AHRQ Final Report for grant R18HS024869

<table>
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<th>Title</th>
<th>Leveraging a Social Network of Elders and Families to Improve Medication Safety at Transitions of Care</th>
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<tr>
<td>Principal Investigator (PI)</td>
<td>Yuri Quintana, PhD</td>
</tr>
<tr>
<td>Organization</td>
<td>Beth Israel Deaconess Medical Center</td>
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<tr>
<td>Inclusive Dates of Project</td>
<td>9/30/2016- 8/31/2020</td>
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<tr>
<td>Federal Project Officer</td>
<td>Eileen Hogan</td>
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<td>Funding Agency</td>
<td>Agency for Healthcare Research and Quality (AHRQ)</td>
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Abstract

**Purpose:** We built a “living laboratory” of aging older adults and their adult caregivers, called InfoSAGE (Information Sharing Across Generations and Environments), to assess families’ informational needs and collaboration patterns affecting the challenging aging process.

**Scope:** Older patients and families often have difficulty reconciling and managing medications after hospital discharge, leading to adverse drug events and harm. This project aims to assess and improve patient and family engagement and self-efficacy, improving care coordination and reducing adverse events from medication mismanagement.

**Methods:** We extended the functionality of the online InfoSAGE platform to include a mobile-first/point-of-care medication manager to help family members keep an accurate medication list, collaborate around medications, track the impact of drugs on symptoms, view medication precautions and drug-drug interactions, and become more engaged with their healthcare partners.

**Results:** We identified facilitators and barriers to the use of a shared online medication list. We assessed the usability and e-health literacy needs for platform adoption and usage. Our research has shown that it is possible to recruit elders over 75 and their families to use online and mobile technologies for information sharing and care coordination.

**Key Words:** Health information technology, Informal caregiving, mHealth, Frail older adults, Health literacy

1. Purpose

InfoSAGE (Information Sharing Across Generations) is an AHRQ-supported research project that seeks to understand and address the information and care coordination needs of older adults aged 75 and above and their families involved in their care. Research participants use an online private social network, built for the project (https://www.infosagehealth.org), to find resources and manage tasks and communications. Our approach uses health information technology in a new way, creating a community-based platform to improve care coordination, patient and family empowerment, and ultimately patient safety.

In this project, we expanded the functionality of the InfoSAGE platform to include a mobile-first/point-of-care medication manager to help older adults and their families keep an accurate medication list, coordinate the list with the prescribing clinicians, track the impact of medications on symptoms, view medication precautions and drug-drug interactions, and become more engaged as partners in their care. We determined facilitators and barriers to using a shared online medication list, assessing the usability and e-health literacy needed for the tool and measuring its adoption and usage. We studied the impact of the tool on medication safety and determined whether increased engagement with the tool improved shared decision making about medications and reduced the inappropriate use of drugs and polypharmacy. This study contributed a set of best practices for using online and mobile tools for complex medication management.

Older patients and families often have difficulty reconciling and managing medications after hospital discharge, leading to adverse drug events and harm. This project aims to assess and improve patient and family engagement and self-efficacy, improving care coordination and reducing adverse events from medication mismanagement.
Patients and their families often have difficulty managing medications, especially across transitions of care.\textsuperscript{1,2} Discrepancies between patients' medication lists at the hospital discharge may be as high as 60\%-70\%,\textsuperscript{3,4} as harm from list discrepancies is difficult to quantify precisely. Still, estimates are that between 11\% and 59\% of these discrepancies are a clinically significant problem. Older patients are often on multiple medications, and side effects and drug-drug interactions may lead to more harm.\textsuperscript{2} Furthermore, because older patients may have help from various family members and aides to manage medications, medication changes must be communicated across the patient’s network and providers/caregivers.

