AHRQ Final Report for grant R18HS024869

Title	Leveraging a Social Network of Elders and Families to Improve Medication Safety at Transitions of Care
Principal Investigator (PI)	Yuri Quintana, PhD
Organization	Beth Israel Deaconess Medical Center
Inclusive Dates of Project	9/30/2016- 8/31/2020
Federal Project Officer	Eileen Hogan
Funding Agency	Agency for Healthcare Research and Quality (AHRQ)
Grant Award Number	R18HS024869-03

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.[1,2] Discrepancies between patients' medication lists at the hospital discharge may be as high as 60%-70%,[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.[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 [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.[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**
   - 1.1. Determine the barriers and facilitators with the use of our patient/family-controlled medication manager tool
   - 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
   - 1.3. Assess the usability of the mobile medication manager
   - 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**
   - 2.1. Assess whether the tool increases patient/family activation and self-efficacy around medication management
   - 2.2. Evaluate the accuracy and maintenance of the patient-controlled list and assess discrepancies with the provider list for potential harm
   - 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.[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,[128] 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,[129] 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.[130-133]

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.[63] 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.

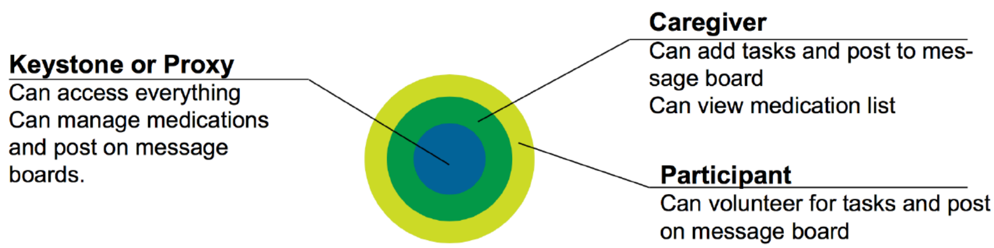


Figure 1. Representation of Early InfoSAGE Family Networks. A network of networks is seen in the center, with a professional caregiver helping two families

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.

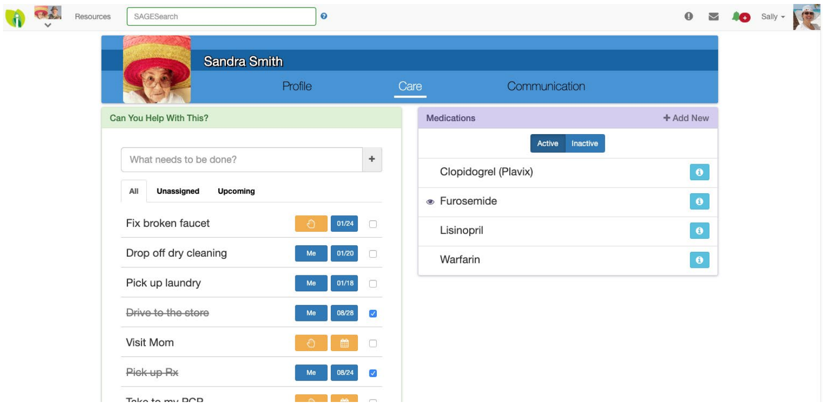


Figure 2. Task Manager

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.

