

Willingness of older adults to share data and privacy concerns after exposure to unobtrusive home monitoring

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L. Boise, K. Wild, N. Mattek, M. Ruhl, H.H. Dodge, J. Kaye. Willingness of older adults to share data and privacy concerns after exposure to unobtrusive in-home monitoring. Gerontechnology 2013;11(3):428-435; doi:10.4017/gt.2013.11.3.001.00. Older adult participants in the Intelligent Systems for Assessment of Aging Changes study (ISAAC) carried out by the Oregon Center for Aging and Technology (ORCATECH) were surveyed regarding their attitudes about unobtrusive home monitoring and computer use at baseline and after one year (n=119). The survey was part of a longitudinal study using in-home sensor technology to detect cognitive changes and other health problems. Our primary objective was to measure willingness to share health or activity data with one's doctor or family members and concerns about privacy or security of monitoring over one year of study participation. Differences in attitudes of participants with Mild Cognitive Impairment (MCI) compared to those with normal cognition were also examined. A high proportion (over 72%) of participants reported acceptance of in-home and computer monitoring and willingness to have data shared with their doctor or family members. However, a majority (60%) reported concerns related to privacy or security; these concerns increased after one year of participation. Few differences between participants with MCI and those with normal cognition were identified. Findings suggest that involvement in this unobtrusive in-home monitoring study may have raised awareness about the potential privacy risks of technology. Still, results show high acceptance, stable over time, of sharing information from monitoring systems with family members and doctors. Our findings have important implications for the deployment of technologies among older adults in research studies as well as in the general community.

Keywords: activity monitoring, user receptivity, mild cognitive impairment

Advances in health and communications technology come at a time of dramatic worldwide increases in life expectancy and skyrocketing health care costs. A burgeoning area of investigation has been the development of new technologies to enhance health and independence for older adults. Increasingly, researchers are using computers and home monitoring technologies to study older adults and to identify changes in their health and behavior in home settings with an eye towards development of new technologies to enhance health and independence. Research in this area has ranged from single-home demonstration projects^{1,2} to deployment of monitoring technology in multiple community-based homes^{3,4}. Technological monitoring studies have included measurement of single health param-

eters^{4,5} and ubiquitous in-home sensor systems^{6,7}. The latter, also known as "smart home" technologies, have been recently reviewed as used with older adults⁸ and Alzheimer's disease patients⁹.

Ultimately, the successful application of monitoring technologies depends on receptivity of potential users. These are identified as older adults as well as family members and others who will receive the information from the monitoring. Receptivity of those with cognitive impairment to monitoring is especially important as these technologies are being studied for their potential to detect dementia and to identify other risks of injury or illness associated with dementia. In recognition of the importance of user receptivity, a second wave of research has investigated

the attitudes and perceptions of older adults as potential recipients of in-home monitoring technology. In recent years, much has been learned from older adults about how they might respond to such systems. In focus groups and interviews^{8,10-15} and surveys^{16,17}, older adults have generally expressed willingness to adopt in-home monitoring technologies. Universally, these studies reported that the importance of maintaining independence superseded concerns about privacy or security. The utility of monitoring systems in achieving the goal of independent living, in responding to emergencies, and in tracking of specific medical parameters was identified by older adults as the most important value of monitoring. An exception to this high acceptance is the general discomfort with video monitoring of the persons being studied.

Most prior studies about older adults' and/or family members' response to home monitoring has explored individuals' attitudes in the abstract rather than from their personal experiences with technologies. In our previous studies, we also gathered qualitative data from older adults on their perceptions about home- and computer-based monitoring without regard for their experience with the technologies of interest¹⁵. As have others before us, we found that older adults generally saw value in such monitoring and had relatively few concerns about privacy or security. Direct experience with technology-assisted monitoring, however, may affect how people think about these technologies. Most focus group and survey research on attitudes and perceptions about technologies has not been tested against the reality of daily interface with ubiquitous sensors. Additionally, most studies to date of consumer (or research volunteer) receptivity to home monitoring have been cross-sectional in design and therefore have not allowed for consideration of how participation over time may affect attitudes and response to the technologies. To our knowledge, the effect of cognitive impairment on attitudes towards monitoring and on concerns about privacy or security of Internet use has not been studied. However, persons with lower cognitive function have been found to have poorer performance on computer tasks independent of computer knowledge¹⁸.

