Addressing the Personal Health Information Management Needs of Older Adults

The SOARING Project

(Studying Older Adults and Researching Information Needs and Goals)

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Project Period:
09/30/2013 – 8/31/2019

Federal Project Officer:
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Funded by AHRQ: 1R01HS022106-01A1

STRUCTURED ABSTRACT

Purpose

The purposes of the SOARING project were to (1) characterize older adults personal health information management (PHIM); (2) explore the role of family, friends, and healthcare providers in older adult PHIM; (3) create a holistic model of older adult PHIM needs and practices, and (4) develop design recommendations for older adult PHIM tools.

Scope

The scope of this 5-year exploratory study included gaining a detailed understanding of the PHIM needs and practices of older adults from Seattle, WA and the role played by supportive stakeholders (i.e. family, friends, and health care providers). Based on our findings, we created and evaluated design guidelines and personas to assist in the design of PHIM systems for older adults.

Methods used

- Applied a holistic framework, the Balance Model of Work, to investigate older adult PHIM.
- Conducted focus groups, in-depth interviews, longitudinal studies with older adults; interviews with friends, family, and various health care providers.
- Performed qualitative analysis of interview and focus group transcripts and photos.
- Conducted a cluster analysis of data looking for evidence of PHIM styles.
- Applied human-centered design (HCD) principles to develop design guidelines and personas based on findings.
- With designers performed focus groups, brainstorming sessions, and interviews to refine design guidelines and connected personas.

Results

We developed a detailed description of PHIM tasks and approaches; a holistic model of older adult PHIM indicating the influence of living situation, technology, social support, and environment; and a vetted design guidebook with connected personas and design recommendations.

Key Words

Aging, HIT, PHIM, UX-Design

NOTE: The following final report of the AHRQ funded SOARING project (1R01HS022106) is organized by the four project specific aims. The study materials and activities described below were approved by the University of Washington Institutional Review Board.

PURPOSE

The overall goal of the SOARING study was to gain an in-depth understanding of the personal health information management needs and practices of older adults and their caregivers for the purpose of informing the design of health information technologies that support older adult health and independence.

A. Aim 1 Describe the PHIM goals, activities, and practices of older adults from different socio-economic groups living in a variety of residential contexts.

A.1 SCOPE

A.1a Background/Context:

Older adults comprise 18% of the US population and are the group with the greatest health care needs and utilization. As a result, it is assumed that older adults have the greatest health information management needs. However, current technologies designed to assist with personal health information management (PHIM) have not been widely adopted by older adults and health information technology (HIT) designers rarely take into consideration the special needs of the aging population when designing HIT. With this in mind, the goal of Aim 1 was to develop a detailed understanding of the PHIM needs and practices of older adults living in a variety of residential settings.

Our underlying assumption was that living situation may impact health information management. Therefore, we focused our study on older adults living in a variety of living situations including independent living, retirement communities, and assisted living. In addition, we sought input from participants that were homeless or had been homeless, to better understand the PHIM needs and practices of this unique population.

A.1b Setting/Participants:

Although older adults are often defined as 65 years and older, we broadened the definition to adults 60 years and older to include individuals who were still working and who would be 65 years by the end of our five-year study. We recruited participants through Seattle area senior centers, retirement communities, assisted living facilities, organizations that provided older adult low-income housing, and the Indian Health Care Authority. Where possible, interviews took place in the residence of the older adult.

A.1c Incidence/Prevalence: N/A. This was an exploratory study of healthy older adults.

A.2 METHODS

A.2a Study Design:

The study was exploratory and involved use of both qualitative and quantitative methods. We performed home visits and conducted semi-structured interviews and surveys with 88 older adults living in a variety of living situations (independent living, retirement communities, assisted living, homeless). A subset of the initial participants participated in a longitudinal study over a 6-month period involving six follow-up phone calls and an additional home visit. The purpose of the longitudinal study was to gain additional information and document the effect of life changes and transitions on PHIM.

A.2b Data Sources/Collection:

Data were collected from transcripts of in-depth interviews with older adults, notes taken during follow-up phone calls in the longitudinal study, and photos taken during home visits. Survey instruments were used to collect information regarding participant demographics, comorbidities (Charlson), social networks (Lubben), decision making preferences (API), problem solving style (IIPSS), and health literacy (eHEALS). Interview data were analyzed through thematic coding. Survey data were summarized using descriptive statistics.