Current interventions to improve medication management are human resource intensive; many involve pharmacists in the reconciliation process or medication packaging process and too often do not directly improve the patient and family’s activation and self-efficacy\textsuperscript{6-9} in using health information exchanges, so other electronic tools are being proposed. These have not yet realized broad success due to limitations in systems, technologies, policies, and user behaviors.\textsuperscript{10}

1.1 Specific Aims
1. To develop and assess the technical and practical feasibility of a patient/family-controlled medication manager within the existing InfoSAGE platform to coordinate medications after hospital discharge
\hspace{1em}1.1. Determine the barriers and facilitators with the use of our patient/family-controlled medication manager tool
\hspace{1em}1.2. Develop an acceptable process for patients/families to import and ‘accept’ medications from multiple sources, such as electronic health records and pharmacy data, into the medication manager
\hspace{1em}1.3. Assess the usability of the mobile medication manager
\hspace{1em}1.4. Assess the adoption of an online medication manager among patients when discharged

2. Measure the impact of a patient/family-controlled medication manager on patient engagement and medication safety following hospital discharge
\hspace{1em}2.1. Assess whether the tool increases patient/family activation and self-efficacy around medication management
\hspace{1em}2.2. Evaluate the accuracy and maintenance of the patient-controlled list and assess discrepancies with the provider list for potential harm
\hspace{1em}2.3. Determine if the tool results in more appropriate medications and decreased polypharmacy for frail elders

2. Scope

2.1 Background
According to the United Nations, the global population age 60+ is expected to triple by 2050. These changes will pose serious challenges for healthcare delivery.\textsuperscript{123-127} Recent census information indicates that the population over age 75 is increasing faster than any other age group. Families will likely need to play an increasingly important role in the caretaking and well-being of the elderly. Family members are increasingly crucial as health facilitators. This ‘facilitating’ role includes maintaining independence and autonomy, administering care, directing the elder to healthy behaviors, and providing health-related information.

Even with the increasing need for familial support, many individuals will live alone and distant from family members. Consumer health information technologies could play a role in reducing this vulnerability. The ‘user’ concept must be flexible, and the technology’s underlying design must be capable of accounting for a variety of ‘user’ models. In some cases, the ‘user’ will be the independent elder, whose physical capabilities can diminish over time. In other cases, the ‘user’ may be a network of elder and family caregivers. In still other cases, the ‘user’ may be a designated healthcare proxy. We also need to increase our understanding of the information needs, information management practices, preferences, and priorities for any of these ‘user’ models – a topic about which we know very little. Our current understanding of how the independent elder seeks and uses healthcare information is limited.

2.2 Context
New technologies provide great opportunities to enhance the quality and safety of healthcare. However, consumer healthcare IT is biased to the young, relatively independent user. It is rare to see underlying designs capable of simultaneously supporting specific physical and cognitive limitations of a user or more general needs of an elderly population, despite published guidelines relating to readability, presentation of information, ease of navigation,
and incorporation of other media (per National Institute on Aging 2009 revised guidelines; Grahame 2004; Nahm 2004; Becker 2004; Given 2007). It is even rarer to see designs that can accommodate evolving user models, such as are required when family members begin to share decision making and management of care with their elderly parents or grandparents.

Sharing the caregiver burden remains a significant challenge. The responsibilities of caring for someone with dementia often fall to women. According to one study, women provide nearly two thirds of all elder care, with wives more likely to care for husbands than vice versa and daughters 28% more likely to care for a parent than sons. In another study by the Alzheimer's Association, over one third of dementia caregivers were daughters. We also studied how technology could support elders and family caregivers in adopting tools to improve their medication adherence and understanding. Medication adherence is a significant challenge in healthcare and for family caregivers.