In order to gain better understanding of the attitudes and perspectives of older adults towards home monitoring while having systems operating in their homes, we developed and administered an annual survey as part of the Intelligent Systems for Assessment of Aging Changes Study (ISAAC) carried out by the Oregon Center for Aging and Technology (ORCATECH). This survey, the ISAAC Technology Survey (ITS), assessed

ISAAC research volunteers' frequency and kinds of computer use, their attitudes toward the unobtrusive home and computer monitoring used in the study, and their willingness to have information obtained from monitoring shared with family members and health providers. In this article we present data from baseline and year 1 surveys to examine three research questions:

- (i) Does exposure to unobtrusive monitoring through motion sensors and computer use change the willingness to share data from monitoring systems with one's doctor or family?
- (ii) Does exposure to unobtrusive monitoring through motion sensors and computers use change the degree of concerns about privacy or security?
- (iii) Are there differences between survey respondents with mild cognitive impairment and those with intact cognition in their attitudes towards unobtrusive monitoring or towards sharing of data with family or doctors?

METHODS

Description of ISAAC study

Survey respondents were individuals enrolled in a larger study: Intelligent Systems for Assessment of Aging Changes (ISAAC). ISAAC is a five-year NIH-funded study of the Oregon Health & Sciences University Oregon Center for Aging & Technology (ORCATECH) that utilizes continuously active, unobtrusive technologies to detect change in mobility and other functions that lead to loss of independence¹⁹. The primary aim of ISAAC is to determine if continuous, unobtrusive monitoring of motor and cognitive activity can detect incident cognitive decline in older adults living in typical community settings. Three technologies are used to detect changes in function: unobtrusive motion sensors installed strategically throughout the home (for instance, in hallways, living areas), contact sensors on doors and refrigerators, and computer-use monitoring. Continuous data from the sensors and computers are sent to a central database in the project data center via a dedicated research computer placed in the participant's home. The sensor and computer data are compared with clinical data on physical and cognitive changes over time to determine if activity in the home is associated with changes in cognition and physical attributes of the subjects (for description of methodology used in this study see Hagler et al.²⁰). At the time of equipment set-up, research volunteers who were unable to send and receive email, or who requested instruction, were invited to participate in six training sessions conducted over 3 weeks using a standard curriculum with individual tutoring administered as needed. Each week, participants in ISAAC submit responses to an electronic health questionnaire that asks whether

situations have arisen that might have affected their activity patterns. In addition, they are provided a suite of games to play at their discretion. Research volunteers are asked to use their computer a minimum of one hour per week for the duration of the monitoring study. Computer usage is monitored for minutes and hours of computer use per day and length of each computer session. Specific content of website viewing by volunteers and communications is *not* monitored. Technical assistance is always available to the research volunteers through dedicated research personnel by phone as well as email and in-home visits. Accessing this help is encouraged so that volunteers maintain computer activity. Volunteers are not compensated for their time. In addition to gathering and analyzing data from sensors and monitoring of computer use, the study sought to identify volunteers' perspectives and attitudes towards the monitoring through the ISAAC Technology Survey (ITS), as reported in this article. IRB approval was obtained for the survey as a component of the ISAAC study.