A.2c Intervention/Measures: N/A.

A.2d Limitations:

The interviews were conducted with older adults from the Seattle, WA area with few illnesses or comorbidities. Therefore, the results may not be generalizable to populations that have more complex health needs, are more ethnically and racially diverse and/or who live in other geographic areas. Researchers may have introduced their personal biases in the coding process. To minimize bias we had two individuals code separately. Inter-coder agreement was high (89.6%).

A.3 RESULTS

A.3a Principal Findings/Outcomes:

We completed 88 onsite in-depth interviews with adults 60 years and older living in a variety of residential settings. Characteristics of the Aim 1 participants are provided below.

Table 1. Participant characteristics.

	N=88 Count / %
Age	
60-69	23 (26)
70-79	32 (36)
80-89	19 (22)
90-99	14 (16)
Gender	
Female	61 (69.3%)
Race	
White	62 (70.5)
Asian	8 (9.1)
Black	6 (6.8)
American Indian / Alaska Native	6 (6.8)
Other / refused	6 (6.8)
Education	
Some high school or high school diploma	10 (11.5)
Some college	23 (26.4)
College graduate	28 (32.2)
Post-graduate education	26 (29.9)
Not reported	1 (1.1)
Living Situation	
Retirement Community	24 (27.3)
Independent shared dwelling	24 (27.3)
Independent	22 (25)
Assisted Living	17 (19.3)
Homeless	1 (1.1)
Income	
Not at all adequate OR can meet necessities only	15 (17)
Can afford some of the things I want but not all I want	39 (45)
Can afford about everything I want	26 (30)
Can afford about everything I want and still have money left over	7 (8)
Relationship Status	
Divorced / Separated	27 (31)
Widowed	27 (31)
Married / Partnered	23 (26)
Single, never married or partnered	11 (12)
Retired	77 (87.5)
Lives Alone	61 (69.3)
Has Medicare	79 (89.8)

Our primary themes regarding older adult PHIM included:

1. Older adults view the value of PHIM in terms of maintaining health and wellness.

2. There are several main tasks related to PHIM which include health information seeking, tracking, organizing, and emergency planning.
3. Approaches to these tasks vary depending on the situation, the individual, and social and environmental support systems (see Table 2 below).
4. For many older adults, other people, such as family, friends and providers are important partners for obtaining, seeking, and organizing health information.
5. Older adults preferred to gain health information from health care providers but often used online sources for health information.

Table 2. Older Adult PHIM Tasks and Approaches

Task	Definition	Approach	Distribution
Seeking	Type of engagement with obtaining health-related information	• Active • Combined • Passive	51.1% 29.5% 19.3%
Tracking	Generating and/or logging of health-related measures	• Never • Sometimes • Consistently	44.3% 28.4% 27.3%
Organizing	Strategy used for handling health-related print materials	• Filing • Piling • Tossing	48.9% 38.6% 12.5%
Sharing	Including others (family/friends) in communication and management of health-related information	• Independent but shares • Collaborative-team partnership • No Sharing • Proxy	44.3% 36.4% 11.4% 8.0%
Emergency Planning	Preparing and maintaining information in case of a health-related emergency	• Yes-by self • Yes-by others • No Planning	38.6% 28.4% 33.0%

A.3b Discussion:

Our findings have important implications for the design of HIT and PHIM tools for older adults. Many of the health maintenance and wellness issues that concern older adults are not currently featured in patient portals (ex. Exercise tracking). The importance of sharing information with others and the dynamic nature of this sharing need to be addressed both from a technological and policy standpoint. Older adults use a variety of approaches which differ depending on the

situation and their particular needs. Therefore, functionality should be broad and flexible to meet the dynamic issues related to health and aging. Older adults continue to be heavily reliant on paper and physical forms of tracking health information. Current practices should be taken into consideration when developing online systems.

A.3c Conclusions/Significance:

Older adults perform certain tasks related to PHIM, and take different approaches to these tasks depending on personal, social, and environmental situations or needs. A primary motivator for PHIM is to maintain health and wellness or to respond to a specific disease situation. Designers should take into consideration the dynamic aspects of aging and diversity among adults when designing PHIM tools to best meet their needs

A.4 PUBLICATIONS/PRESENTATIONS/PRODUCTS

A.4a Publications:

Hartzler AL, Osterhage K, Demiris G, Phelan EA, Thielke SM, Turner AM. Understanding views on everyday use of personal health information: Insights from community dwelling older adults. Informatics for Health and Social Care. 2017; 43:3, 320-333. doi: 10.1080/17538157.2017.1297815.