3.0 Methods

3.1 Study Design

The approach was a mixed method, including qualitative and quantitative assessments to understand the tool and use of standardized instruments to assess patient/family activation and self-efficacy. Secondarily, we aimed to assess to what degree a social network can affect patient safety by improving medication list accuracy and influencing polypharmacy through (1) improved information to patients and (2) symptom tracking through the application to allow patients and clinicians to judge the usefulness of the medications. We will draw from a population of hospitalized elderly patients over 75 at discharge from across an Accountable Care Organization. In this population, medication management is often difficult but exceedingly important.

3.2 Data Sources and Environment

The InfoSAGE (Information Sharing Across Generations) living laboratory was created in 2013 through funding from the Agency for Healthcare Research and Quality with a population of community-dwelling older adults (age ≥ 75) in and around metro Boston. The living laboratory was created in partnership with Hebrew SeniorLife, an academic clinical and residential organization affiliated with Harvard Medical School and Beth Israel Deaconess Medical Center. The term ‘living laboratory’ refers to a human-centric research and development approach. New technologies were implemented, tested, and evaluated in the users’ context then continuously adapted to their changing needs. Living laboratories are used to develop and test innovations but, at the same time, constitute an innovation in research methods when compared with conventional methods in the field.

Through the internet, the ‘living laboratory’ has quickly moved beyond the environs of eastern Massachusetts. Older adults and their families can sign up from any location and opt into participating in the living laboratory, expanding the project’s reach. InfoSAGE is free to use for any person or family worldwide. Participants in the living laboratory have care from doctors and hospitals in eastern Massachusetts, such as Beth Israel Deaconess Medical Center, Cambridge Hospital and Cambridge Health Alliance, Harvard Vanguard Medical Associates, and Hebrew SeniorLife; these sites have teamed up as a single Accountable Care Organization.

3.3 Interventions

InfoSAGE is a secure personal network website with a mobile (iOS, Android, and mobile web) version that supports connections and information sharing among family members and friends caring for an older person. The software and interface have been optimized to help with older participants’ use. However, the application supports any care network built around a person with any care or coordination need, regardless of age.

The InfoSAGE design was based on a series of focus groups held before creating the online social network to generate hypotheses and better understand privacy and security concerns. We learned that family members in particular desired support with medication management and that sharing medication lists with all professional providers was important. The additional qualitative analysis determined that some patients were wary of sharing lists with all people in their network.
3.4 Key Features

- Privacy and Control: Networks are entirely family/elder built, with tiers of access allowing for separation of sensitive health information
- Task Management: Shared to-do list, available with user assignment
- Curated Search: Aging resources and health information filtered through a custom Google search
- Medication Management: Connecting to NIH databases, medications can feature pill images, indications, and scheduling and reminders
- Drug-Drug Interactions: Medication lists are checked against NIH databases for drug-drug interactions

3.5 User Roles

We took an approach to privacy that maximizes the older user’s autonomy, the Keystone, yet makes it easy to delegate control to family, friends, or other trusted persons. Families can use InfoSAGE with or without the Keystone being an active online user.

![Diagram of InfoSAGE User Roles]

InfoSAGE has three circles with different permissions. **Keystones** and their **Proxies** can see and do all activities the site allows. **Proxies** are delegates who can take actions on behalf of a **Keystone**, such as inviting new family members and friends into the care network. **Proxies**, once they sign in, can even simulate logging in as the **Keystone**.

**Caregivers** are family members or friends who help in care. Practically speaking, on InfoSAGE, **Caregivers** can add tasks and post to their network’s message board and view a **Keystone’s** medication list. **Participants** are family members or friends who are in the Keystone’s social network but who do not need to have clinical information, such as medication lists. For example, participants may help with volunteering or providing some comments on the network’s message board.

Medication lists can be maintained by a **Keystone or Proxy** using our built-in medication manager. The name, strength, and dosing schedule for each medication are conveniently listed in one place, with options to export to email or print. Medications can be labeled active or inactive and can be shared or not shared, giving the **Keystone or Proxy** complete control over the amount of information shared to the care network.

