



InfoSAGE

Information Sharing Across Generations

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Introduction

InfoSAGE, short for 'Information Sharing Across Generations,' is an innovation and research program created to help elderly people and their families more easily find resources and better coordinate care with one another and with clinicians. The program was created by researchers and specialists in health information from Harvard Medical School, and the project funded is funded through a grant from the US Department of Health and Human Services.

InfoSAGE can help families keep track of appointments, tasks, and ensure that all family members who need to see a message do. While we still use telephones, and now even text messaging, it's helpful to have a clear record of communication between family members for ease of care coordination. In InfoSAGE, you can go back, and you can post to the entire family or network, so you don't leave anyone out.

InfoSAGE helps families stay connected with their elders. Many seniors are capable of controlling their medical needs, but if and when they do need help, families are there to assist. However, many families experience challenges in the coordination of care. Families often have to juggle their own responsibilities, while also ensuring that their elderly parent or parents are safe and healthy. When the need arises for family members or friends to take a more active role in the medical care of an elderly parent, it can be a very challenging and stressful time.

InfoSAGE helps families connect, share, and coordinate care better.

Overview

InfoSAGE is an existing AHRQ supported research project that seeks to understand and address information and care coordination needs of older adults, age 75 and above, and their families who are involved in their care. Research participants use an online private social network, built for the project, 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 improve patient safety.

Elderly patients may face diminishing cognitive function and may need to transfer aspects of control of their personal health information and decision making to one or more family members. We hypothesize that these elders will still want to retain governance over their healthcare information and decision-making, but gradually transition to a shared model for care coordination.

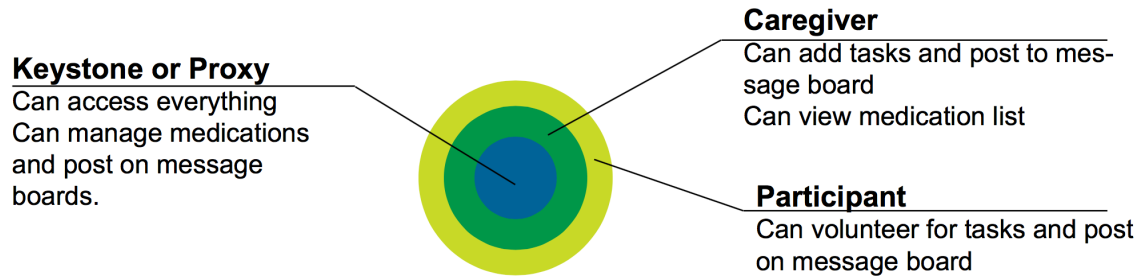
The goal of InfoSAGE is to gain an understanding of the healthcare information 'ecosystem' that can support the special needs of the independent elder, yet also be capable of supporting an incremental transition to shared management of information, decision making and communication. To achieve this goal, four specific aims were developed.

1. Create a novel, family-centered information management and collaborative environment that is based on the requirements and needs identified through our ongoing research.
2. Identify the information needs and decision-making dynamics of elders and those helping to care for them, with a particular focus on how needs evolve as elders' transition from full independence to family-supported care.
3. Using the InfoSAGE web platform, to longitudinally study patient and family collaborative interactions and information management behaviors in the context of real healthcare decision-making and care tasks.
4. Evaluate the extent to which our platform improves communication, coordination, and collaboration for elders and their family members through surveys.

The outcome of this work will be a robust model of the healthcare information management infrastructure needed to meet the growing needs of elders, their adult children and other caretakers.

How it Works

There are three levels of participation on InfoSAGE. We took an approach to privacy that maximizes the autonomy of the older user, 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.



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 also can view a **Keystone's** medication list.

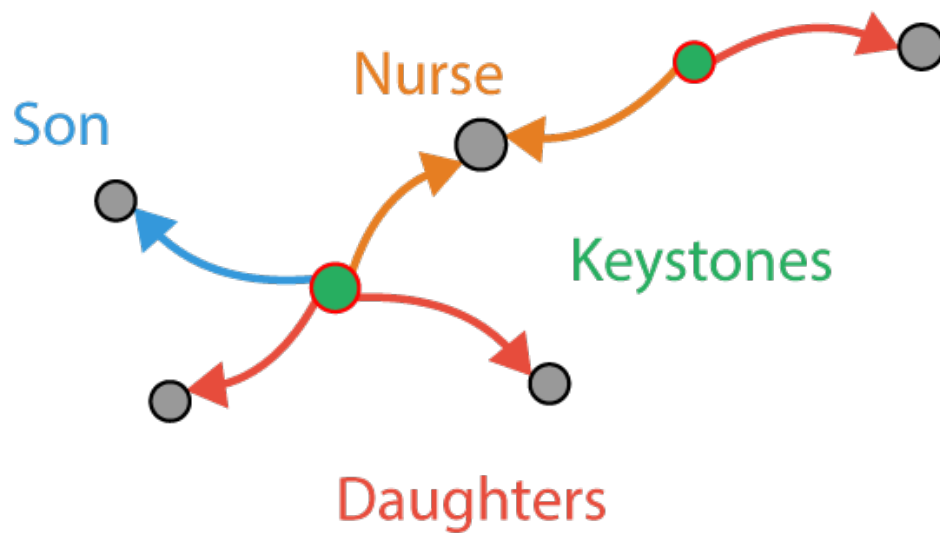
Participants are family members or friends who are in the social network of the **Keystone**, yet don't really have a need to have clinical information, such as medication lists. For example, participants may help with volunteering for some errands or providing some updates on the network's message board.

