing and input	<ul style="list-style-type: none"> <li>- Participants understood the PHR-EMR difference with a metaphor representation of a medication list</li> <li>- We found the ideal inputs for easy medication management</li> </ul>
4	Verify medication management and identify common questions patients have during transitions of care	<ul style="list-style-type: none"> <li>- Participants were able to add medications with improved input mechanisms</li> <li>- Participants wanted to prepare for doctor's appointment</li> </ul>
5	Confirm medication management enhancements and evaluate appointment preparation module	<ul style="list-style-type: none"> <li>- Participants wanted textual input to capture all medications and disease symptoms</li> </ul>
6	Evaluate entire system design	<ul style="list-style-type: none"> <li>- Participants were able to use an interoperable PHA</li> </ul>

### 5.1 Low Fidelity Prototype Studies

During the early iterations of our user studies, we wanted to evaluate multiple prototypes. Therefore, we rapidly designed paper-based low-fidelity prototypes [Rettig 1994] for the first two user studies. From these studies, we found that although participants liked the idea of having pictorial representation of different features, it was difficult for them to recognize what feature the picture represented. Furthermore, we were able to discover the complexities involved in designing an interface for medication reconciliation.

5.1.1 *Study 1: The Overall Look.* Goal: Identify what should the look and feel of CCT be based on our qualitative needs assessment

Study Design: The study design of user study 1 was driven by the results obtained from qualitative needs assessment of CCT [Haverhals et al.]. During the needs analysis of CCT, we found that older adults set highest priority in learning about what medication they had to take and at what time should they take it. These questions led us to design the clock prototype, shown in Figure 2.a, that consisted of a clock with medication pictures representing the medication to be taken at the corresponding time. The clock prototype had a menu bar on top that contained links to other features of CCT.



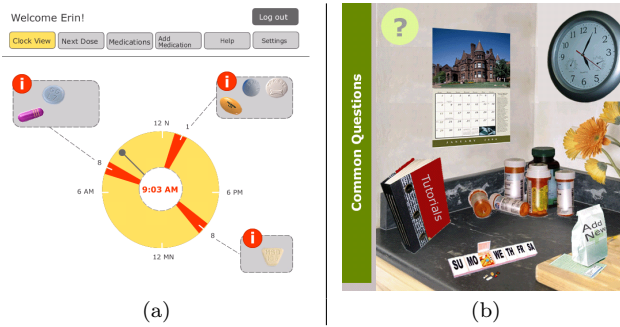
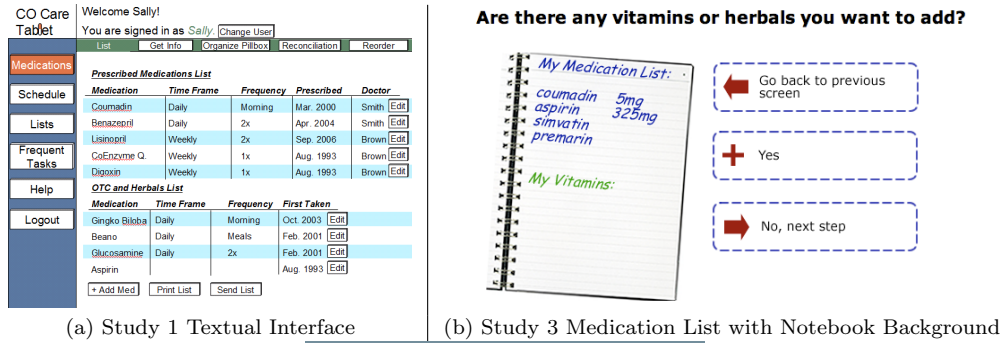
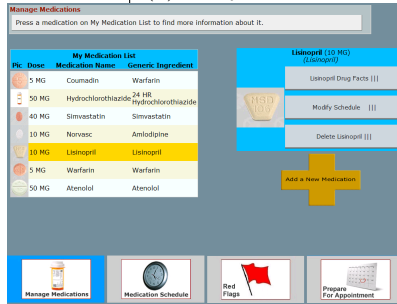