A shared task list enables **Keystones or Proxies** to delegate tasks, errands, or appointments to **Caregivers**. Tasks can also be added and unassigned, permitting **Caregivers** or **Participants** the opportunity to volunteer to pitch-in. Tasks can be marked for a specific date and time and will automatically be placed on the care network’s calendar. This calendar gives families the means to a shared overview of the monthly events and provides families with a tool to set reminders, schedule family events, or view upcoming appointments.

**InfoSAGE** also maintains a message board for each care network. Users can post status updates and comments or share in conversations with their network, all in one private and secure place. Users can also upload photos to share with their network. Each user can add contact information for themselves and others, such as addresses and phone numbers, enabling the network to maintain a repository of up-to-date communication means that are easily accessible to the **Keystone** or **Caregivers**.

3.6 Task Manager
A task manager allows users to enter tasks that can be completed by the user or the caregivers.

3.7 Medication Manager
The InfoSAGE medication manager allows users to add medication and their dosage. The medication manager enables quick and accurate accounting of drugs. A planned symptom manager will facilitate tracking medication and morbidity related symptoms, empowering patients and families and informing providers of the patient status trend. The system can send reminders to the user and optionally to their proxy or caregivers. InfoSAGE connects to the RxNorm database to retrieve information on the medication and potential drug-drug interactions. The Reason field can explain the reasons for taking any medication.
3.8 Recruitment
A usability study received ethical approval by the Beth Israel Deaconess Medical Center Institutional Review Board, and informed consent was obtained from each participant. Recruitment began in April 2018 and continued until January 2019. Primary recruitment was conducted through local online bulletin board postings and through collaborating healthcare facilities. In total, 11 subjects were enrolled in the study before data saturation was reached.
4.0 Results

4.1 Usage
As of November 18, 2020, there were 587 users, 366 Keystones, and 221 non-Keystones. These were in 173 networks. Figure 8 shows the distribution of users. The Keystone users’ average age was 75.5 years, and the average age of the caregiver users was 56.6 years. Of these users, 54% self-reported as Caucasian, 4% self-reported as African American, and the rest were unknown. Of those who did describe their relationship with a Keystone, 47% were daughters, 25% were sons, 9% were spouses, and 19% were other, including formal caregivers.

Figure 8. InfoSAGE Access By Metro Area

We evaluated the platform based on the (1) adoption and usage of the system by elders and families; (2) network structures; and (3) feedback from user surveys. The population of users represents people drawn from early partnerships with local continuing care retirement communities. For site usage, we recorded user logins. We more broadly measured site usage and behavior using Google Analytics, which included information about user location, flow through the site, and search terms. However, these data were not linked to individual users. We created a geographic representation of Keystone networks based on the location of each users’ logins. The study team met regularly to reflect on barriers to enrollment and use, based on solicited early user feedback and meetings with prospective users. Figure 9 shows a sample family network.

Figure 9. Sample InfoSAGE Family Network
4.2 Usability Study

Testing was performed in a controlled office environment using fixed recording equipment. Testing was performed on an iPad Pro (2017) using the standard, publicly available InfoSAGE app. A camera recorded hand movements and the iPad screen, and interactions with the iPad were recorded via the InfoSAGE app and the device screen recording feature. Additionally, voice recordings were taken during testing, and participants were asked to ‘speak aloud’ to record thoughts and motivations behind their actions.

All subjects were naïve users of InfoSAGE and were given a brief explanation of the system, the InfoSAGE tiered role framework, and the medication management feature. Eight scenarios were developed with increasing complexity and user-interaction requirements. Participants were asked to enter prescription medications into the medication manager without aid. Scenarios one and two were devised as a baseline and comparison to gauge how rapidly users would become accustomed to the system, with a change only in drug type from one to the next. Scenario three introduced additional medication entry requirements, and scenarios four, five, seven, and eight dealt with finding and using features related to already added medications (details, side effects, interactions). Scenario six required modification of an existing drug.