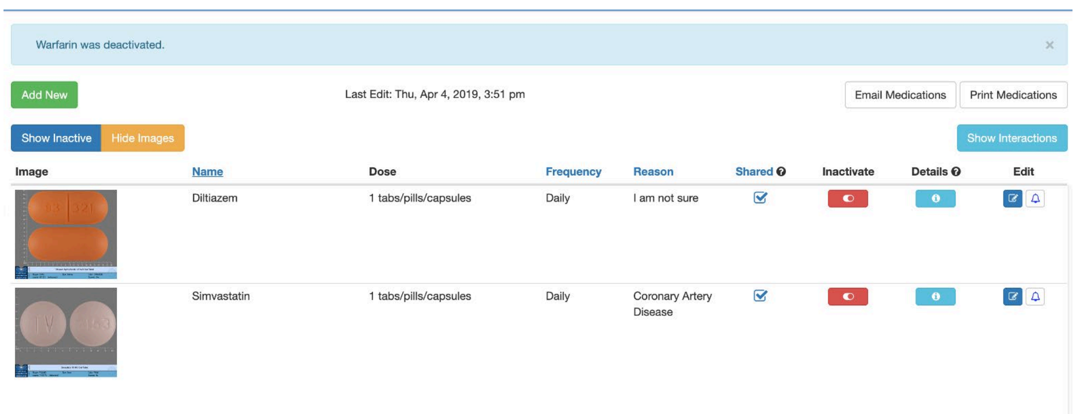


Figure 3. Medication Dashboard

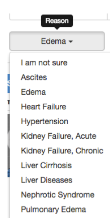


Figure 4. Entering the Reason for Taking a Medication

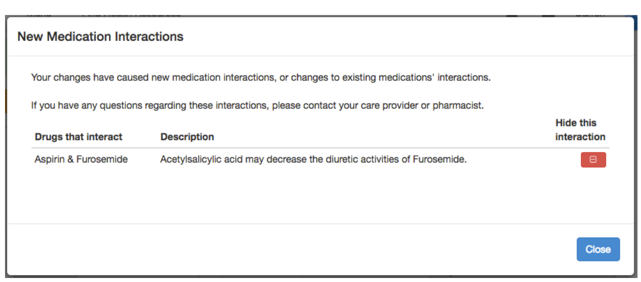


Figure 5. Drug Interaction Information from RxNorm

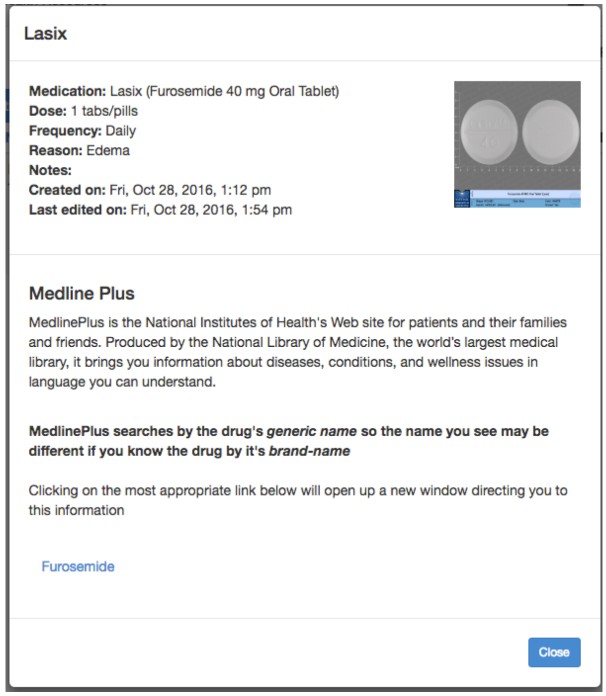


Figure 6. Information About the Drug is Displayed from MedlinePlus

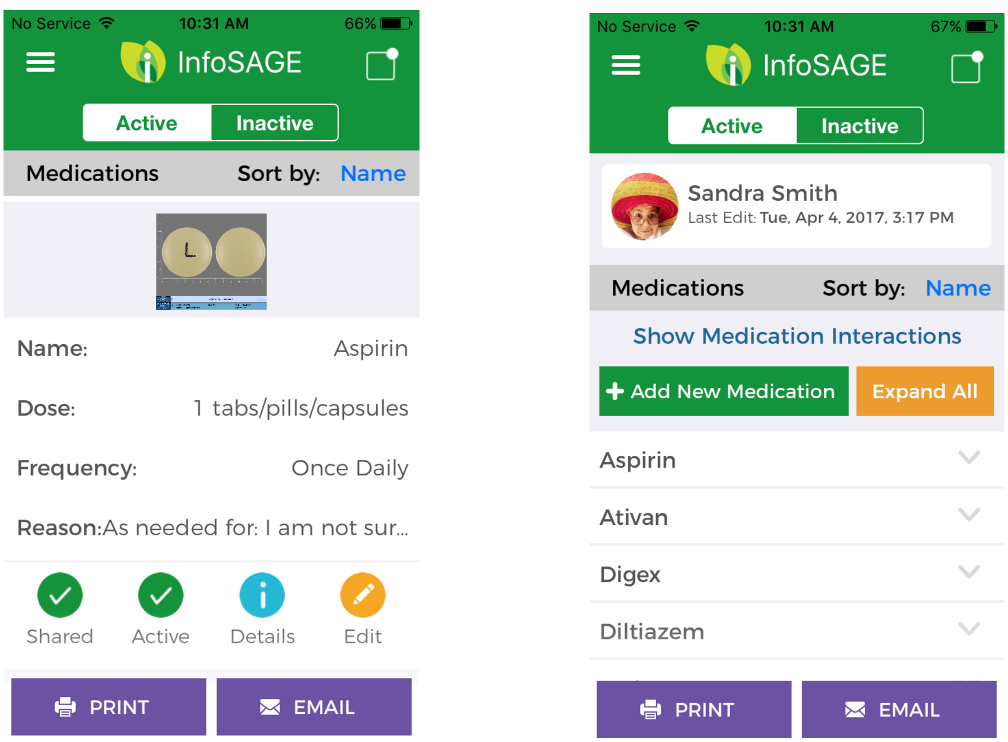


Figure 7. InfoSAGE Mobile App

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.

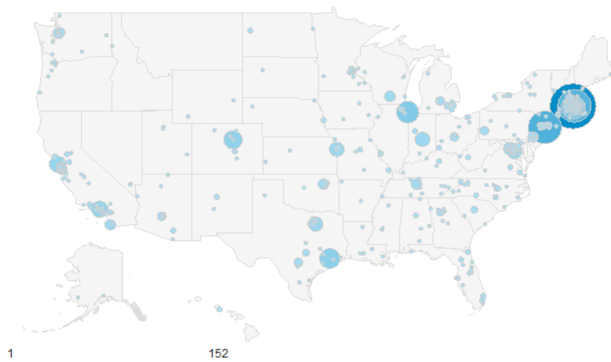


Figure 8. InfoSAGE Access By Metro Area

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.