Fig. 2. (a) Clock Prototype (b) Kitchen Counter Prototype



(a) Study 1 Textual Interface (b) Study 3 Medication List with Notebook Background



(c) Study 6 Medication List with Medication Pictures

Fig. 3. Evolution of CCT

In addition, during our needs assessment, we found that the target population organizes their PHI around the house based on context and routine. For example, a calendar was prominently featured in participants' homes and was typically located near a well defined PHI management area. Based on these findings, we created the kitchen counter prototype, shown in Figure 2.b, that was built on the metaphor of a common health information management area - the kitchen counter - but provided participants information about their medication management regimes by clicking on the various objects on the counter. The final interface, shown in Figure 3.a, was informed by common information management interfaces that are easy to develop

with basic database interfaces. This prototype used two menus (horizontal and vertical) and was text rich.

During our first expert review sessions, we discovered that doctors' number one concern for older adults during transitions of care was medication reconciliation. We explored what medication reconciliation meant to patients by conducting semi-structured interviews.

Results: Study 1 showed that participants liked the visual qualities of the clock and kitchen counter prototypes and found the textual prototype confusing. Furthermore, although participants liked the idea of having pictures of different objects in kitchen counter prototype, they did not understand the meaning of the pictures. In addition, participants wanted directions on each screen to help them identify the task each screen helped them accomplish.

The results of semi-structured interviews were particularly interesting because we found that patients believed doctors did the medication reconciliation since the doctors had electronic medical records (EMRs). Conversely, doctors knew that they did not have complete medication lists because EMRs are not interoperable across hospitals. In addition, doctors believed that patients did medical reconciliation because patients are expected to keep medication list. This discrepancy left both parties wondering, "Don't they do that?" When we described medication reconciliation further to participants, one participant remarked that it sounded like *breaking into his doctor's files*.

5.1.2 *Study 2: Refine Look & Medication Management.* Goal: Refine the look of the prototype and define medication management interfaces

Study Design: Findings from study 1 revealed that the interfaces we developed were either too abstract or had too much information on the screen. Therefore, for study 2, we further investigated how to integrate pictures and text on a single organized menu bar. Furthermore, we developed a basic medication management prototype that provided participants with an interface to create a medication list. Finally, we designed and evaluated multiple prototypes for medication reconciliation. We started study 2 with a card sorting exercise to identify what pictures and associated text to put on the menu. Participants were asked to sort twenty picture cards, containing various health and medication related images. The first sorting exercise had participants sort the pictures into any piles they wanted to and describe how they created each pile. For the second sorting exercise, we specifically gave participants categories (e.g., medication information) and asked participants to sort cards based on these categories. We then asked participants to rank cards within each category for each sorting exercise.

Since the primary aim of CCT was to provide users a way to manage their medications, we created a prototype for basic medication management. The prototype provided participants an interface to create a medication list. Based on the feedback from the first study, we designed a medication list creation wizard where participants could read instructions on each page and navigate between wizard screens to add their medications. Medications were added by typing in the name of the medication.

We designed four different interfaces to study medication reconciliation. Although study 1 showed that participants did not believe they had to do this activ-

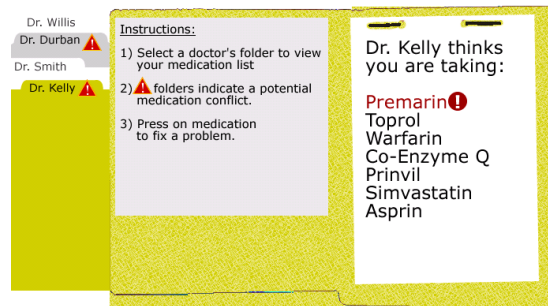


Fig. 4. Medication Reconciliation Prototype 2

ity, the expert review panel feedback encouraged us to present medication reconciliation in different ways to see if it would resonate with participants. The first interface provided participants the opportunity to select different doctors and see what medications were on each doctor's list. The second interface was informed by the feedback from a participant in study 1 and looked like as if the participants were viewing their doctors' files (Figure 4). The third interface was borrowed from standard database list interfaces and had the participant view multiple lists at once and add or delete medications to make the lists match. Finally, the fourth interface was a simplified design where participants answered simple yes/no questions about list inconsistencies.