Voice recordings were transcribed by a member of the research team and confirmed by another. Video recordings and screen captures were analyzed using the Behavioral Observation Research Interactive Software (BORIS), version 7.0.8. Using a heuristic method, activity codes were developed and redefined as the team’s initial videos were analyzed and discussed. Codes were thematically grouped for analysis. The thematic grouping is shown in Table 2. Each video was coded for analysis by at least two team members and reviewed by the entire team. Coded events did not have perfect synchrony between team members, and events often had a subjective nature, which lent to interpretation variances despite a shared code dictionary. Conflicts were noted and adjudicated by a noncoding team member if incorrectly coded according to the definitions.

We recruited a convenience sample of informal caregivers and older adults (Table 1). Ten of the participants were involved in an older family member’s care, while one was independently self-caring. The caregivers were predominantly female (72%). All were naïve users of InfoSAGE and reported a range of ability to use mobile applications despite general comfort with the internet (100% comfortable or very comfortable). After-scenario responses were mixed, as satisfaction (mean 2.2±1.4), ease of use (mean 2.5±1.4), and future utility (mean 1.6±0.7) scored high, but the usefulness of the in-app help was divisive and found to be lacking (mean 3.6±2.6).

Evaluation of inter-rater reliability

We conducted two kinds of tests to validate the consistency of our definitions for the subjects’ interactions and responses with the app and the degree of consensus between raters. We used the intra-class correlation test (ICC), because it incorporates the magnitude of the disagreement between coders to compute the inter-rater reliability estimates. For each study subject, we aggregated the occurrences of each type of behavior across the seven study
scenarios and then calculated the ICC value for consistency in the count of each behavior between the two raters for a given study subject.

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<tr>
<td>Very uncomfortable</td>
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<td>Do you currently care for an elderly family member?</td>
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<td>Yes</td>
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<td>On average, I access InfoSAGE</td>
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<td>I would personally rate my skills with online websites as</td>
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<table>
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<th>Overall, I am satisfied with the ease of completing these tasks (mean, SD)</th>
<th>Mean</th>
<th>SD</th>
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<td>Overall, I am satisfied with the amount of time it took me to complete these tasks</td>
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<td>1.4</td>
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<td>Overall, I am satisfied with the usefulness of the in-app help for completing these tasks</td>
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<td>2.6</td>
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<td>How would you rate the difficulty of completing the task scenarios</td>
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<td>1.4</td>
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<tr>
<td>Overall, after completing these tasks, I feel that this could potentially be used regularly as part of my patient care/loved one’s patient care and for communicating my current list of medications with my care provider/loved one’s care provider</td>
<td>1.6</td>
<td>0.7</td>
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</table>

**Table 1 – Usability Testing**

**Sample interpretation**

IRR was assessed using a two-way mixed, consistency, average-measures ICC to determine the degree that coders provided consistency in their empathy ratings across subjects. The resulting ICC was in the excellent range (ICC =
0.96), indicating that coders had a high degree of agreement and suggesting that empathy was rated similarly across coders. The high ICC indicates that the independent coders introduced a minimal amount of measurement error, and therefore statistical power for subsequent analyses is not substantially reduced. Empathy ratings were consequently deemed suitable for use in the present study's hypothesis tests.

<table>
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<th>Table 2: ICC Coefficients</th>
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<tr>
<td>Subject 2</td>
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<tr>
<td>Subject 3</td>
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<td>Subject 4</td>
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<td>Subject 6</td>
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<td>Subject 7</td>
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<td>Subject 8</td>
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<tr>
<td>Subject 9</td>
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<tr>
<td>Subject 10</td>
</tr>
<tr>
<td>Subject 11</td>
</tr>
</tbody>
</table>

Table 2 illustrates the calculated ICC values for each study subject.