Sakaguchi-Tang D, Bosold A, Choi Y, Turner AM. Patient Portal Use and Experience Among Older Adults: Systematic Review. JMIR Med Inform. 2017; 5(4):38. PMID: 29038093.

Turner AM, Osterhage K, Loughran J, Painter I, Demiris G, Hartzler AL, Phelan EA. Emergency information management needs and practices of older adults: A descriptive study. Int J Med Inform. 2017; 111:149-158. doi: 10.1016/j.ijmedinf.2017.

Turner AM, Osterhage K, Hartzler A, Joe J, Lin L, Kanagat N, Demiris G. Use of Patient Portals for Personal Health Information Management: The Older Adult Perspective. AMIA Annu Symp Proc. 2015; 1234–1241. PMID: 26958263.

Petrescu-Prahova M, Osterhage K, Taylor J, Painter I, Choi Y, Turner AM. Older adult health and personal health information management support networks. (Accepted with revisions 9/19 to Innovation in Aging)

A.4b Presentations:

Turner AM. Engaging older adults in the design, implementation and evaluation of Health IT Didactic Panel. Presented at AMIA Annual Symposium; Chicago, IL; November 2016.

Turner AM. It’s in the Fridge: The practices of older adults in managing advanced directives and other emergency information. Presented at 2016 H3IT Conference; Chicago, IL; November 2016.

Turner AM. Addressing the Personal Health Information Management Needs of Older Adults: The SOARING Project. Presented at Gerontological Society of America (GSA) Annual Meeting; Washington, DC; November 6, 2014.

Hartzler A, Turner AM. Defining Wellness Through the Voice of Community-Dwelling Older Adults. Presented at GSA Annual Meeting; Washington, DC; November 6, 2014.

Turner AM. Personal Health Information Management Needs of Older Adults: Use of Patient Portals. Presented at H3IT Conference; Washington, DC; November 14, 2014.

Turner AM. SOARING Project Update: Personal health information management of older adults. Presented at UW Geriatric Grand Rounds; Harborview Medical Center, Seattle, WA; July 24, 2015.

Turner AM. Personal Health Information Management in Older Adults. Research presentation to the faculty of the UW Department of Health Services; University of Washington, Seattle, WA; February 21, 2017.

Capurro, D**,** Turner, AM, Demiris, G**.** The wave of patient generated data: insight into patient needs. Panelist MEDINFO '19 19th World Congress on Health and Biomedical Informatics; Lyon, France; August 24-30, 2019

Demiris, G, Turner, AM, Iribarren, S, Sward, K. Citizen Science: Using informatics to engage vulnerable populations in scientific research. AMIA 2019 Symposium panel, Washington DC, Nov. 21, 2019

A.4c Posters:

Turner AM, Demiris G. Addressing the Personal Health Information Management Needs of Older Adults: The SOARING Project. Presented at Biomedical Informatics Research; Seattle, WA; March, 2014.

Turner AM, Osterhage K, Hartzler A, Demiris G. SOARING: Addressing the Personal Health Information Management Needs of Older Adults. Presented at Washington Public Health Association Annual Conference; Wenatchee, WA; Oct 11, 2014.

Turner AM, Choi YK, Osterhage K. Health literacy and personal health information management (PHIM) in older adults. Presented at Health Literacy Research (HARC) Conference; Bethesda, MD; October 2016.

B. Aim 2. Examine the roles, needs, and practices of key stakeholders involved in the management of older adults' health information.

B.1 SCOPE

B.1a Background/Context:

Family, friends, home health care nurses, and other health care providers are critical stakeholders in the work surrounding older adults' PHIM. However, prior to the funding of this grant, little work had been done to characterize the roles, needs, and barriers of these stakeholder groups. The Aim 2 studies were designed to investigate the role other stakeholders, such as family, friends, and providers, to performing PHIM activities.