Research volunteers were recruited for ISAAC from local senior centers and retirement communities in the Portland, Oregon metropolitan area and from other OHSU Alzheimer Disease Center studies. Eligibility criteria for ISAAC included being a non-demented man or woman (Clinical Dementia Rating (CDR)²¹ score ≤ 0.5 ; Mini-Mental State Examination (MMSE)²² score >24), age 80 or older (or 70 or older for non-whites and for individuals residing with a participant age 80 or older), living independently (cohabitation with a companion or spouse was allowed, but not with a formal caregiver), in a larger than one-room 'studio' apartment, and in average or better health (well-controlled chronic diseases and co-morbidities or none at all). Medical illnesses with the potential to limit physical participation (for instance, wheelchair bound) or likely to lead to untimely death over the 35 months of the study (such as certain cancers) were exclusions. Subject enrollment focused on those living in retirement communities, but also included older persons living in free-standing single-family homes¹⁹. 87 % of ISAAC research volunteers live in CCRCs (continuing care retirement communities) and 13% live elsewhere, mostly in single family homes. At the time of enrollment, consent for participation was obtained as approved by the university's Institutional Review Board. The purpose of the study was explained in the consent form as follows: "...to understand how technology can be used to assess activity in the home" and "to make new systems that may help people live on their own longer, especially if they are at risk for memory or health problems." ISAAC volunteers are assessed at baseline, at six-

month intervals (by telephone), and during annual in-home visits with research personnel who administered standardized health and function questionnaires and physical and neurological examinations. Further details of the ISAAC study enrollment and assessment procedures are described elsewhere^{19, 23}.

Determination of MCI was made using Peterson criteria²⁴ defined as: absence of dementia, normal general cognition function (MMSE ≥ 24), none or minimal functional impairment (dependent on two or fewer activities on Functional Assessment Questionnaire²⁵), subject or collateral memory complaint, and having objective impairment on one or more of six neuropsychological tests²⁶ considered to be representative of five cognitive domains. Impairment on neuropsychological testing was defined as a score 1.5 SDs or more below the model-derived predicted mean values stratified by age, education and sex.

Survey development and administration

The ISAAC Technology Survey (ITS) was developed and refined largely from data gathered in previous focus groups¹⁵. The ITS includes 34 questions organized around the following topics: frequency and types of computer use, attitudes about unobtrusive monitoring and monitoring of computer use, attitudes about sharing monitoring information with one's family or doctor, and concerns about privacy or security. Volunteers rated their level of agreement to survey statements on a five-point scale (Strongly Agree to Strongly Disagree) with a neutral mid-value of "neither agree nor disagree". Two questions asked about the respondent's level of concern that information could be given to people or organizations that do not have a right to it or that could be used in a way that would harm them. These two questions used a four-point scale (Very Concerned, Somewhat Concerned, Not Very Concerned, Not Concerned At All). In this article, we report on the survey results as administered at baseline (prior to computer training of participants) and at year 1.

Statistical analysis

Survey results were imported into SAS v9.2 software (SAS Institute, Inc., Cary, NC) for all analyses. Demographic characteristics and computer usage were summarized for both cognitive groups. Response options for questions about attitudes and privacy concerns were dichotomized as: Agree vs. Disagree, or Concerned vs. Not Concerned. Pearson's chi-square test for categorical variables (or Fisher's Exact Test as appropriate for small cell sizes) was used to compare the response proportions according to cognitive function (normal vs. mild cognitive impairment) at baseline and at year 1. We were interested in

comparing proportions among within-person paired samples (each participant responded to the baseline survey questions and the year 1 survey questions). McNemar's test was used to test for changes in attitudes between baseline and year 1 for each cognitive status group separately.

RESULTS

The baseline survey was administered to 153 ISAAC participants. Of these, 121 (79%) also completed the survey at year 1. Of the 32 participants for whom we do not have a completed annual survey, 4 withdrew from the study and the others were not complete at the year 1 follow-up visit. The 32 participants did not differ significantly from participants included in the analysis according to gender, age, education, or computer and Internet use. Of the 121 participants who completed the baseline and year 1 surveys, 2 participants did not receive mental status classification (MCI or Normal), so they were not included in this analysis, thus the sample size for this analysis was 119. Overall, participants were older adults (mean age: 83 years, SD: 5 years), highly educated (mean years of school: 15 years, SD: 3 years) and women (78%). 27 (23%) were cognitively impaired. 61 % of participants reported using their computer daily at baseline while only 29% reported using the Internet daily. Demographic characteristics and frequency of computer and Internet use at baseline for those with normal cognitive function (n=92) and for those with MCI (n=27) were similar with respect to age, gender, education and ethnicity (Table 1). There were no significant differences between the two cognitive groups in daily computer or Internet use at baseline.