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 all in one place, with options to export to email or print. Medications can be labeled active or inactive, and shared or not shared, giving the **Keystone or Proxy** complete control over the amount of information shared to the care network.

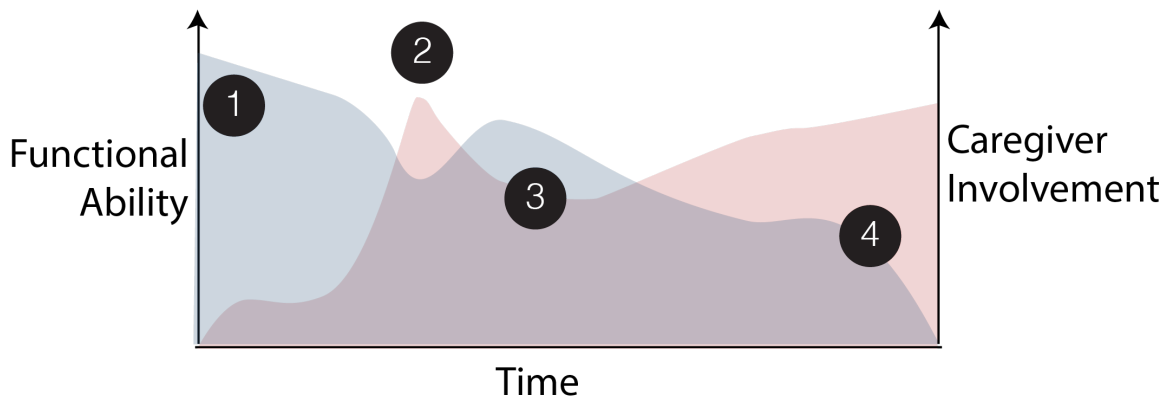
A shared task list enables **Keystones or Proxies** to delegate tasks, errands, or appointments to **caregivers**. Tasks can also be added, unassigned, permitting **caregivers** or **participants** the opportunity to volunteer to pitch-in. Tasks can be marked for a specific date and time, and will automatically be placed on the care network's calendar. This calendar gives families the means to a shared overview on 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, comments, or share in conversations with their network, all in one private, secure place. Users can also upload photos, sharing 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, easily accessible to the **keystone** or **caregivers**.



Care Coordination and Informational Sharing Need



- 1 Independence: Patients and families prepare for future needs
- 2 Acute Illness: During times of illness, families may step in as needed
- 3 Recovery: Patients and families negotiate assistance and access to information.
- 4 Dependence: As functional status declines, families become more involved.

Figure 1: This figure depicts a hypothetical patient's decline in functional status (gray area) and related increase in caregiver involvement by family (pink area).

Recent census information indicates that the population over age 75 is increasing at a faster rate 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 important as health 'facilitators'. This 'facilitating' role includes such things as helping to maintain independence and autonomy, administering care, directing the elder to healthy behaviors and providing health-related information.

Even with the increasing need for familial support, each year a larger proportion of individuals will live alone (spouseless), and at a distance from immediate family members. More often than not, neither the elder nor their family how to readily access or share such information.

Consumer health information technologies could play a role in reducing this vulnerability. In order to successfully do so for this unique population, special considerations need to be given to the design and functionality of these tools and

resources. First, the concept of the 'user' must be flexible, and the underlying design of the technology 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. Second, we 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. Some studies have examined elder use of information technology and the Internet to support their health information needs.

Studies have found, for example, that with training, elders were both willing and successful in using the Internet to find relevant health information. However, as a group, these elders perceived the value of the information retrieved to be low, and they continued to prefer direct contact with a traditional healthcare provider as their primary source of health information. Internet use by the elder population has also been shown to increase satisfaction with their medical treatment during the period of Internet use.

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 (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 models of the user, such as are required when family members begin to share decision-making and management of care with their elderly parents or grandparents.

Our Partners



Hebrew SeniorLife is a nonprofit organization committed to improving the lives of older adults in the Greater Boston area and beyond. Hebrew SeniorLife is involved in aging research with the goal to redefine the experience.



Lasell Village is an award winning senior housing community with a unique take on senior living, emphasizing active, intellectually enriched lifestyles.



Cambridge Health Alliance is an award-winning healthcare system serving Cambridge and the surrounding communities with an emphasis on community health and underserved populations.