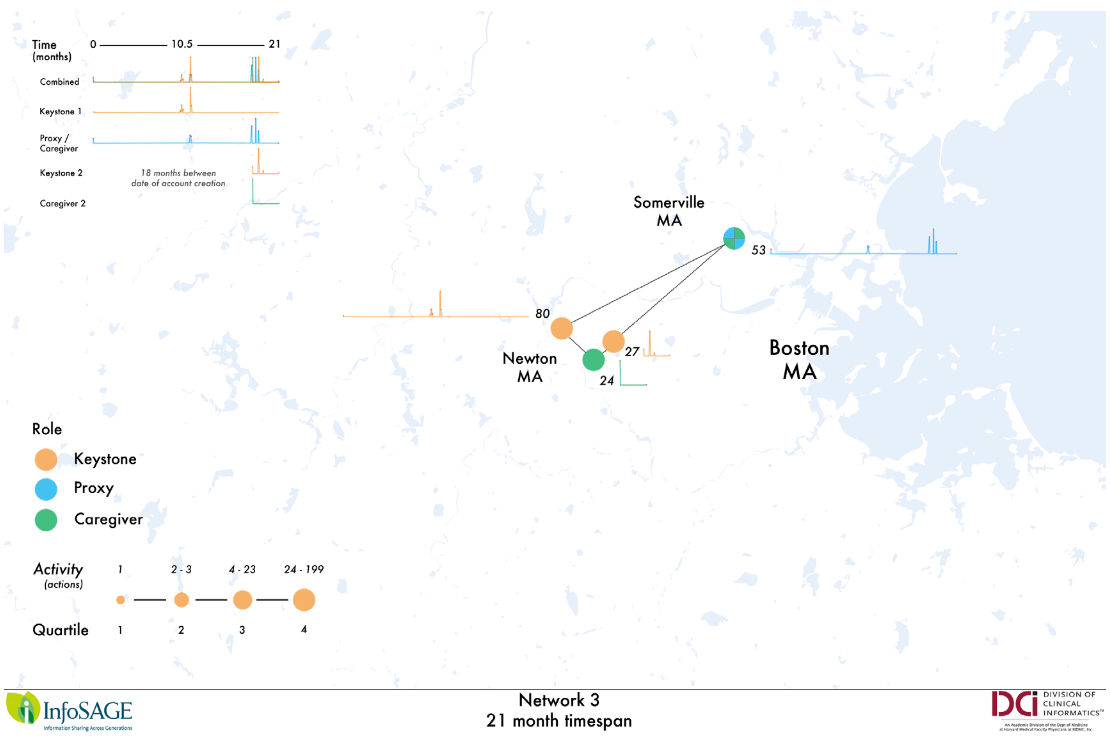


Figure 9. Sample InfoSAGE Family Network

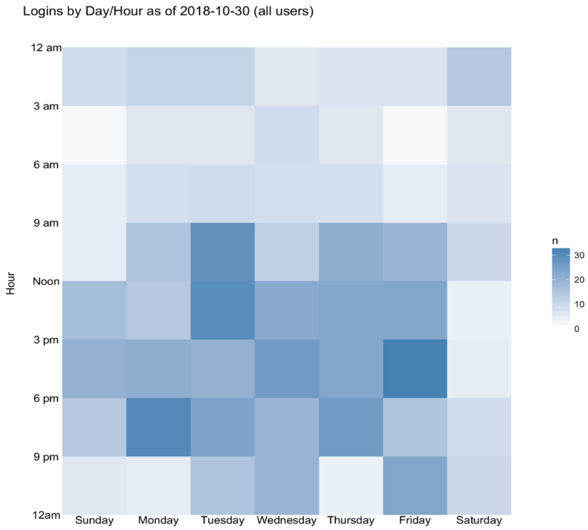


Figure 10. Log-In Patterns

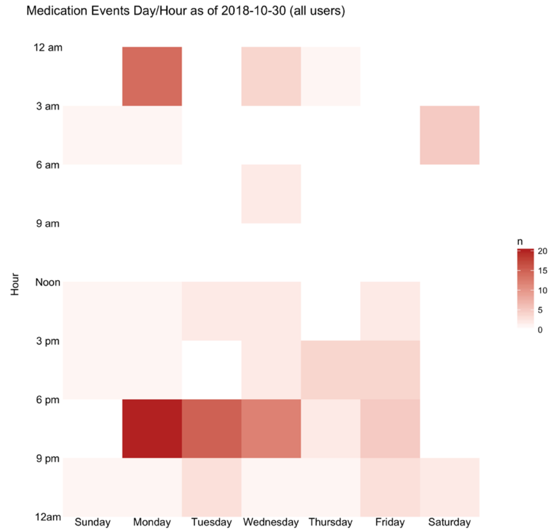


Figure 11. Medication Usage

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.

Age (median, IQR)	53	18
Female (%)	8 (72%)	
Ethnicity		
Hispanic or Latino	1	
Not Hispanic or Latino	10	
Prefer not to answer	0	
Race		
American Indian or Alaska Native	0	
Asian	0	
Black	1	
Native Hawaiian or Other Pacific Islander	0	
White	10	
Prefer not to answer	0	
Level of education		
4-year college graduate	7	
Some graduate school	1	
Masters or doctoral degree	3	
What is your comfort level with using the Internet?		
Very comfortable	9	
Comfortable	2	
Somewhat comfortable	0	
Neutral	0	
Uncomfortable	0	
Very uncomfortable	0	
Do you currently care for an elderly family member?		
Yes	10	
On average, I access InfoSAGE		
Never	11	
I would personally rate my skills with online websites as		
Beginner	1	
Intermediate	5	
Expert	5	
I would personally rate my skills with mobile apps as		
Beginner	4	
Intermediate	5	
Expert	2	
	Mean	**SD**
Overall, I am satisfied with the ease of completing these tasks (mean, SD)	2.2	1.4
Overall, I am satisfied with the amount of time it took me to complete these tasks	1.9	1.3
Overall, I am satisfied with the usefulness of the in-app help for completing these tasks	3.6	2.6
How would you rate the difficulty of completing the task scenarios	2.5	1.4
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	1.6	0.7

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 =

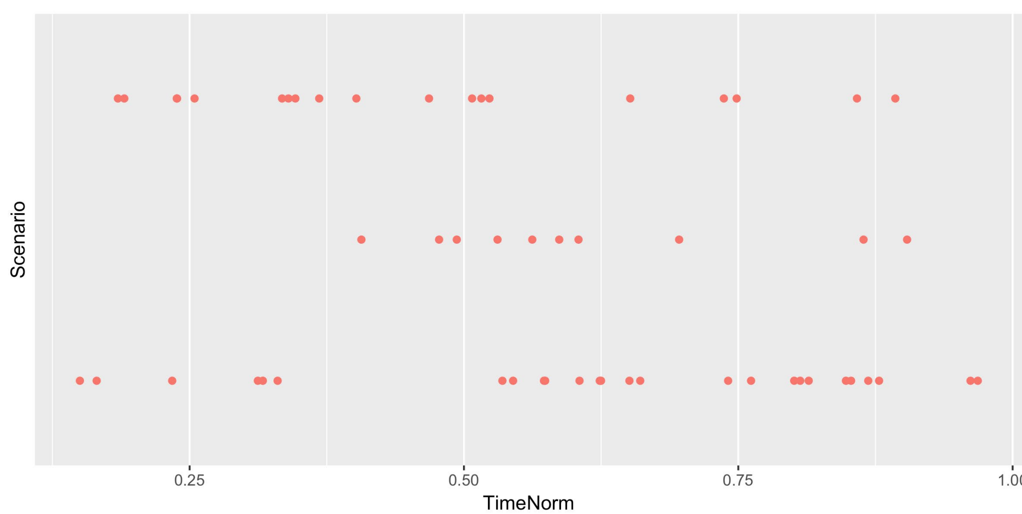
0.96), indicating that coders had a high degree of agreement and suggesting that empathy was rated similarly across coders. The high ICC indicates that the independent coders introduced a minimal amount of measurement error, and therefore statistical power for subsequent analyses is not substantially reduced. Empathy ratings were consequently deemed suitable for use in the present study's hypothesis tests.

Table 2: ICC Coefficients				
	Raters	ICC	95% CI	P
Subject 1	2	0.946	[0.855, 0.98]	$9.57 \times e^{-08}$
Subject 2	3	0.883	[0.749, 0.951]	$3.24 \times e^{-08}$
Subject 3	2	0.935	[0.836, 0.974]	$8.24 \times e^{-08}$
Subject 4	2	0.598	[-0.043, 0.845]	0.0303
Subject 5	2	0.791	[0.458, 0.92]	0.000867
Subject 6	2	0.724	[0.284, 0.894]	0.00451
Subject 7	2	0.796	[0.471, 0.921]	0.000746
Subject 8	2	0.188	[-1.108, 0.687]	0.332
Subject 9	2	0.786	[0.458, 0.915]	0.000763
Subject 10	2	0.158	[-1.126, 0.667]	0.355
Subject 11	2	0.826	[0.66, 0.944]	$2.24 \times e^{-05}$

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, 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.

Figure 12. Navigation Errors Observed in Scenarios 1-3

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.

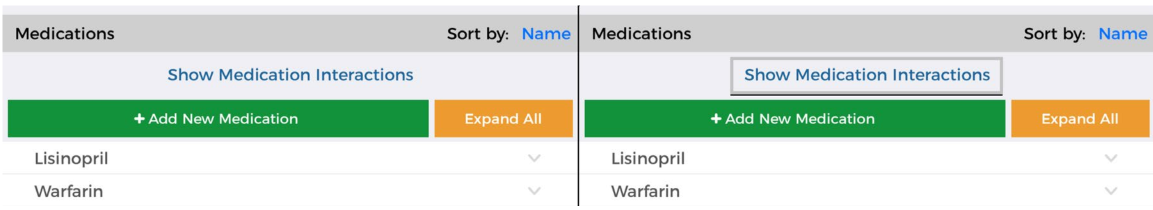


Figure 13. Selection Flow

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.