Table 2 reports on respondents' attitudes about unobtrusive and computer-use monitoring, at

Table 1. Participant characteristics at baseline; At a confidence level of 0.05 no differences were found between the two groups

Parameter	Cognition (Mean ± standard deviation)	
	Intact (n=92)	Impaired (n=27)
Age, years	83 ± 5	84 ± 4
Gender, % women	78	78
Education, years	16 ± 3	15 ± 3
Ethnicity, % non-white	10	22
Self-reported daily computer use, %	67	58
Self-reported daily internet use, %	32	20

titudes about sharing monitoring information with one's family or doctor, and concerns about privacy or security among cognitively intact and those with MCI at baseline and year 1. The reported percentages represent the proportion of participants who 'strongly agreed' or 'agreed' with the statements or who were 'very concerned' or 'somewhat concerned'. With respect to attitudes towards monitoring, a strong majority endorsed the concept of being monitored (Q1) and most participants reported that they did not mind being monitored if the data is useful for their doctor (Q2). However, cognitively intact volunteers were largely non-receptive to being videotaped at baseline (20% would agree to be videotaped around the house, Q4) and the percentage agreement dropped to 7% at year 1 (p=0.04). A significantly higher proportion of survey respondents with MCI reported that they did not mind being videotaped at baseline (45%, p=0.02). This percentage declined at year 1 to 30%, but the change was non-significant.

With respect to the sharing of data, only a small proportion of respondents in both cognitive status groups reported that they did not care who has access to information about them from activity or computer monitoring (Q3). Nearly all participants in both groups reported willingness to have activity monitoring shared with family members and doctors (Q7-10). There were no significant changes in responses to these questions between baseline and year 1 among either group.

Despite the general receptiveness to being monitored, a number of participants expressed concerns about privacy and the security risks of monitoring or computer use. At baseline, about two-thirds of cognitively intact respondents reported being concerned that their information could be exploited, i.e., that it could be "given to people that don't have a right to it" (Q13) or that it could be "given to people who would use it to harm you" (Q14). The proportion of cognitively intact respondents who reported these concerns increased significantly at year 1 to 85% and 93%, respectively (p<.001 and p<.0001). Fewer respondents with MCI (44%) expressed concern that their information could be exploited at baseline. Similar to respondents with normal cognition, more of the MCI participants expressed concern that their information could be exploited at year 1 (76%). Less than half of cognitively intact reported privacy concerns in relation to in-home activity monitoring (Q15) or computer use (Q16) and less than one-third of MCI participants reported privacy concerns at baseline. There was no significant change in responses to these questions at year 1.

Sharing data and privacy

Table 2. Comparison of attitude and concerns between cognitively intact and impaired participants, and between baseline and follow-up within the two groups; percentages are the sum of strongly agree and agree or of very concerned and somewhat concerned; Chi-square was used for differences between groups at baseline or follow-up; With McNemar's test the within-person changes were assessed; AD=Alzheimer's disease; a: $p=0.0352$ (McNemar); b: $p<0.01$ (Chi-square); c: $p<0.001$ (McNemar); d: $p=0.0255$ (McNemar); e: $p<0.0001$ (McNemar)