**Time-series observation plotting**

Additionally, we performed time-series plots of observed events for every subject and overlaid each coder’s plots. By examining the overlays for clustering similar events, we further conformed to the validity of our event definitions and consistency between independent observers. Each scenario consisted of multiple defined milestones to measure successful completion or failure. Participants were generally able to complete the scenarios, although none met all the scenarios’ success criteria. Several points were problematic; for example, in scenario 3.6, marking a medication to be taken ‘as needed,’ only two of 11 participants passed the point without assistance. Inter-rater reliability showed excellent agreement across the three raters (ICC: 0.958, 95% CI: [0.918, 0.98]). Due to recording errors, two checkpoints were unable to be determined for one participant and are marked as missing. Usability events were grouped into thematic categories: navigation/UI events, health literacy events, technological literacy events, and emotional response events.

**4.3 Usability Discussion**

The aggregated event timelines and success/failure table highlighted specific areas of difficulty within the study scenarios and hint at a failure in user design and experience. These data support our observations from the testing procedure, in which the layout, navigation, and field design were consistently challenging to participants.

The variety of potential drugs, from over-the-counter to prescription medications to herbal remedies and vitamins, necessitated a robust medication entry system. Each new medication requires several steps to correctly
select the strength, route, and dose, leading to a sense of redundancy expressed by participants. Although initially designed to encompass the most common prescribing practices while maintaining the flexibility and specificity to handle less common administration or complex dosing, the volume and perceived repetition of the data fields required led to failures inaccurate entry.

For example, the entry flow of scenario 3 required a user to enter seven separate fields of information, two that could be regarded as redundant: medication form and dose. Medication forms are queried from the RxNorm database and displayed to the user in a scrollable list. Scenario 3 required selecting a 500-mg tablet of acetaminophen, taken as a 1000-mg dose. This dose was incorrectly entered by 36% of the participants. Future iterations of the app will feature a simplified version of medication entry yet still allow users to utilize the existing method through an ‘advanced add’ button to reduce potential health literacy barriers.

We theorize that some of the observed difficulties in navigation were problems of technology literacy. Although only 9% self-rated their comfort and ability to use the internet as beginners, and 36% self-rated their comfort and ability to use mobile apps as beginners, participants were frequently observed hesitating or hovering or expressing frustration at the inability to continue in a navigation pathway. Several noted aloud during testing or feedback that ‘flat’ buttons were not always obviously navigation elements. Modern design may be more suited to experienced or habitual app users and is more prone to confusion in aging populations. Figure 14 demonstrates the aggregated occurrences of navigation errors in scenarios 1-3. Navigation errors were reduced after learning how to advance through the medication addition process, in comparing scenarios 1 and 2, but were significantly increased when more complexity was introduced in scenario 3. The late navigation errors in scenario 3 were associated with the dose and frequency selection.

Hesitation and frustration issues steadily declined in progression as scenarios were completed but remained the most frequently observed event in each scenario. This suggests that further improvement of the user interface is needed. Distinctly, participants were observed to hover frequently while searching for navigation elements. It was explicitly noted that there is an inconsistency in the placement of ‘next’ and ‘back’ buttons throughout the app. Consistent order reduces searching time and speeds up navigation, reducing frustration, even in cases with a reduction in visual appeal. The emergence of voice-controlled virtual assistants, such as Amazon’s Alexa or Apple’s
Siri, can reduce the complexity of entering detailed medication information by engaging users through dialog and could appeal to users with low technological ability.

![Figure 15. Medication Form](image)

Over-choice was frequently seen when selecting medications, particularly with acetaminophen. The search ‘hits’ are numerous and required participants to scroll through similar-sounding results before reaching the requested choice. This problem could be solved by using ordered lists of the most commonly prescribed medications.