**Results:** The card sorting exercise helped us identify what pictures represented the appropriate CCT functionality for the menu structure. For the medication input wizard part of the study, we found that participants had enough difficulty adding medication names and did not want to be burdened by inputting dose and schedule information while creating their initial medication list. In addition, participants wanted a less textual way of adding medications - typing was too time consuming.

The results of testing medication reconciliation prototypes revealed that participants did not want to reconcile their medication lists even if they knew that their doctors can not perform medication reconciliation. Interestingly, an overarching concern for participants during the medication list creation and medication reconciliation was how their PHR list would affect their doctors' lists. Participants were concerned that somehow they would modify their doctors' lists. We found that if the participants had to choose one of the medication reconciliation interface, they would prefer the fourth interface because the computer did most of the reconciliation for them and they only had to answer a few questions instead of clicking on each doctor to compare lists.

## 5.2 High Fidelity Prototype Studies

After obtaining sufficient information about user needs and interface expectations from the first two studies, we were able to design and evaluate high-fidelity prototypes for the rest of the studies. Initially, we developed a high-fidelity prototype using images and HTML for study 3, while for study 4 and 5, we used Adobe Flex. Finally, the prototype for study 6 was developed using PHP, JavaScript and HTML. We used a Lenovo ThinkPad X60 Tablet PC that had finger-touch sensitive

screen. The high-fidelity prototypes provided the functionality of adding medications by scanning the medication barcode. For this purpose, we used Socket Mobile Bluetooth Cordless Hand Scanner Series 7.

*5.2.1 Study 3: Refine Medication List Management.* Goal: Refine medication list management viewing and input

*Study Design:* The results of study 2 indicated that the interface must convey to participants that the information was their own personal information and that it was independent from their doctors' records. While brainstorming the design of the medication list, we noticed that during our needs assessment, the patients mostly had hand written medication lists, whereas the lists they were given from their doctors were printed. Hence, we designed the medication list interface (Figure 3.b) to display the participant's medication list in comic sans handwriting superimposed on a notebook note image. Furthermore, we designed an organized menu bar that contained pictures and text to represent the appropriate CCT functionality based on findings from study 2.

We also brainstormed new ways to input medications to decrease the input time. We included two more methods for adding medications: pharmacy fulfillment and barcode scanning. For pharmacy fulfillment interface, we assumed that CCT was able to connect to the pharmacy system and obtain the list of medications that a participant had recently picked-up. These medications were displayed on a screen and participants were asked to select the medications that they wanted to add to their medication list. The barcode scanning method required the user to scan the barcode on the medication bottle by using a cordless barcode scanner. Alternatively, the user could enter the barcode number to add the medication. In addition to these modifications, we further simplified the interface for adding and removing medications. Finally, since the study 2 results showed that older adults were not willing to do medication reconciliation, we automated it and provided participants a way to communicate these issues with their doctors.

*Results:* Study 3 findings were particularly interesting as this was the first time we used the tablet-PC-based prototype. Although none of the participants had used a touch-screen device before, everyone liked the idea of using a touch-screen application to manage medications, and everyone asked about the cost of the system. We found that the touch-screen did not react well to participants' fingers or fingernails. We had to hold the screen completely rigid during most of the sessions.

The participants liked the idea of adding medications by scanning the barcode, but did not think typing barcode numbers on the touch-screen was convenient. Participants also liked the pharmacy fulfillment interface as it required very few input steps. In addition, participants understood that they were editing their own medication list and not their doctors' medication list. All of the participants found the menu bar easy to use.