#	Question	Cognition			
		Intact (n=92)		Impaired (n=27)	
	Text	Baseline	Follow-up	Baseline	Follow-up
General attitude toward monitoring					
1	I do not mind being monitored unobtrusively in my home.	84	83	92	72
2	I do not mind being monitored as long as the data collected is useful for my doctor.	93	87	85	81
3	I do not care who has access to information from in-home activity or computer monitoring.	13	10	27	12
4	I would not mind being videotaped to monitor my movement around the house.	20	7 ^a	45 ^b	30
5	I would want information about my activity sent to me if there was a change in my activity.	92	90	92	72
6	I would want information about my activity sent to me if the changes suggest that I might have AD.	87	91	93	89
Attitude towards sharing information from monitoring					
7	I would want information about my activity sent to a family member if the changes suggest that I might have AD.	81	82	95	76
8	I would want information about my activity sent to my doctor if the changes suggest I might have AD.	90	93	100	88
9	I am willing to have information from activity monitoring shared with my family.	87	81	100	84
10	I am willing to have information from activity monitoring shared with my doctor.	89	90	100	85
11	I am willing to have information from my computer use shared with my family.	79	70	92	84
12	I am willing to have information from my computer use shared with my doctor.	73	66	85	73
Privacy and security concerns					
13	I am concerned information could be given to people/organizations that do not have a right to it.	61	85 ^c	44	76
14	I am concerned information could be given to people/organizations that would use it in a way that would harm me.	65	93 ^d	44	76 ^e
15	I am concerned about privacy in relation to in-home activity monitoring.	44	52	32	52
16	I am concerned about privacy in relation to monitoring of computer use.	41	48	29	54

DISCUSSION

This article reports the results of the ISAAC Technology Survey (ITS) regarding attitudes towards home-based motion and computer monitoring, the sharing of data from monitoring, and concerns about privacy and security for research volunteers of the ISAAC study. Most survey respondents did not mind being monitored unobtrusively in their home (with the exception of being video-recorded, a method of data collection not used in this study). These findings are not surprising as

the subject pool for this survey were older adults who chose to enroll in this home and computer monitoring study. Receptivity was also generally high for reporting information from activity monitoring and computer use to one's doctor or to family members and there were no significant changes over one year in participants' willingness to share this information. The high acceptance of health-related monitoring may in part be due to participants' awareness of currently available out-of-office medical monitoring for a number

of health conditions (for instance, blood glucose assessment, blood pressure monitoring, and cardiac monitors)²⁷. Vital sign monitoring has also been shown to be well-accepted by older adults in research settings²⁸ adding further support to our findings that home monitoring, unobtrusive or more visible, is well accepted by older adults. Another possible factor influencing these findings may be that studies such as our own utilize volunteers who are more sophisticated technology users than their peers in the general population.

Conversely, research participants' naivety about the potential risks and hazards of on-line communication may affect their attitudes. Despite this cohort's high acceptance of being monitored, many participants reported concerns about the potential risks of intrusion through sensor or computer monitoring and the potential that information could be given to the wrong people. These concerns increased substantially over one year. This may have been related in part to alerts about security breaches issued by the staff of ISAAC during the study period. A number of ISAAC participants received 'spam' messages while they were surfing the web stating that a virus had been detected on their computer and asked the user (the research participant) to pay (for instance, \$99) to "fix the problem". Several participants received a phone call from someone who directed them to go to a website not affiliated with the project and to type in personal information and make an online payment. In addition, print and broadcast media often report on incidents of unlawful access to personal data, i.e., social security numbers, credit card numbers and the like. Thus, it is not surprising that the study participants became more aware of and thus, more concerned, over time, about the risks of inappropriate or harmful access to personal information. In spite of apparent increased risk awareness, no participant has withdrawn from the ISAAC study for reasons related to privacy concerns and this did not appear to influence the participants' willingness to share data for legitimate purposes.

The differences we found between MCI volunteers and those who are cognitively intact are interesting and thought-provoking. In contrast to the cognitively intact group, nearly half of the study participants with MCI reported a willingness to be videotaped in their home at baseline (45%) and this percentage did not significantly decrease at year 1 as it did for the cognitively intact (20% versus 7%). Also, significantly fewer volunteers with MCI than those who were cognitively intact reported concerns at year 1 that information could be used to harm them. To our knowledge there are no prior studies that have examined differences between persons with nor-

mal cognition and those with mild cognitive impairment in attitudes toward monitoring but our experience in working with persons with mild cognitive impairments suggests that those with MCI may be more willing to accept monitoring because they are aware that their impairment threatens their ability to live independently. Alternatively, those with MCI may be less attentive to news about the risks of Internet use.