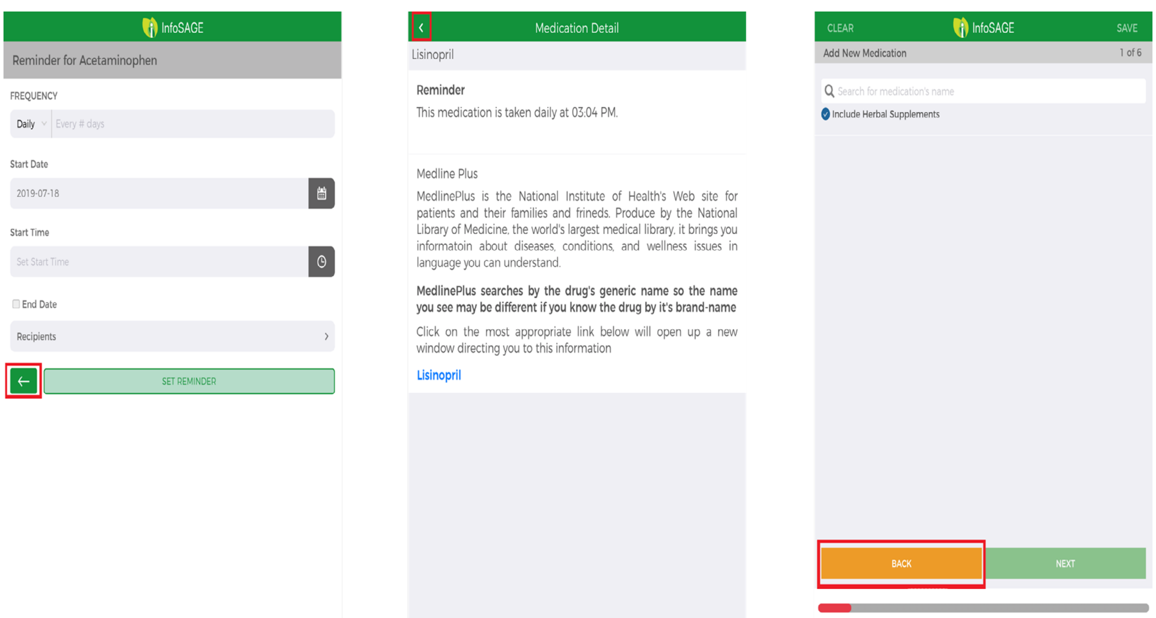


Figure 14. InfoSAGE Mobile App

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.

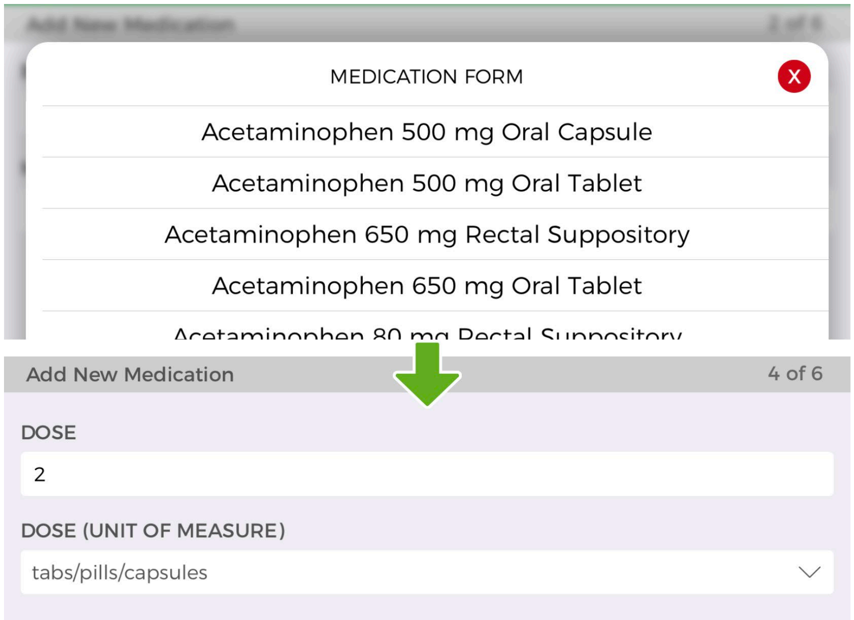


Figure 15. Medication Form

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[18] but require frequent attention to maintain accuracy, especially in patients with multiple providers who may not effectively share health records.[19] Use of a cloud-based app, such as InfoSAGE, for medication management may save time for both for 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,[20] and increasing age has been linked to the inability to accurately and precisely use a computer mouse or trackpad.[21-23] 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.[24,25]

The literature has also reported that common barriers to adoption, as expressed by the elders, are trust and privacy.[26] 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.[27] Studies have observed that trust is significantly associated with Internet use among those age 65 or above.[28] 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.[29] 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.[30,31]

5.0 List of Products

Websites

InfoSAGE https://www.infosagehealth.org

Publications

**denotes mentees.

Quintana Y, Crotty B, Fahy D, Orfanos A, Jain R, Kaldany E, Lipsitz L, Engorn D, **Rodriguez J, **Pandolfe F, Bajracharya A, Slack WV, Safran C. InfoSAGE: Use of Online Technologies for Communication and Elder Care. Stud Health Technol Inform. 2017;234:280-285. PMID: 28186055.

Quintana Y, Crotty B, Fahy D, Lipsitz L, Davis RB, Safran C. Information sharing across generations and environments (InfoSAGE): study design and methodology protocol. BMC Med Inform Decis Mak. 2018 Nov 20;18(1):105. doi: 10.1186/s12911-018-0697-4. PubMed PMID: 30458840.

Quintana, Y, Fahy, D, Crotty, B, Jain, R, Kaldany, E, Gorenberg, M, Lipsitz, L, Engorn, D, Rodriguez, J, Orfanos, A, Bajracharya, A, Henao, J, Adra, M, Skerry, D, Slack, WV. InfoSAGE: Supporting Elders and Families through Online Family Networks. In Proceedings of the American Medical Informatics Association Annual Symposium, (November 3-7, 2018, San Francisco, CA, USA). Bethesda, Maryland, USA: American Medical Informatics Association. 2018 Dec 5;2018:932-941. eCollection 2018. PubMed PMID: 30815136.

Quintana Y, Quintana Y, Fahy D, Crotty B, Gorenberg M, Jain R, Kaldany E, Lipsitz L, Chen YP, Henao J, Safran C. A Usability Evaluation of the InfoSAGE App for Family-Based Medication Management. Stud Health Technol Inform. 2019;257:352-357. PubMed PMID: 30741222.