B.1b Setting/Participants:

We focused Aim 2 on the following stakeholder groups: (1) *friends and family members of older adults (FF)*, identified by the older adult as being important in their health and PHIM (Taylor, et al.); (2) *home health care nurses (HCNs)* who held a registered nurse license, had one year or more of work experience, and were either full time or part time employees at two different Medicare-certified home health care agencies (Kang, et al.); and (3) various *health care providers* of older adults in the greater Seattle area (Turner, et al.).

We conducted phone interviews with family and friends identified by older adult participants as important for their health and health information management to better understand the role of family and friends in older adults' PHIM. We interviewed a variety of health care providers in the workplace to gain a better understanding of providers' perceptions and role in older adult PHIM.

B.1c Incidence/Prevalence: N/A

B.2 METHODS

B.2a Study Design: We used an exploratory study design which included qualitative interviews and thematic analysis to investigate the role of family, friends and providers in the personal health information management of older adults.

B.2b Data Sources/Collection:

We conducted semi-structured telephone interviews with 52 FF identified by older adults as being important in their health and PHIM and 17 HCNs from two home health agencies. Additionally, we interviewed 27 health care providers who worked with older adults (medical practitioners, social workers, pharmacists, and assisted living staff) in the greater Seattle, WA area. All interviews were audio recorded, and transcribed. We analyzed interview transcripts using thematic analysis.

B.2c Interventions/Measures: N/A

B.2d Limitations:

Our FF sample was dependent on identification by older adult participants in the primary SOARING study and reflects the limited size of the original participant population. The HCN sample came from three health care agencies located in urban areas, so may not be generalizable to other agencies, particularly rural ones. The provider sample was small and from one metropolitan area, which may affect generalizability of results. We did not include all possible

health care provider types (such as physical therapists). Bias could have been introduced in the coding of interviews, or in interpretation of results for all interviews.

B.3 RESULTS

B.3a Principal Findings/Outcomes:

Friends and Family (FFs): We found that FFs engaged in diverse tasks related to older adult PHIM in areas of helping to maintain health, facilitating medical encounters, helping with decisions, and assisting in daily life. The crosscutting activity of monitoring was a key process that informed PHIM related tasks, and involved detection of issues or concerns, interpretation of diverse forms of information, and related action. Barriers to monitoring included older adults' choices and constraints, FF constraints, difficulty with technological tools, resources, health information exchange between providers, social network dynamics, and physical distance.

Home Health Care Nurses (HCNs): The five thematic areas that emerged from interviews with HCNs focused on how they obtained and provided health information to and from older adults, and the use of tools and technology. HCNs reported using multiple methods to obtain and provide health information, including verbal communication and written or printed formats. Developing trusting relationships with older adults was an important facilitator of this process. HCNs cited access and use of a laptop during work with older adults as a huge asset for both educational purposes and access to medical records. However, HCNs were hesitant to help older adults with their portals for privacy reasons.

Health Care Providers: Each type of provider described a unique role in supporting older adult PHIM, including assisting with medication management, interpreting information, and providing resources and referrals. Common barriers to older adults PHIM as identified by providers include (1) difficulty with communication and information exchange, (2) lack of resources such as time, and (3) the older adult's difficulty interpreting vast and complex health information. Facilitators included communication with caregivers and patient portal technologies.

B.3b Discussion:

The stakeholders we interviewed had varying roles in the PHIM of the older adults in their lives. All stakeholders gathered personal health information from and for the older adult. Family members and friends monitored in order to detect and interpret information that related to the older adult's well-being, and also gathered information directly from older adults. Family and friends' detection and interpretation of the older adult's personal health information sometimes occurred with health care providers, including HCNs, who also gathered information from older adults. All stakeholders experienced barriers to effective support of older adult PHIM, in particular in relation to time, and information exchange between stakeholder groups.

All stakeholders reported providing some level of help in understanding health information, either through interpreting or educating the older adult. Stakeholders reported that some older adults used a combination of stakeholder assistance and available resources (including

communication through face-to-face, phone, and digital methods) to improve their understanding of health information.

B.3c Conclusions/Significance:

There is an opportunity for an HIT system to provide consistent and reliable access to personal health information for older adults and stakeholders and creatively bridge the current barriers related to privacy and interoperability of differing organizational systems. An HIT system that could help older adults and those who support them to find, interpret, and use applicable health information without overwhelming them would also be a valuable contribution and relieve burdens for both older adults and their stakeholders.