LIMITATIONS

This study presents data on a select group of older adults, those who enrolled in a longitudinal study of unobtrusive technology home monitoring. They tended to be relatively frequent users of computers, with above-average levels of education. Thus, our survey results are more applicable to the population of older adults who might currently be considered early adopters and cannot be generalized to the larger population of older adults. Another limitation is the relatively small number of persons with MCI, limiting the power to detect differences between the two cognitive status groups. Also, given the warnings issued on potential Internet security breaches during the study, it is possible that the proportions of volunteers with concerns about privacy and security were unduly high.

IMPLICATIONS

There are many potential health-related applications of home-monitoring technology, some of which are presently available and many more under development. As adoption of monitoring technologies becomes more pervasive in real-world settings, continuing research is needed to better understand how older adults, the primary beneficiaries of these technologies, view home monitoring and its risks. The older adults in our study expressed high willingness to share monitoring data with physicians and family members, but they also reported a justifiably high concern that data could be given to people who do not have a right to it and this concern increased over time. Our findings that those with MCI reported less concern than those with intact cognition suggest that special attention, through training and privacy and security safeguards may need to be provided to persons with mild (or more severe) cognitive impairment or other cognitive deficits. Including persons with mild cognitive impairment, with adequate safeguards, is particularly important for studies of the benefits of home and computer monitoring as persons with MCI are likely to be the focus of family concerns that could be addressed through monitoring systems.

In general, research and service programs utilizing home monitoring systems or Internet technologies must consider and establish protections

against the potential risks to participants of Internet data transmission. Although the scams confronting ISAAC study participants were quickly attended to both by the technical assistance staff and by the anti-virus program installed as part of the computer set up for all participants, they did represent potentially serious security violations. Unfortunately, such occurrences are not rare in today's world of ubiquitous computing. They should be considered as a potential risk for participants in all technology studies or programs involving the Internet with strong security protections established to protect participants. Human subjects review, through the Institutional Review Boards, provides a measure of protection in research studies to the extent that they require safeguards for subjects in studies that use Internet-based communications and data transmission. Programs that deliver services, especially those not affiliated with a responsible oversight organization, may not provide the same degree of scrutiny. When personal health information from medical records such as that covered by HIPAA (Health Insurance Portability and Accountability Act of 1996) is transmitted via networks, the potential risk is particularly concerning.

An additional consideration in studies such as ours, as well as in community programs that introduce and/or train individuals to use computers, is the window opened to Internet use. The training provided through such programs is likely to lead some participants to further exploration and use of the Internet beyond the specific program parameters. While there are benefits there are also risks. When research studies engage

older adults directly in Internet use, it can be expected that some of the participants will be novice and/or naive users. The personal information security risks and more benign, though irritating solicitation intrusions associated with Internet use may not be considered by some older adults when signing on to technology research projects or computer training programs. Researchers and project managers should offer information and strategies that participants can use to protect themselves from potential harm as a result of Internet use. A nascent, but important, literature is beginning to tackle the ethical issues around technology use with older adults and provide useful guides for programs involving older adults in technology interventions²⁹⁻³². Continuing development of useful guidelines for research and for practice is needed as the field of technology-based monitoring continues to grow.

As the rapid pace of technology development proceeds, there is great need for continuing investigation of how older adults respond to these new technologies. Studying the responses and experience of participants in longitudinal, in-home technology studies provides valuable feedback from those with direct interaction with the technologies of interest. The ISAAC volunteers, largely octogenarians who regularly use computers, may be early adopters within their age group. As such, they may represent next-generation older adults, i.e., persons currently aged 50 - 64, of whom 74% are regular Internet users³³, rendering these findings highly relevant for developing monitoring technologies and designing studies involving the next generation of older adults.

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