*5.2.2 Study 4: Medication Management & Common Questions.* Goal: Verify medication management and identify common questions patients have during transitions of care

*Study Design:* After analyzing the results of study 3, we developed a more robust high fidelity prototype to evaluate how older adults could add and remove medica-

tions, navigate through the interface, and edit an established medication list. Apart from modifying the medication management interface, we worked on addressing another issue that had emerged during our needs assessment study in which patients expressed difficulty in communicating with their doctors. Consequently, we conducted semi-structured interviews to find out what common questions and concerns the participants had and how would they like to share this information with their doctors.

Results: Study 4 results showed that generally, the participants performed the basic medication management tasks comfortably. As in study 3, participants liked adding medications by scanning the barcode. However, participants had difficulty in editing the medication list when the medication item and action was not explicitly linked. For example, participants were not sure if they deleted medications properly because the medication was not highlighted when selected and appropriate feedback was not presented once the delete action was selected.

Participants were enthusiastic about communicating with their doctors by asking questions with the CCT. The participants provided different questions that they would ask their doctors. For example, participants wanted to ask “*What will be the side effect of this medicine?*”. All the participants said that they ask their doctors questions during their appointments, however they usually forget to ask important questions.

5.2.3 *Study 5: Sharing Medication Regime & Concerns.* Goal: Confirm medication management enhancements and evaluate appointment preparation module

Study Design: In study 4, once we confirmed that participants could perform the basic medication management tasks, we developed a set of wizard screens for study 5 that would help a participant set-up CCT the first time they start the application. In addition, we created a wizard that would be linked to a hospital system and prompt the participant to confirm their medications after they were released from the hospital. Furthermore, based on the semi-structured interview results from study 4, we created a “Prepare For Appointments” wizard where participants could verify their medication list, select common questions, and share this information with their healthcare providers. The common questions and concerns were “stubs” - incomplete sentences that captured the question, but did not provide specific information. They were designed to help remind the participant about their question without requiring too much typing input. For example, a participant could select, “Is there something I can take besides...”. We created these stubs because in previous studies, participants wanted to have minimal interaction with a keyboard.

Results: Participants were able to easily complete the two set-up wizards and modify medication lists by adding and deleting medications. They were concerned with the simplified pharmacy fulfillment input because they did not get all of their medications or supplements from pharmacies. Additionally, participants liked the idea of preparing for appointments and thought the stubs could provide them enough information to remember what they wanted to ask the doctor. They also wanted the ability to fill in more information in case they did not have an appointment in the near future. The expert panel also wanted more information so that they could look at common questions before appointments and identify possible

complications that should be evaluated before the scheduled appointment.

### 5.3 Functioning Prototype Studies

The defining difference between the high fidelity prototypes and the functioning prototype was that the high fidelity prototypes (studies 3-5) used a local MySQL database for data storage and information access (e.g., mocked-up medication information databases), whereas the functional prototypes (study 6) was integrated into an interoperable PHR system and linked to authoritative information. The CCT functional prototype interconnected with four different systems: (1) common, interoperable platform PHR (<http://www.projecthealthdesign.org/overview-phr>); (2) RxNorm; and (3) Micromedex. The Common Platform provided a PHR repository to store medications present in the medication list. The RxNorm database was used to obtain National Drug Codes (NDCs) of medications and provided the different variations of medications in terms of unit strength, dosage form, brand names, and generic ingredient. The Micromedex provided authoritative medication information and medication images.

*5.3.1 Study 6: Enhanced Medication & Symptoms Recording.* Goal: Evaluate entire system design

Study Design: Previous iterations of the CCT prototype had two main medication input mechanisms: pharmacy fulfillment and barcode scanning. In the real world, however both the aforementioned methods can not be easily implemented since most of the pharmacy systems are not interoperable and medication barcodes are not standardized. This argument was further bolstered during study 5 when participants raised their concern that they may want to add medications that do not come from pharmacy, such as herbals or over-the-counter medications. Consequently, we designed a wizard where a user could add a medication by entering the medication name using a touch-screen keyboard. If the user spelled the medication name incorrectly, CCT would suggest the correct spelling or alternative medications. Otherwise, CCT displayed the different strength and forms of the queried medication. Once the user selected the desired strength and form, CCT would display a set of images associated with that medicine. Alternatively, we provided users an option to select a generic medication bottle image in case none of the images matched the medication they had. When the user selected the image, they were shown the medication's name, strength and form, and image so that they could confirm whether it was the correct medication to add. Furthermore, from our qualitative studies, we found that often times older adults remembered their medication's physical appearance, such as the "blue pill" rather than the actual medication name. Therefore, we provided an option to add medications by entering free text.