Quintana Y, Henao J, Kaldany E, Gorenbeg M, Chen YP, Adra M, Lipsitz L, Safran C. InfoSAGE: Usage Pattern of a Family-Centric Care Coordination Online Platform. Stud Health Technol Inform. 2019 Aug 21;264:1972-1973. doi:10.3233/SHTI190740. PubMed PMID: 31438434.

Quintana Y, Fahy D, Abdelfatta AM, Henao J, Safran C. The design and methodology of a usability protocol for managing medications by families for aging older adults. BMC Medical Informatics and Decision Making. (2019) 19:181 PMID: 31488134

References

1. Riley-Lawless K. Family-identified barriers to medication reconciliation. J Spec Pediatr Nurs. 2009;14(2):94-101. PMID: 19356203
2. Manias E, Hughes C. Challenges of managing medications for older people at transition points of care. Res Social Adm Pharm. 2015;11(3):442-447. PMID: 25455760
3. Wong JD, Bajcar JM, Wong GG, et al. Medication reconciliation at hospital discharge: evaluating discrepancies. Ann Pharmacother. 2008;42(10):1373-1379. PMID: 18780806
4. Vira T, Colquhoun M, Etchells E. Reconcilable differences: correcting medication errors at hospital admission and discharge. Qual Saf Health Care. 2006;15(2):122-126. PMC2464829
5. Tam VC, Knowles SR, Cornish PL, Fine N, Marchesano R, Etchells EE. Frequency, type, and clinical importance of medication history errors at hospital admission. A Systematic Review. CMAJ. 2005;173(5):510-515. PMC1188190
6. Bayoumi I, Howard M, Holbrook AM, Schabort I. Interventions to improve medication reconciliation in primary care. Ann Pharmacother. 2009;43(10):1667-1675. PMID: 19737997
7. Haynes KT, Oberne A, Cawthon C, Kripalani S. Pharmacists' recommendations to improve care transitions. Ann Pharmacother. 2012;46(9):1152-1159. PMC3575733
8. Farris KB, Carter BL, Xu Y, et al. Effect of a care transition intervention by pharmacists: an RCT. BMC Health Serv Res. 2014;14:406. PMC4262237
9. Heyworth L, Clark J, Marcello TB, et al. Aligning medication reconciliation and secure messaging: a qualitative study of primary care providers' perspectives. Journal of medical Internet research. 2013;15(12):e264. PMC3868963
10. Nagykaldi ZJ, Yeaman B, Jones M, Mold JW, Scheid DC. HIE-i-health information exchange with intelligence. J Ambul Care Manage. 2014;37(1):20-31. PMID: 24309392
11. Frankenthal D, Lerman Y, Lerman Y. The impact of hospitalization on potentially inappropriate prescribing in an acute medical geriatric division. Int J Clin Pharm. 2015;37(1):60-67. PMID: 25428445
12. Galvin R, Moriarty F, Cousins G, et al. Prevalence of potentially inappropriate prescribing and prescribing omissions in older Irish adults: findings from The Irish Longitudinal Study on Ageing study (TILDA). Eur J Clin Pharmacol. 2014;70(5):599-606. PMC3978378
13. Runciman WB, Roughead EE, Semple SJ, Adams RJ. Adverse drug events and medication errors in Australia. Int J Qual Health Care. 2003;15 Suppl 1(suppl 1):i49-59. PMID: 14660523
14. Fialova D, Onder G. Medication errors in elderly people: contributing factors and future perspectives. Br J Clin Pharmacol. 2009;67(6):641-645. PMC2723202
15. Gurwitz JH, Field TS, Harrold LR, et al. Incidence and Preventability of Adverse Drug Events Among Older Persons in the Ambulatory Setting. JAMA. 2003;289(9):1107-1116.
16. Gurwitz JH, Field TS, Harrold LR, et al. Incidence and preventability of adverse drug events among older persons in the ambulatory setting. JAMA. 2003;289(9):1107-1116. PMID: 12622580
17. Institute of Medicine. To Err Is Human:. National Academies Press; 2000.
18. Beard K. Adverse reactions as a cause of hospital admission in the aged. Drugs Aging. 1992;2(4):356-367. PMID: 1504448
19. Beer C, Hyde Z, Almeida OP, et al. Quality use of medicines and health outcomes among a cohort of community-dwelling older men: an observational study. Br J Clin Pharmacol. 2011;71(4):592-599. PMC3080648
20. Sarzynski EM, Luz CC, Rios-Bedoya CF, Zhou S. Considerations for using the brown bag: a strategy to reconcile medications during routine outpatient office visits. Qual Prim Care. 2014;22(4):177-187. PMID:
21. Armor BL, Wight AJ, Carter SM. Evaluation of Adverse Drug Events and Medication Discrepancies in Transitions of Care Between Hospital Discharge and Primary Care Follow-Up. J Pharm Pract. 2014. PMID: 25312264
22. Staroselsky M, Volk LA, Tsurikova R, et al. An effort to improve electronic health record medication list accuracy between visits: patients' and physicians' response. Int J Med Inform. 2008;77(3):153-160. PMID: 17434337
23. Arnold ME, Buys L, Fullas F. Impact of pharmacist intervention in conjunction with outpatient physician follow-up visits after hospital discharge on readmission rate. American Journal of Health-System Pharmacy: official journal of the American Society of Health-System Pharmacists. 2015;72(11 Suppl 1): S36-42. PMID: 25991594
24. Balling L, Erstad BL, Weibel K. Impact of a transition-of-care pharmacist during hospital discharge. J Am Pharm Assoc (2003). 2015;55(4):443-448. PMID: 26161488
25. Caroff DA, Bittermann T, Leonard CE, Gibson GA, Myers JS. A Medical Resident-Pharmacist Collaboration Improves the Rate of Medication Reconciliation Verification at Discharge. Jt Comm J Qual Patient Saf. 2015;41(10):457-461. PMID: 26404074
26. Farley TM, Shelsky C, Powell S, Farris KB, Carter BL. Effect of clinical pharmacist intervention on medication discrepancies following hospital discharge. Int J Clin Pharm. 2014;36(2):430-437. PMC4026363
27. Herring H, Smith W, Ripley T, Farmer K. Pharmacist involvement at discharge with the joint commission heart

