

A National Web Conference on the Use of Health IT to Improve Care Planning and Communication With Aging Adults

Questions and Answers

July 17, 2017

QUESTION:

When will the Elder Tree system be available on smartphone platforms?

ANSWER:

David Gustafson:

We don't have a plan for making it available on a smartphone, since in our study we're dealing with populations of up to age 100. For many of these people, the smartphone panel just doesn't do the job. Therefore, we will continue to work through systems like laptops with touchscreens like the Chromebook.

QUESTION:

Do InfoSAGE participants need to be located in the United States, or can they be international as well?

ANSWER:

Charles Safran:

To our surprise, when we put the smartphone app in the Apple store and the Android store, we began to detect users from around the world. Not surprisingly, anything associated with our hospital is frequently explored by hackers from China and Russia in particular, but we have usage from every continent but Antarctica. The app is free to use and supports any illness (e.g., cancer, diabetes), although it was designed for elder care.

QUESTION:

What are the privacy issues of taking photos of the home environment?

ANSWERS:

Eneida Mendonca:

Taking photos or scans of one's home can reveal a lot of detail about the home. These images are a very personal data type. A scan could clearly show personal items, such as photos or reminders on a refrigerator, or capture things that could reflect some illegal activity or reportable behavior. The technologies we use can prevent some of this information from being revealed. We also want to learn from the individuals (patients) about privacy issues they find important. We will be conducting focus groups with the community in an attempt to understand how they perceive privacy issues. Future health-care policies must address both privacy protections and expected use of home scans and the resulting point clouds for patients with complex discharge training.

Kevin Ponto:

These technologies can capture a lot of information very rapidly. Since we will be distributing the homes that we've captured for the VizHome Project publicly at the end of the project, we were very concerned about privacy issues. Therefore, we had all the participants mark off areas of the home in which they had concerns, such as photographs, pieces of paper with identifiable

information, and other things that they felt were unique in the home that they would not want the public to know about. In addition, we went through a redaction process in which we either removed or blurred out private information. Plus, we made sure that the data would be stored securely.

QUESTION:

Is the Elder Tree system available in languages other than English?

ANSWER:

David Gustafson:

The system is not available in another language. We have a Spanish-speaking version of a couple of our programs, but they're in such areas as breast cancer and substance abuse. We do want to convert the system, but it hasn't happened yet.

QUESTION:

Did your research for InfoSAGE look at dual eligibility status?

ANSWER:

Charles Safran:

No, it did not.

QUESTION:

About how much do 3D scanners and other equipment cost?

ANSWER:

Kevin Ponto:

The scanner we use costs about \$40,000. However, there are cheaper versions. Law enforcement uses versions that are in the \$3,000 range. We've also utilized camera-based methods, in which you use a simple camera and take photographs and use those to do reconstruction. Also, it looks like very soon we're going to have technology on our cell phones that allows us walk around our homes and capture these kinds of datasets. Therefore, while the technology is currently rather expensive, we think in the near future it may be significantly less of an issue.

QUESTION:

In addition to medication lists, what functionality is currently available to family members on InfoSAGE?

ANSWER:

Charles Safran:

In addition to medication lists, InfoSAGE has a patient profile, which is about the individual, their family, their hobbies, who they are as a person, and their preferences. This information allows providers to know something about this patient when they're admitted to the hospital in the middle of the night. Users can upload photos of themselves and their family members. InfoSAGE has a to-do list and a calendar of events. These help siblings work together to care for their aging parents. There's also a micro blog that lets siblings communicate with each other.

In addition, InfoSAGE provides community resources (e.g., bingo, Meals on Wheels). With the help of the Health on the Net Foundation, we identified worldwide Web sites that deal with issues of aging. Then we had our own division of aging nominate additional Web sites and audit the list for undue commercial influence and the accuracy of the content. InfoSAGE also has a

modified Google search, where items are geotagged to the location of the keystone so that you can get information that is relevant to the area. There's a really good introductory video on the landing page that demonstrates these features.

QUESTION:

Is the information available on InfoSAGE different for caregivers vs. family members?

ANSWER:

Charles Safran:

With role-based authentication, such as we have, it's possible to restrict any particular option. However, we've chosen to provide that feature only for medications. Therefore, the keystone or the proxy can choose to suppress any particular medication that they don't want to share with anybody. In general, participants can't see the medication list. Caregivers can see the medication list, but they can't assign tasks to people. keystones and proxies can assign tasks on the to-do list to others. That's the extent of our suppression.

When you build a Web site or a feature in health care based on what you **can't** do, it's a challenge to get it disseminated. The problem in health care is trying to spread and share information, rather than repress it. In focus groups, elders are very concerned about privacy, about their autonomy being taken away, and about online security. However, the problem that we face as clinicians, and as children of parents, is that not enough information is being shared. Therefore, our baseline preference is to share things and make it a little harder to suppress the information that's **not** shared.

Additional Q&A Addressed Following the Webinar

QUESTION:

How do you go to the home to do the viewing? Does the patient sign a consent first?