Another major enhancement we made in CCT was triggered by the feedback from our expert review panel where healthcare providers wanted a mechanism that could be used to monitor worsening symptoms in participants. Thus, we developed a wizard for "Red Flags." Red flags consisted of different questions such as "I developed a fever of more than \_\_ degrees". We gathered 7 common red flags questions from doctors and provided an "Other \_\_" option where participants could provide any symptom they thought would be worth recording.

Results: The participants found adding medications by entering name more complex than the other two methods since the former involved multiple interaction steps. Furthermore, the participants easily navigated the red flags interface and expressed that it would definitely help them monitor their own or loved one's worsening symptoms and share it with their doctors. Additionally, the ease with which the participants performed common medication management tasks further verified the design of our medication management interface.

#### 5.4 What the Participants Said

In this section, we show that CCT did not evolve from a technological deterministic approach, rather it originated from genuine needs of people. As mentioned earlier, we conducted four focus groups and twenty one in situ interviews to investigate the needs and concerns that older adults and caregivers had with managing medications and their PHI. Our needs assessment's findings were bolstered by the comments made by the participants in appreciation of CCT during our user studies. One participant said *"This (managing her mother's medications) has been my life for the last eight years. Anything to help (with meds management) is great."* Another participant mentioned that she liked the medication information feature of CCT because she did not know where to find authoritative medication information on the Internet: *"So many websites out there, it is hard to know what to trust."* Similarly, during another user study, one participant mentioned that she wished she had CCT when she cared for her mother who passed away last year. She said *"I would have used this to log and keep track of what had been ordered, as my mother suffered from dementia and often forgot what had been ordered and would try to order medicine from pharmacy multiple times"*. It is clear from these examples that CCT is not based on a technological deterministic approach because the participants wanted CCT yesterday. CCT is an excellent example of user centered design in health informatics because people face problems in medication management that have to be addressed.

## 6. DISCUSSION

We set out to design a PHA that was iteratively designed by all stakeholders - older adults, caregivers, and doctors - that could assist older adults manage their complex medication regimes. The six studies described in this paper gave us a better understanding of their needs, wants, and realistic expectations for medication management. In addition, we were able to share our findings with medical experts in transitions of care and alert them about misconceptions in their own expectations of patients' responsibilities (e.g., medication reconciliation). Here we present design guidelines to help future designers of PHAs and personal health information management systems. Furthermore, we discuss the limitations associated with our studies and where do we go from here.

### 6.1 Guidelines

The guidelines presented in this section are novel because they remind and provide the design community concrete examples of the benefits of transdisciplinary design. This approach is seldom found. If the design community is going to help design PHAs that will be used in everyday life, then we must reflect on best practices and

showcase successful examples. We also describe envisioned systems that can help address the PHA design challenges.

One of the emergent themes from our qualitative studies was similar to Leysia Palen and Stinne Aaløkke's [2006], and Anne Moen and Patricia Brennan's [2005] work that physical reminders were important to older adults for their medication management. Based on this theme, we developed the kitchen counter prototype where we anticipated that pictures of various objects on kitchen counter would remind participants about different medication management activities. The results of study 1, however, revealed that participants could not derive meaning from interfaces that were too abstract. In contrast, we found the target population felt overwhelmed when viewing the textual interface. We found the right balance by displaying intuitive, participant selected, health-related images paired with meaningful, informational text. From these findings, we suggest that designers work with all stakeholders to "*find the right balance between metaphor and textual information to effectively present health information*". Our guideline complements earlier research done by Roger Morrell and Denise Park [1993] where it was shown that older adults made less errors following instructions composed of text and images as compared to text only instructions. Interestingly, Suzanne Prior and colleagues [2008] reported that older adults found an instant messaging interface based on a cafe setting more intuitive than a traditional chatting interface. These findings differ from our findings where older adults did not understand the meaning of the pictures in the kitchen counter prototype. Although the differences in findings can be attributed to the different application mediums (health vs. everyday communication).