failure core measure: challenges and lessons learned. Hospital Pharmacy. 2014;49(11):1017-1021. PMC4319801
28. Keeys C, Kalejaiye B, Skinner M, et al. Pharmacist-managed inpatient discharge medication reconciliation: a combined onsite and telepharmacy model. American Journal of Health-System Pharmacy: official journal of the American Society of Health-System Pharmacists. 2014;71(24):2159-2166. PMID: 25465589
29. Kilcup M, Schultz D, Carlson J, Wilson B. Postdischarge pharmacist medication reconciliation: impact on readmission rates and financial savings. J Am Pharm Assoc. 2013;53(1):78-84. PMID: 23636160
30. Kogut SJ, Goldstein E, Charbonneau C, Jackson A, Patry G. Improving medication management after hospitalization with pharmacist home visits and electronic personal health records: an observational study. Drug Healthc Patient Saf. 2014;6:1-6. PMC3900312
31. Kripalani S, Roumie CL, Dalal AK, et al. Effect of a pharmacist intervention on clinically important medication errors after hospital discharge: a randomized trial. Ann Intern, Med. 2012;157(1):1-10. PMC3575734
32. Musgrave CR, Pilch NA, Taber DJ, et al. Improving transplant patient safety through pharmacist discharge medication reconciliation. Am J Transplant. 2013;13(3):796-801. PMID: 23332093
33. Phatak A, Prusi R, Ward B, et al. Impact of pharmacist involvement in the transitional care of high-risk patients through medication reconciliation, medication education, and postdischarge call-backs (IPITCH Study). J Hosp Med. 2016;11(1):39-44. PMID: 26434752
34. Sarangarm P, London MS, Snowden SS, et al. Impact of pharmacist discharge medication therapy counseling and disease state education: Pharmacist Assisting at Routine Medical Discharge (project PharmD). American Journal of Medical Quality: the official journal of the American College of Medical Quality. 2013;28(4):292-300. PMID: 23033542
35. Varkey P, Cunningham J, O'Meara J, Bonacci R, Desai N, Sheeler R. Multidisciplinary approach to inpatient medication reconciliation in an academic setting. American Journal of Health-System Pharmacy: official journal of the American Society of Health-System Pharmacists. 2007;64(8):850-854. PMID: 17420202
36. Walker PC, Bernstein SJ, Jones JN, et al. Impact of a pharmacist-facilitated hospital discharge program: a quasi-experimental study. Arch Intern Med. 2009;169(21):2003-2010. PMID: 19933963
37. McDonald HP, Garg AX, Haynes RB. Interventions to enhance patient adherence to medication prescriptions: scientific review. JAMA. 2002;288(22):2868-2879. PMID: 12472329
38. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. Health Aff (Millwood). 2013;32(2):207-214. PMID: 23381511
39. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004;39(4 Pt 1):1005-1026. PMC1361049
40. Cameron KA, Ross EL, Clayman ML, et al. Measuring patients' self-efficacy in understanding and using prescription medication. Patient Educ Couns. 2010;80(3):372-376. PMC3184839
41. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev. 1977;84(2):191-215. PMID: 847061
42. Coulter A. Patient engagement--what works? J Ambul Care Manage. 2012;35(2):80-89. PMID: 22415281
43. Bell SK, Folcarelli PH, Anselmo MK, Crotty BH, Flier LA, Walker J. Connecting Patients and Clinicians: The Anticipated Effects of Open Notes on Patient Safety and Quality of Care. Jt Comm J Qual Patient Saf. 2015;41(8):378-384. PMID: 26215527
44. Wright E, Darer J, Tang X, et al. Sharing Physician Notes Through an Electronic Portal is Associated With Improved Medication Adherence: Quasi-Experimental Study. Journal of Medical Internet Research. 2015;17(10):e226. PMC4642386
45. Chrischilles EA, Hourcade JP, Doucette W, et al. Personal health records: a randomized trial of effects on elder medication safety. J Am Med Inform Assoc. 2014;21(4):679-686. PMC4078278
46. Schnipper JL, Gandhi TK, Wald JS, et al. Design and implementation of a web-based patient portal linked to an electronic health record designed to improve medication safety: the Patient Gateway medications module. Informatics in Primary Care. 2008;16(2):147-155. PMID: 18713531
47. Borycki EM, Househ MS, Kushniruk AW, Nohr C, Takeda H. Empowering Patients: Making Health Information and Systems Safer for Patients and the Public. Contribution of the IMIA Health Informatics for Patient Safety Working Group. Yearbook of Medical Informatics. 2012;7:56-64. PMID: 22890342
48. Wachter RM. The digital doctor: hope, hype, and harm at the dawn of medicine's computer age. New York: McGraw-Hill Education; 2015.
49. Wolfstadt JI, Gurwitz JH, Field TS, et al. The effect of computerized physician order entry with clinical decision support on the rates of adverse drug events: a systematic review. J Gen Intern Med. 2008;23(4):451-458. PMC2359507
50. Bleich HL, Beckley RF, Horowitz GL, et al. Clinical computing in a teaching hospital. N Engl J Med. 1985;312(12):756-764. PMID: 3838364