ANSWER:

Eneida Mendonca/Kevin Ponto:

Since the model can be viewed using a Web browser, the location of the viewing can happen just about anywhere. However, for the vizHOME project we had participants come into the lab where our virtual reality facility is. All participants in the project signed consent forms before experiencing the virtual reality environment.

QUESTION:

How long does it take to collect the virtual home image? How much manpower does it take to convert the images to a Web-based format?

ANSWER:

Eneida Mendonca/Kevin Ponto:

The amount of time it takes to create a model for a house depends on the size and complexity of the environment. A single-story apartment or house usually takes about 2 to 3 hours to capture. For a two- or three-story building, it often takes 5 to 6 hours to capture. These estimates are based on our preferred methodologies; there are many parameters, such as scanner quality settings, that can greatly change these times.

Once the scans have been collected, they are taken into software that we have developed. The software converts these scans into Web-accessible formats. This processing often takes a few

hours to complete depending on the complexity of the scans. This software is currently in development with the hope that this process will become easy enough for a novice user to perform in the future.

QUESTION:

Are there plans to introduce these new IT concepts in developing countries?

ANSWER:

Eneida Mendonca/Kevin Ponto:

Not at this moment.

QUESTION:

Do any of these products connect to actual electronic care plans (not just electronic health records) that are specific to older adults, as is done in a Program of All-inclusive Care for the Elderly (PACE) program?

ANSWER:

Eneida Mendonca/Kevin Ponto:

No.

QUESTION:

Is InfoSAGE free and open for use by anyone, or only by people in the study?

ANSWER:

Charles Safran:

Anyone can use InfoSAGE.

QUESTION:

Can the 3D scan measure rooms to make sure hospital equipment would fit in the room?

ANSWER:

Eneida Mendonca:

Yes. The 3D scan can take measurements.

QUESTION:

How did the keystone participants find the iPhone application developed for the project?

ANSWER:

Charles Safran:

We don't know yet. We think keystones use larger Web-based screens. The smartphone interface is relatively new. We will know more when we complete 12-month follow-up surveys.

QUESTION:

How involved were public librarians in the Elder Tree project?

ANSWER:

David Gustafson:

It depended on the study sites. In all three counties, libraries hosted several meetings and helped study participants who had problems with the site. In our statewide expansion, librarians in many counties will provide information about Elder Tree Wisconsin (ETW), enroll participants,

and answer their questions. In some counties, librarians are the primary link to ETW. In others, that role is shared by several people, such as Meals on Wheels drivers, church leaders, etc.

QUESTION:

Did you look at baseline computer and Internet use? Were the Super Posters high-level Internet users prior to the study?

ANSWER:

David Gustafson:

No—just the opposite. The Super Posters tended to have virtually no experience with computers or the Internet.

QUESTION:

Do your data allow you to conduct analyses stratified by language spoken, socioeconomic status (SES), and race/ethnicity?

ANSWER:

David Gustafson:

We have data on race/ethnicity. SES can be estimated from the data, but it is not identified directly. The language must be English at this time.

QUESTION:

How were volunteers/participants recruited for the study?

ANSWER:

David Gustafson:

We used a wide range of recruitment strategies, including churches, Meals on Wheels, community-based aging events, announcements on radio stations that older adults tend to use, clinic visits, public service announcements, etc.

QUESTION:

What was the average age of your participants?

ANSWER:

David Gustafson:

The average age of Elder Tree users in the study was 77.

QUESTION:

How can clients from other states not listed on the PowerPoint utilize the InfoSAGE system??

ANSWER:

Charles Safran:

InfoSAGE is available for free worldwide. Folks can register online for an InfoSAGE account at www.infosagehealth.org. Once you have an account, you can also download either an iOS app or an android app from their respective app stores. We have had usage from every state in the US except Montana.

QUESTION:

Can a keystone be restricted in any way from editing medication lists in the event of a dementia diagnosis?

ANSWER:

Charles Safran:

We have keystones who do not use the system at all, but their proxies (e.g. children) are the primary users. Our research explores what happens in our “living laboratory” of families over time. We know from past clinical experience that an elder’s cognitive ability may wax and wane over time. We anticipate (and our focus groups have confirmed) that elder’s want control over who can see their information. We have not yet had the experience of a keystone user whom the proxy feels should no longer have access to the system because of their cognitive ability.

QUESTION:

Is the system available in other languages other than English? Are there any plans to expand to other languages?

ANSWER:

Charles Safran:

InfoSAGE is architected to allow for multiple languages. We are actively planning to develop a Spanish version.

QUESTION:

How were volunteers/participants for the study recruited?

ANSWER:

Charles Safran:

First, we have worked closely with two assisted living organization in the Boston area to recruit their residents and families. Second, we approach families of persons over the age of 75 who are about to be discharged from our hospital. Third, we developed an online consent form for those persons who find our website. Lastly, we have employed a social media campaign to find additional subjects.

QUESTION:

What was the average age of your participants?

ANSWER:

Charles Safran:

We formally enrolled dyads into our initial study. A dyad consists of an elder (keystone) over the age of 75 and a proxy who is usually an adult child. A keystone/proxy can then invite others into the care network. Entering the age of anyone in a care network is optional except the keystones in the initial study. Overall the average age for Keystones is 76.96 (n=159).