We addressed the challenge of finding the balance between metaphor and textual interface by conducting a card sorting exercise to find the most meaningful metaphors for our target population. Another example of a successful metaphor balance adoption from our interface was the use of notebook image to help participants understand that they were editing their own medication list and not their doctors' medication lists. Once the participants had seen the medication list with notebook image in the set-up wizard, they implicitly understood the medication list with medication pictures shown in Figure 3.c was their own list. We envision future systems where participants can select their own images to specifically help them identify icons for functionality. For example, they can then use an image of their scheduling mechanism - a calendar or pill box - to denote scheduling functionality. Of course, a trade-off with this customizability is that it increases participant input, that was not favorable with our target population.

One of the major findings that affected the participants and expert panel members was the obvious conflict between doctors' and patients' understanding of medication management. Doctors assumed patients compared their medication lists with doctors' lists and notified the doctors of any list discrepancies, whereas patients assumed doctors had all of the medication list information and did the comparisons themselves. Indeed, the reactions from the two groups were quite interesting - the doctors were surprised participants did not already reconcile their medications - especially since participant's safety was at risk - and thought perhaps more educational programs were needed to alert patients of medication reconciliation



importance. Whereas, participants were surprised to hear that EMRs were not interoperable. In addition, they were not interested in doing medication reconciliation because it was too much work - if the doctor did not do it, then the computer should do it.

Based on these findings, we encourage the community to *design PHAs with all stakeholders and work on methods to effectively communicate between participants, health experts, and interaction design researchers*. Indeed, this guideline requires researchers and designers to help each group bridge between discipline specific cultures (you patient - me doctor) and see each other as equals in the participatory design process. Although the ISO 13407 standard ([http://www.iso.org/iso/catalogue\\_detail.htm?csnumber=21197](http://www.iso.org/iso/catalogue_detail.htm?csnumber=21197)) that provides best practices to design effective human-centered interactive systems emphasizes on the need for multidisciplinary research to build such systems, multidisciplinary research involves lower levels of collaboration among different disciplines [Bruce et al. 2004]. Transdisciplinary research on the other hand may dissolve the boundaries of collaborating disciplines to obtain the best possible solution [Bruce et al. 2004]. Similarities can be found between transdisciplinary research and soft systems methodology where a problem is solved without being strongly tied to specific domains of collaborating disciplines [Checkland and Scholes 1990]. Katie Siek and Kay Connelly [2010] stressed the importance of collaboration between different stakeholders including patients and doctors, and defined how each discipline can effectively collaborate with each other. Similarly, Thomas Eng and colleagues [1999] explained that for a successful interactive health communication application, it is essential that patients, doctors, and developers/designers are actively involved in the evolution of the application.

Currently, these interdisciplinary collaborations take considerable time to develop a common lexicon and work ethic - as evident by the timeline in Figure 1 and the delayed publication of this paper. We envision a future where there are more specially trained researchers (e.g., health informatics) that can help bridge the gaps between researchers knowledge and disciplinary understandings to decrease this start-up time. In addition, we are already beginning to see the expert, highly informed patient advocate (<http://www.diabetesmine.com/>) who uses social media and access to research journals to connect with her community. These patient advocates can help the design community learn about the problems a specific population has before conducting needs assessments.

We draw another guideline from studies 2-5 where the participants expressed the need for multiple, easy ways to input medication. We iteratively designed new input mechanisms - some not possible in today's diverse, non-interoperable healthcare systems - to find the correct set of input mechanisms that provided participants an easy way of creating medication lists. From our experience, we propose that researchers and practitioners *develop transdisciplinary ties and iteratively work with participants, healthcare providers, system designers, and the healthcare industry to create rich input mechanisms that can support patients in easily maintaining health information*. Based on our studies, we further argue that the community should *design PHAs for the future, while at the same time acknowledge the current limitations*. We stress on designing more usable PHAs because on a broader scale, PHAs have the potential to help global citizens manage their health data, however

without truly transdisciplinary research teams the applications will not be as usable or integrated into individuals' lives.