### 4.4 Usability Recommendations

We recommend that app developers for mixed populations of ages, especially those with an emphasis on aging older adults (65+), should employ prominent navigation elements, such as shadows and raised buttons or linear navigation. Consistency in navigation elements, such as buttons for submission and going back, reduces errors due to misclicks. Buttons should also be apparent, utilizing drop shadows or conspicuous shapes and placement. Clickable text should stand out, using underlining, color change, or larger font. Linear navigation, which avoids scrolling, simplifies routes through the app.

Specifically, for medication managers, visual aids should be applied wherever possible. Feedback from participants indicated that it would help organizations if there were a daily view of medications to be taken, especially in regimens with frequent use, multiple different drugs, and irregular scheduling. This could be accomplished with a ‘virtual pillbox,’ using already-selected pill images to reference the drugs to be taken. Other visualization could incorporate a daily calendar with user-selectable times for each medication.

There is a need for usability frameworks to test mHealth apps to ensure the rigorous application of clinical informatics principles. Design for two age groups requires well-thought-out approaches to navigation and terminology when low health and technological literacies are expected. Through our testing, we discovered specific instances in our app that were unclear, confusing, and frustrating, mainly centered around inconsistencies in navigation elements and poor UI choices that led to the redundancy of participant information entered. We have identified design recommendations for researchers and enterprise developers, targeting the elderly population or their informal caregivers through these flaws.

### 4.5 Overall Reflections

**Adoption of Use**

Our research has shown that it is possible to recruit elders over age 75 and their families to use online and mobile technologies for information sharing and care coordination. One system design was based on the belief that families are the key to the community of care around an elder. Still, most existing approaches have
a single-user, rather than family-centric, focus.

Recruitment proved to be more difficult than anticipated. We hypothesized that the main barrier to participation was overcoming existing communication methods, such as email, phone, or in-person visits. Potential participants had to be open and flexible to learning and using a new communication system made doubly difficult by a dyad-based study design. Additionally, in the elder communities, a sense of reluctance and mild distrust was exhibited in sharing medical information online, despite the privacy and security controls that constitute the backbone of InfoSAGE. Other studies have experienced similar difficulties with recruiting from this population, speaking to the importance of user engagement and the utilization of continual feedback.

**Information needs**

We have also observed that information and support needs vary over time and are not monotonic. Needs increase and decrease depending on the care trajectory of the elder. Further investigation is needed to understand online usage patterns, how they relate to health status changes, and how the system could be more useful in emergent care needs.

**Privacy**

Elders and families indicated that privacy controls were important. We do not know the optimal balance of privacy versus information sharing/cascading to family members. With changes over time and the care trajectory, privacy needs and information sharing needs may change. Hence, having a system that allows control of the privacy level to an increasing number of family members may be more valuable over time.

**Usage**

Apps such as InfoSAGE compete for attention as the communication channel of choice. Some families are in the habit of making many phone calls to support care coordination and to update family members. Regular email is also used to update families at a distance. Usage of this system requires that it has a higher value than existing communication channels. We added medication management and interaction alerts based on user feedback, and we noticed higher usage after those features were launched.

The InfoSAGE platform is more useful if the user (elder or family) is already registered and familiar with the system before needing it, meaning that InfoSAGE, or other technologies like it that are designed to support elders in their homes, have many functions and potential uses, such as medication lists, calendars, to-do lists, microblogs, personal stories, etc., that may play a role at different points in care. From a family’s perspective, these tools are most useful during the transitions of care. For example, the system may be more valuable during a visit to the emergency room or a discharge from hospital to home. However, the family needs to be familiar with using the tools before these transitions occur to make information available when required.

Reduction in isolation requires more significant family support and communication. One barrier to adopting InfoSAGE in this context is the family’s perception, structure, and support for using the tools. The perception of 'no need,' alternate forms of contact, and the lack of family caregivers are reasons for non-use. One possible gap here is the difficulty of incorporating formal caregivers (home health aides, visiting nurses, social workers) and informal caregivers within one network. Future research may explore these barriers in more depth; they may be related to an added time burden for physicians, the lack of an informal or family caregiver, difficulty incorporating formal and informal caregiving, and unclear compensation or liability for additional usage of external tools.