51. Gray JE, Safran C, Davis RB, et al. Baby CareLink: using the Internet and telemedicine to improve care for high-risk infants. Pediatrics. 2000;106(6):1318-1324. PMID: 11099583
52. McCray AT. Promoting health literacy. Journal of the American Medical Informatics Association: JAMIA. 2005;12(2):152-163. PMC551547
53. Holden RJ, Karsh BT. The technology acceptance model: it's past and its future in health care. J Biomed Inform. 2010;43(1):159-172. PMC2814963
54. Monkman H, Kushniruk AW. The Consumer Health Information System Adoption Model. Stud Health Technol Inform. 2015;218:40592. PMID: 26262522
55. Ancker JS, Miller MC, Patel V, Kaushal R, Investigators H. Sociotechnical challenges to developing technologies for patient access to health information exchange data. J Am Med Inform Assoc. 2014;21(4):664-670. PMC4078272
56. Nohr C, Borycki EM, Kushniruk AW, Kuziemsky CE. Theories and Methods for Context Sensitive Health Informatics. Stud Health Technol Inform. 2015;218:40587. PMID: 26262517
57. Sittig DF, Singh H. A new sociotechnical model for studying health information technology in complex adaptive healthcare systems. Qual Saf Health Care. 2010;19 Suppl 3:i68-74. PMC3120130
58. Coiera E. Putting the technical back into socio-technical systems research. Int J Med Inform. 2007;76 Suppl 1:S98-103. PMID: 16807084
59. Aarts J, Callen J, Coiera E, Westbrook J. Information technology in health care: socio-technical approaches. Int J Med Inform. 2010;79(6):389-390. PMID: 20403726
60. Westbrook JI, Braithwaite J, Georgiou A, et al. Multimethod evaluation of information and communication technologies in health in the context of wicked problems and sociotechnical theory. J Am Med Inform Assoc. 2007;14(6):746-755. 2213479
61. Eriksson M, Niitamo V-P, Kulkki S. State-of-the-art is utilizing Living Labs approach to user-centric ICT innovation-a European approach. Lulea: Center for Distance-spanning Technology. Lulea University of Technology Sweden: Lulea. 2005.
62. Lamine E, Zefouni S, Bastide R, Pingaud H. A system architecture is supporting the agile coordination of homecare services. Collaborative Networks for a Sustainable World: Springer; 2010:227-234.
63. Crotty BH, Walker J, Dierks M, et al. Information Sharing Preferences of Older Patients and Their Families. JAMA Internal Medicine. 2015;175(9):1492-1497. PMID: 26147401
64. Crotty B, O'Brien J, Dierks D, Lu X, Feldman H, Safran C. Not Just For The Millennials: A Cross-Sectional Analysis Of Secure Messaging Use Among Elders, Families, And Physicians. Paper presented at American Medical Informatics Association Annual Symposium 2014; Washington, D.C.
65. Nielsen J. Usability inspection methods. Paper presented at Conference: Companion on Human Factors in Computing Systems 1994.
66. Ferranti JM, Musser RC, Kawamoto K, Hammond WE. The clinical document architecture and the continuity of care record: a critical analysis. J Am Med Inform Assoc. 2006;13(3):245-252. PMC1513652
67. Klann JG, Mendis M, Phillips LC, et al. Taking advantage of continuity of care documents to populate a research repository. J Am Med Inform Assoc. 2015;22(2):370-379. PMID: 25352566
68. Botsivaly M, Spyropoulos B, Koutsourakis K, Mertika K. Enhancing continuity in care: Implementing the ASTM E2369-05 Standard Specification for Continuity of Care Record in a homecare application. AMIA Annu Symp Proc. 2006:66-70. PMC1839263
69. Burton LC, Anderson GF, Kues IW. Using electronic health records to help coordinate care. The Milbank quarterly. 2004;82(3):457-481. PMC2690228
70. Kibbe DC, Phillips RL, Jr., Green LA. The continuity of care record. Am Fam Physician. 2004;70(7):1220, 1222-1223. PMID: 15508532
71. Lu SC. CCR exchange: building a patient-driven web-based healthcare community around an emerging personal health record standard. Stud Health Technol Inform. 2007;127:58-64. PMID: 17901599
72. D'Amore JD, Mandel JC, Kreda DA, et al. Are Meaningful Use Stage 2 certified EHRs ready for interoperability? Findings from the SMART C-CDA Collaborative. J Am Med Inform Assoc. 2014;21(6):1060-1068. PMC4215060
73. Plaisant C, Chao T, Wu J, et al. Twinlist: novel user interface designs for medication reconciliation. AMIA Annu Symp Proc. 2013;2013:1150-1159. PMC3900136
74. Plaisant C, Wu J, Hettinger AZ, Powsner S, Shneiderman B. Novel user interface design for medication reconciliation: an evaluation of Twinlist. Journal of the American Medical Informatics Association: JAMIA. 2015;22(2):340-349. PMID: 25665706
75. Knoben JE, Phillips SJ. New drug information resources for pharmacists at the National Library of Medicine. J Am Pharm Assoc (2003). 2014;54(1):49-55. PMID: 24362595
76. Bennett CC. Utilizing RxNorm to support practical computing applications: capturing medication history in live electronic health records. J Biomed Inform. 2012;45(4):634-641. PMID: 22426081
77. Nelson SJ, Zeng K, Kilbourne J, Powell T, Moore R. Normalized names for clinical drugs: RxNorm at 6 years. J Am

Med Inform Assoc. 2011;18(4):441-448. PMC3128404
78. Richesson RL, Smith SB, Malloy J, Krischer JP. Achieving standardized medication data in clinical research studies: two approaches and applications for implementing RxNorm. J Med Syst. 2010;34(4):651-657. PMC2977947
79. Peters L, Bodenreider O. Using the RxNorm web services API for quality assurance purposes. AMIA Annu Symp Proc. 2008:591-595. PMC2656097
80. Parrish F, Do N, Bouhaddou O, Warnekar P. Implementation of RxNorm as a terminology mediation standard for exchanging pharmacy medication between federal agencies. AMIA Annu Symp Proc. 2006:1057. PMC1839491
81. Czaja SJ, Zarcadoolas C, Vaughon WL, Lee CC, Rockoff ML, Levy J. The usability of electronic personal health record systems for an underserved adult population. Hum Factors. 2015;57(3):491-506. PMC4710573
82. Harris L, Thomas V, Fox M. The Influence of Health Care Literacy on the Use of PHRs among Older Adults. Medsurg nursing: official journal of the Academy of Medical-Surgical Nurses. 2015;24(4):283-285. PMID: 26434047
83. Lober WB, Zierler B, Herbaugh A, et al. Barriers to the use of a personal health record by an elderly population. AMIA Annu Symp Proc. 2006:514-518. PMC1839577
84. Logue MD, Effken JA. An exploratory study of the personal health records adoption model in the older adult with chronic illness. Informatics in primary care. 2012;20(3):151-169. PMID: 23710840
85. Mackert M, Kahlor L, Tyler D, Gustafson J. Designing e-health interventions for low-health-literate culturally diverse parents: addressing the obesity epidemic. Telemedicine Journal and e-Health: the official journal of the American Telemedicine Association. 2009;15(7):672-677. PMC2956510
86. Noblin AM, Wan TT, Fottler M. The impact of health literacy on a patient's decision to adopt a personal health record. Perspectives in Health Information Management/AHIMA, American Health Information Management Association. 2012;9:1-13. PMC3510648
87. Sox CM, Gribbons WM, Loring BA, Mandl KD, Batista R, Porter SC. Patient-centered design of an information management module for a personally controlled health record. Journal of Medical Internet Research. 2010;12(3):e36. PMC2956329
88. Borycki EM, Monkman H, Griffith J, Kushniruk AW. Mobile Usability Testing in Healthcare: Methodological Approaches. Stud Health Technol Inform. 2015;216:338-342. PMID: 26262067
89. Kushniruk AW, Patel VL. Cognitive and usability engineering methods for the evaluation of clinical information systems. J Biomed Inform. 2004;37(1):56-76. PMID: 15016386
90. Monkman H, Griffith J, Kushniruk AW. Evidence-based Heuristics for Evaluating Demands on eHealth Literacy and Usability in a Mobile Consumer Health Application. Stud Health Technol Inform. 2015;216:358-362. PMID: 26262071
91. Carvalho CJ, Borycki EM, Kushniruk AW. Using heuristic evaluations to assess the safety of health information systems. Stud Health Technol Inform. 2009;143:297-301. PMID: 19380951
92. Kim, MI, Johnson KB. Personal health records: evaluation of functionality and utility. J Am Med Inform Assoc. 2002;9(2):171-180. PMC344574
93. Segall N, Saville JG, L'Engle P, et al. Usability evaluation of a personal health record. AMIA Annu Symp Proc. 2011;2011:1233-1242. PMC3243224
94. Bellwood P, Borycki EM, Kushniruk AW. Awareness of technology-induced errors and processes for identifying and preventing such errors. Stud Health Technol Inform. 2015;208:61-65. PMID: 25676948
95. Borycki EM, Kushniruk AW, Bellwood P, Brender J. Technology-induced errors. The current use of frameworks and models from the biomedical and life sciences literature. Methods Inf Med. 2012;51(2):95-103. PMID: 22101488
96. Kushniruk AW, Triola MM, Borycki EM, Stein B, Kannry JL. Technology induced error and usability: the relationship between usability problems and prescription errors when using a handheld application. Int J Med Inform. 2005;74(7-8):519-526. PMID: 16043081
97. Kushniruk AW, Borycki EM. Integrating Low-Cost Rapid Usability Testing into Agile System Development of Healthcare IT: A Methodological Perspective. Stud Health Technol Inform. 2015;210:200-204. PMID: 25991130
98. Rosenfeld L, Shepherd A, Agunwamba AA, McCray AT. Iterative evaluation of a web-based health information resource. Journal of Health Communication. 2013;18(8):974-990. PMC3711962
99. Svanaes D, Alsos OA, Dahl Y. Usability testing of mobile ICT for clinical settings: methodological and practical challenges. Int J Med Inform. 2010;79(4):e24-34. PMID: 18789753
100. Grindrod KA, Gates A, Dolovich L, et al. ClereMed: Lessons Learned From a Pilot Study of a Mobile Screening Tool to Identify and Support Adults Who Have Difficulty With Medication Labels. JMIR Mhealth Uhealth. 2014;2(3):e35. PMC4147709
101. Lethbridge-Çejku M, Rose D, Vickerie J. S. Summary Health Statistics for U.S. Adults: National Health Interview Survey. 2006; http://www.cdc.gov/nchs/data/series/sr_10/sr10_228.pdf Accessed 2016-01-18.
102. Kutner M, Greenberg E, Jin Y, Paulsen C. The Health Literacy of America's Adults: Results From the 2003