B.4 PUBLICATIONS/PRESENTATIONS/PRODUCTS

B.4a Publications:

Kang Y, Taylor JO, Osterhage K, Turner AM. The perspectives of home health care nurses regarding the personal health information management among older adults. Home Healthcare Now. 2019; Nov/Dec. (in Press).

Taylor JO, Hartzler AL, Osterhage KP, Demiris G, Turner AM. Monitoring for change: the role of family and friends in helping older adults manage personal health information. JAMIA. 2018; 25(8):989-999. Doi: https://doi.org/10.1093/jamia/ocy037. *Article nominated for the 2019 AMIA Diana Forsythe Award

B.4b Presentations:

Taylor JO, Turner AM. Webinar: Monitoring for change: the role of family and friends in helping older adults manage personal health information. Selected for discussion the JAMIA Journal Club; June 14, 2018.

B.4c Posters:
Kang Y, Osterhage K, Turner AM. Personal Health Information Management of older adults in the home health care setting. Presented at the 2017 IAGG World Congress; San Francisco, CA; July 26, 2017.

Kang Y, Osterhage K, Turner AM. The Role of Home Health Care Nurses in Older Adult Health Information Management. Presented at Washington State Public Health Association. Wenatchee, WA; October, 16, 2017.

C. Aim 3 Develop a model of attributes of PHIM needs and practices for older adults and their key stakeholders

C.1 SCOPE

C.1a Background/Context:
To gain a more comprehensive understanding of PHIM in older adults, we took a holistic approach to PHIM through application of the Balance Model of Work which was first described by Smith and Carayon in 1995 and later applied to PHIM by Moen and Brennan in 2005. In designing our Aim 1 and 2 studies, we took into consideration the elements of the Balance Model, specifically individuals, social connections, environment, organizations, and tools and technologies, that played a role in or influenced older adult PHIM. In Aim 3, we sought to synthesize the findings from Aim 1 and 2 and expand on the Balance Model to incorporate our findings regarding the PHIM practices and needs for older adults and their key stakeholders.

C.1b Setting/Participants:

We synthesized findings from the interview transcript and surveys of participants in Aims 1 and 2. Aim 1 in-depth interview participants that were available and willing to participate were invited to participate in a validation survey to confirm initial findings.

C.1c Incidence/Prevalence: N/A

C.2 METHODS

C.2a Study Design/

In Aim 3 we sought to develop a model of older adult PHIM based on findings from the Aim 1 and 2 studies.

C.2b Data Sources/Collection:

We gathered data from coded in-depth interviews, demographic and instrument data (Aim 1), the longitudinal study (Aim 1), coded interviews with family, friends, and providers (Aim 2), performance of a cluster analysis, and a validation survey (Aim 3) to create a model of older adult PHIM.

Cluster analysis: To determine if participants formed clusters in terms of PHIM, we used data collected in Aim 1 to evaluate the PHIM approaches identified from the coded interview transcripts and the demographic and survey data to conduct a hierarchical cluster analysis with complete linkage on the participants using the number of approaches that two participants differed on as the distance measure. Statistical significance of clusters was determined using multiscale bootstrap resampling with 1000 samples.

Validation survey: We conducted a validation survey with 38 Aim 1 participants that had previously agreed to be contacted for follow-up studies. The online RedCap survey was administered in-person with a member of the research team using a tablet to access questions and input answers directly.

C.2b Interventions/Measures: N/A.

C.2c Limitations:

The cluster analysis and validation survey were performed using data from a limited sample of older adults in the Seattle, WA area. They may not be generalizable to a larger sample of individuals or older adults living in different geographic locations. Our interpretation of qualitative interviews may have been biased by our own experience.

C.3 RESULTS

C.3a Principal Findings/Outcomes (NOTE: Because the cluster analysis and model development are still in progress, a general overview of Aim 3 results is provided below).

Our cluster analysis did not indicate that older adult individuals have a consistent PHIM style.

Our validation studies supported the idea that individuals took different approaches to PHIM tasks depending on the situation rather than on their personal style.

Based on our findings, we created an expanded model of PHIM for older adults which incorporates PHIM tasks, processes, approaches as well as internal and external influencing factors.

C.3b Discussion

PHIM in older adults involves a set of tasks that are approached differently depending on the individual, their social support, health, and living environment.