**Technology issues**

In our recruitment, we found that, although older adults do not necessarily have smartphones, almost all their children do. Thus, in some sense, a website designed to be adaptive to mobile devices and mobile apps, such as InfoSAGE, is intended for baby boomers who have the burden of supporting their parents. One size does not fit all, in that we have many active users of InfoSAGE who are well above age 65 years.

We have also found that smartphones have a poor form factor for people with poor eyesight or movement disorders, including most of our elders over age 75 years. We are currently conducting formal usability evaluations on the mobile app. Although not widely deployed in elder homes, voice assistants, such as Amazon’s
Alexa, Apple’s Siri, or Google Home devices, could improve upon problems with the form factor.

**Integration**

The effort expended on data entry by/for the users’ needs to be minimized to make this tool easier to use. Integration with the existing healthcare environment is difficult but important. There is a significant cost in setting up internet data connections to import or export medication lists between a consumer-controlled website or app and a healthcare-provider system. Interoperability standards could help, but there is still a cost justification that needs to occur. Clinicians do not necessarily want another communication channel with patients, given the data overload and time pressures that already exist.

There are many fragmented sources of information, each with its focus and associated politics. For instance, most community resources that have websites are designed to capture the user to their site. However, each website uses a different design. It would be useful to have a community resource information standard that would define an information package that could plug-in in apps like InfoSAGE to make resources more widely discoverable and easily integrated into other systems. Furthermore, we need to improve the quality of the information’s wording to make it easier to understand for elders. The look and feel could also be standardized. Finally, we have used curated resources from the Health on the Net Foundation, but more information resource sharing from providers with curated resources would be useful.

**Medication management**

Accurate medication lists reduce medication errors and adverse drug events but require frequent attention to maintain accuracy, especially in patients with multiple providers who may not effectively share health records. Use of a cloud-based app, such as InfoSAGE, for medication management may save time for both patient and provider and may reduce harm by 1) hosting a more accurate medication list that includes nonprescription medications; 2) minimizing unintentional medication discrepancies or errors by sharing with multiple providers who care for the patient an accurate medication list; and 3) providing the patient with medication interaction information. We need to improve the interface between the medications and related decision support, make it easier for the elders to use, and study the impact of this technology on improving patient safety.

**Challenges and barriers of elder e-health adoption**

Although the proportion of older Americans who regularly use the internet continues to rise, barriers to further technology adoption are unique to this population segment. Advancing age produces new health conditions that inhibit the accessibility of technology that is often not designed with an older user in mind. For example, an estimated 20% of adults in North America age 75 or older self-reported as having eyesight conditions, and increasing age has been linked to the inability to accurately and precisely use a computer mouse or trackpad. Beyond physical barriers, the design of websites and computer programs often assume a certain level of familiarity with computer interfaces, which puts late adopters, such as the elderly, at a disadvantage. The design of the user interface and user experience can cause indecision and frustration in this population, especially with elements of web navigation, such as hyperlinks. The literature has also reported that common barriers to adoption, as expressed by the elders, are trust and privacy. Mistrust is regularly experienced by older online users and is described as a feeling of being on constant guard against perceived threats to privacy and security. Studies have observed that trust is significantly associated with Internet use among those age 65 or above. Trust is a significant factor of behavior change for those with internet experience because of information found online. Online encyclopedias, such as Wikipedia, are user-curated information hubs and have become de-facto health information sources, appearing in 71%-85% of searches involving common health keywords. The accuracy and trustworthiness of any individual article cannot be assured. Several studies that have examined drug information have found the quality and quantity to be inconsistent, potentially increasing consumers’ risks.
5.0 List of Products

Websites

InfoSAGE https://www.infosagehealth.org

Publications

**denotes mentees.


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