National Assessment of Adult Literacy (NCES 2006-483). 2006;
http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2006483 Accessed 2016-01-18.
103. Morris NS, Grant S, Repp A, Maclean C, Littenberg B. Prevalence of limited health literacy and compensatory strategies used by hospitalized patients. Nurs Res. 2011;60(5):361-366. PMC3212986
104. U.S. Department of Health and Human Services. Healthy People 2010: Understanding and Improving Health. 2000; http://japha.org/article.aspx?articleid=1043637 Accessed 2016-01-18.
105. Palinkas LA, Aarons GA, Horwitz S, Chamberlain P, Hurlburt M, Landsverk J. Mixed-method designs in implementation research. Adm Policy Ment Health. 2011;38(1):44-53. PMC3025112
106. Ostlund U, Kidd L, Wengstrom Y, Rowa-Dewar N. Combining qualitative and quantitative research within mixed method research designs: a methodological review. Int J Nurs Stud. 2011;48(3):369-383. PMID: 21084086
107. Yen PY, Bakken S. Review of health information technology usability study methodologies. J Am Med Inform Assoc. 2012;19(3):413-422. PMC3341772
108. Parker SJ, Jessel S, Richardson JE, Reid MC. Older adults are mobile too! Identifying the barriers and facilitators to older adults' use of mHealth for pain management. BMC Geriatrics. 2013;13:43. PMC3673892
109. Tieu L, Sarkar U, Schillinger D, et al. Barriers and Facilitators to Online Portal Use Among Patients and Caregivers in a Safety Net Health Care System: A Qualitative Study. Journal of Medical Internet Research. 2015;17(12):e275. PMC4704882
110. Kontos EZ, Bennett GG, Viswanath K. Barriers and facilitators to a home computer and internet use among urban novice computer users of low socioeconomic position. Journal of Medical Internet Research. 2007;9(4):e31. PMC2223190
111. Holden RJ. What stands in the way of technology-mediated patient safety improvements?: a study of facilitators and barriers to physicians' use of electronic health records. Journal of Patient Safety. 2011;7(4):193-203. PMC3220192
112. Mays N, Pope C. Rigour, and qualitative research. BMJ. 1995;311(6997):109-112. PMC2550154
113. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol. 2008;8(1):45. PMC2478656
114. Crabtree BF, Miller WL. Doing Qualitative Research. SAGE; 1999.
115. Crabtree BF, Miller WL. Doing qualitative research. Vol v. 3. Newbury Park, Calif.: Sage Publications; 1992.
116. Crotty BH, Anselmo M, Clarke DN, et al. Opening Notes To Patients: A Qualitative Study of Resident and Faculty Perceptions. Acad Med. 2015 (in Press). PMID:
117. Slack WV. The patient's right to decide. Lancet. 1977;2(8031):240. PMID: 79024
118. Schnipper JL, Liang CL, Hamann C, et al. Developed a tool within the electronic medical record to facilitate medication reconciliation after hospital discharge. J Am Med Inform Assoc. 2011;18(3):309-313. PMC3078655
119. Shekelle PG, MacLean CH, Morton SC, Wenger NS. Acove quality indicators. Ann Intern Med. 2001;135(8 Pt 2):653-667. PMID: 11601948
120. By the American Geriatrics Society Beers Criteria Update Expert P. American Geriatrics Society 2015 Updated Beers Criteria for Potentially Inappropriate Medication Use in Older Adults. J Am Geriatr Soc. 2015;63(11):2227-2246. PMID: 26446832
121. Joint Center for Housing Studies of Harvard University. Projections and Implications for Housing a Growing Population: Older Households 2015-2035. Harvard University; (2016).
122. Front Public Health. 2017; 5: 335. URL: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5732407
123. AHRQ Multiple Chronic Conditions https://www.ahrq.gov/patient-safety/settings/long-term-care/resource/multichronic/mcc.html
123. CDC https://www.cdc.gov/aging/dementia/ and Alzheimer's Association https://www.alz.org/alzheimers-dementia/facts-figures
125. CDC http://www.cdc.gov/ncipc/factsheets/fallcost.htm; CDCReport: A Toolkit to Prevent Senior Falls https://www.cdc.gov/steadi/materials.html
126. Parkinson's Foundation https://www.parkinson.org/Understanding-Parkinsons/Statistics
127.Social Security Administration, Summary of the 2019 Annual Reports, accessed at www.ssa.gov/oact/TRSUM/, on June 27, 2019.
128. Bott NT, Sheckter CC, Milstein AS. Dementia Care, Women's Health, and Gender Equity: The Value of Well-Timed Caregiver Support. JAMA Neurol. 2017;74(7):757–758. doi:10.1001/jamaneurol.2017.0403 Available at URL: https://jamanetwork.com/journals/jamaneurology/fullarticle/2624330
129. Alzheimer's Association. 2016 Alzheimer's disease facts and figures. *Alzheimer's Dement*. 2016;12(4):459-509. https://www.ncbi.nlm.nih.gov/pubmed/27570871
130. Compliance Packaging: A Patient Education Tool, American Pharmacy, Vol. NS29, No. 2, February 1989