C.3c Conclusions/Significance

Our initial assumption was that older adults would demonstrate certain styles of PHIM, which we would use to tailor the design and function of PHIM tools and technologies. Our cluster analysis did not indicate that older adult individuals have a consistent PHIM style or approach for particular PHIM tasks. Instead, our validation studies supported the idea that individuals took different approaches to PHIM depending on the situation.

A health information system that supports older adults should support health information gathering, storage, and use. Designers should account for a wide variation of approaches to PHIM tasks and enable flexible and dynamic structures to accommodate different situations and changes in needs as one ages.

C.4 PUBLICATIONS/PRESENTATIONS/PRODUCTS

C.4a Publications

Turner AM, Osterhage KP, Taylor JO, Hartzler AL, Demiris G. A closer look at health information seeking by older adults and involved family and friends: design considerations for health information technologies. AMIA Annu Symp Proc. 2018; 2018:1036-1045. PMID: 30815147.

Demiris G, Lin S, Turner AM. The role of personal health information management in promoting patient safety in the home: A Qualitative Analysis. MEDINFO 2019 Proceedings. (in press).

C.4b Presentations/Panels:

Demiris G, Turner AM, Capurro, D. Informatics tools as facilitators for patient engagement. Presented at MEDINFO 17th World Congress on Health and Biomedical Informatics; Taipai, Taiwan; August 24, 2017.

Demiris G, Turner AM, Capurro D, Koch S. Designing and Evaluating Patient-Centered Informatics Tools to Promote Shared Decision Making. Presented at MEDINFO 15th World Congress on Health and Biomedical Informatics; Sao Paulo, Brazil; August 21, 2015.

Turner AM, Osterhage K, Hartzler A, Taylor J, Demiris G. Personal health information practices of older adults: One size does not fit all. Presented at MEDINFO 19th World Congress on Health and Biomedical Informatics; Lyon; France Aug. 24-30, 2019.

Turner AM. Putting it all together: SOARING Implications for minority populations. Presented to the UW HPRC Community Advisory Board (CAB). Tukwila, WA; Jan 25, 2019.

D. Aim 4: Apply a user-centered design approach to create a set of evidence-based design guidelines for health information management tools for older adults

D.1 SCOPE

D.1a Background/Context:

One of our goals in Aim 4 was to improve the design of health information technologies (HIT) to support the health and autonomy of older adults. To achieve this aim, we applied the human centered design (HCD) process to develop a set of resources that designers can use in creating HIT for older adults. The HCD process is an iterative approach that places impacted people at the center of the design process to ensure that the design and development of the product is usable, meets people's needs and goals, and addresses people's challenges or pain points.

There are a variety of artifacts that can result from HCD methods. For our project we chose to create personas, scenarios, and design guidelines. Personas represent different people (in our case older adults and supportive stakeholders) and their needs. They provide a sense of their behaviors, attitudes, needs, and goals in specific contexts. Personas often include a scenario or narrative that illustrates the context surrounding the individual.

We combined personas, scenarios, guidelines, and an overview of the SOARING project into a design book. In the book, we also provided design ideas based on the guidelines and a table that

connects the personas with design guidelines, so HIT designers can better understand how and when to apply the guidelines.

D.1b Setting/Participants:

Through the HCD process, we reached out to older adults living in retirement communities to provide feedback on the preliminary design requirements. We conducted three focus groups with 21 older adults in senior living communities and facilities. We also asked student designers to evaluate our personas, scenarios and guidelines. We conducted a two-part study with 16 student designers at the University of Washington.

D. 1c Incidence/Prevalence: N/A

D.2 METHODS

D.2a Study Design

We applied the principles and methods of Human Centered Design and usability testing to develop a set of design tools for health information technology designers

D.2b Data Sources/Collection:

Persona process

We used the interviews with older adults, family and friends and providers as the basis for creating personas, scenarios, and design guidelines. Once we drafted the personas, we sought feedback from subject matter experts, including members of the SOARING team, on the accuracy and completeness of content and design. We conducted 5 feedback cycles, incorporating new feedback after each cycle. As a result, we created six sets of connected personas (e.g. an older adult persona that is grouped with at least one stakeholder persona). Connected personas provide a fuller picture of the older adult's needs and experiences, and details about the role that family, friends, and providers play in managing the older adult's health information.