An example of this guideline is how we incorporated alternative forms of input into CCT - including pharmacy fulfillment and barcode scanning. We included these alternative forms to evaluate how future participants could interact with this system because the expert panel had alerted us that both input mechanisms are not currently available in the United States. The reason behind this is that pharmacy systems are not interoperable - although there are insurance systems, not all medications have to be reported through this mechanism. In addition, there is no standardized way to represent medication information - some pharmacies use institution-dependent barcodes, whereas others do not use barcodes at all. Furthermore, iteratively working with participants revealed that participants wanted to add health supplements that were not present in pharmacies. This example also provides yet another reason for interdisciplinary research - where people in the systems, database, and policy community can work together to help the United States healthcare system create an interoperable, standardized system.

## 6.2 Limitations

Although we successfully designed a PHA for older adults to manage their complex medication regimes in a laboratory setting, we acknowledge limitations to our research - namely small sample sizes and differences in participant roles for managing medications. We had only 4 users in most of the user studies. Although these user study numbers may seem small, researchers have found that conducting usability studies with as few as 4-6 participants can provide enough data to determine the effectiveness and usability of a system [Connelly et al. 2008; Virzi 1992]. In addition, the iterative nature of our study design provided us ample opportunity to confirm previous findings with participants in follow-up studies. Another limitation is that during the last 2 studies, there were only 3 older adults while the rest of the participants were caregivers. In most cases, the caregivers were younger than the older adults, thus this may have skewed our results for confirming the system with caregivers and future CCT users.

## 6.3 Where do we go from here?

Given the findings and guidelines to the design community - where do we go from here? From the perspective of designing PHAs for medication management, we urge the community to research alternative ways to input medications and concerns such as voice input or entering medications by taking pictures. The former example has some limitations because some medications are difficult to pronounce, but the free-form recorded text could easily capture participants concerns when recovering from a transition of care. The picture input could also assist caregivers. For example, caregivers often discussed with us the problem of suddenly becoming a caregiver after an independent loved one becomes ill and needs immediate help. In these situations, caregivers would like tools to assist them quickly transition from outside family member to in-the-trenches caregiver. In this situation, we envision a tool where new caregivers could take pictures of their loved one's medications and receive information on the medications to assist the caregiver and older adult modify the medication regime per doctor's prescription. Unfortunately, before any of these

ideas can happen, we must address some of the previously mentioned challenges in this area. Namely, we need a freely available standard library of pictures and medication information. In addition, this repository must have digital input signatures for voice input recognition.

Finally, this paper addresses a small, albeit important, part of personal health information management. The design community needs to look at how to design personal health information management systems for different user segments of the population with different conditions. For example, medication management is important for many chronic conditions, however tweens and caregivers dealing with cystic fibrosis medication management will need different applications and tools to help the tween transition from dependent child to informed, responsible young adult - all the while providing the caregiver the piece-of-mind needed to ensure their tween is successfully managing their illness. In addition, we need more longitudinal *in situ* studies to test the efficacy of PHAs.

## 7. CONCLUSION

Older adults and caregivers find it difficult to manage and share medication management information during transitions of care. If they cannot effectively manage their medication regime, older adults can have serious health consequences. PHAs can potentially assist this population manage and share their medication regime, however current PHAs are not easy for older adults to use. In this paper, we describe how we iteratively designed a PHA with feedback from multiple stakeholders - older adults, caregivers, and doctors - to design an effective, futuristic system. Based on our experiences of designing the PHA, we urge the design community to create meaningful ties with all stakeholders - including doctors, system designers, and policy makers - to find the right balance between design, stakeholder expectations, and health system potential and limitations.

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