Design guidelines process

Our design guidelines are a list of design considerations that apply specifically to HIT for older adults and complement the connected personas. We drew from the diverse perspectives of HCD designers, older adults, and subject matter experts to inform the guidelines. We first invited undergraduate and graduate students to participate in an applied class that helped to develop the design guidelines. We brainstormed a list of preliminary design requirements. Students helped to prepare video scenarios of these preliminary design requirements to show to older adults. We conducted three focus groups with 21 older adults living in senior living communities and facilities to gain their feedback on the preliminary design requirements. After each video scenario, participants were asked whether the scenario resonated with their experience and their perspectives on concepts such as information sharing and privacy. At study completion, field notes were coded by two researchers using thematic analysis. Results from the thematic analysis

were used to refine the design guidelines. We shared the refined design guidelines draft with subject matter experts through four feedback cycles, and modified them based on their feedback.

Study with designers

We conducted a two-part study with a total of 16 student designers to understand their perceptions of the connected personas in comparison to individual personas and how they would use the connected personas in their design process. We conducted two sessions with designers. In the first session, designers worked in groups of 3-5 people and were asked to brainstorm ideas for a design challenge. To compare the designers' differing experiences with an individual persona versus connected personas, we used a three-phased approach, where the groups worked first with just the older adult persona and then were given the connected personas. All sessions were video and audio-recorded. After the first sessions, we conducted a thematic analysis. We identified themes and used those themes to code the rest of the videos. We triangulated the themes with the data gathered through group discussion feedback forms and individual exit surveys, while being open to additional themes that emerged.

D.2b Interventions/Measures: N/A

D.2c Limitations:

We did not focus on a particular HIT or explore other activities beyond personal health information management. Our results may not be generalizable to other technologies, activities or contexts. We created our connected personas and design guidelines independently from a team of designers. Prior studies have found that designers who are not involved in the development of personas may not use them to make design decisions. Research into the use of these personas in actual practice is needed.

D.3 RESULTS

D.3a Principal Findings/Outcomes:

Drafting personas and emergence of connected personas

We started by following the typical persona development process, with the goal of developing a set of "stand-alone" personas that represented the different experiences of older adults and their family members, friends, and providers. However, as subject matter experts reviewed the "stand-alone" family and friend persona drafts, they noticed that although the personas were representative, they did not illustrate the connected nature of the network of people who support older adults in their health information management. As a result, we decided to break from the typical persona method of individual persona groups, and to instead create connected personas.

Development of design guidelines: Focus groups with older adults

In total, 21 older adults participated in the focus groups. The average age among participants was 79 years old. Most participants were female (76%) and a majority identified as white (95%), with a college degree or higher (71%). Most older adult participants reported using a computer on a

daily basis (71%) and about half (52%) described their computer experience as being at an intermediate level, meaning between some experience and very experienced. In addition, about half (52%) of participants said that they were using patient portals. Several themes emerged from these focus groups: keep it simple, support autonomy, maintain privacy and ease of use, and recognize the diversity among older adults in their use of and attitudes toward information technologies.

Assessment: Designers' experiences with personas and design guidelines

A total of 16 designers participated in the study. In general, the connected personas were well received by designers. A primary benefit of the connected persona expressed by designers was that it provided them with a broader perspective on the older adults' situation and problem space. It also cultivated empathy for the older adult. They suggested providing an overview summary of key information for each set of personas, or a video summary about each persona set. They also expressed that the design guidelines were useful and helped them to prioritize their design ideas.

D.3b Discussion:

Connected personas incorporate the insights we gained from taking a holistic approach to investigating older adult PHIM through application of the Balance Model, which considers the individual in the context of their tasks, tools and technologies, environment, and organizational structures[3]. We observed crucial PHIM needs within the connections between older adults and their family, friends, and providers that would not easily be communicated with stand-alone personas. We found an HCD approach to be flexible and robust, allowing us to help designers navigate and appreciate the complexities of older adult personal health information management. Using an HCD approach provides researchers with a method to translate and communicate complex processes that are critical to the work people do and are necessary for HIT design.

D.3c Conclusions/Significance:

Overall, the connected personas and design guidelines helped designers to develop a greater understanding of older adults and their PHIM needs and practices. Having this knowledge led to the generation of more sophisticated and mature design ideas. We believe these tools will lead to HIT that meets the needs of older adults and as a result is used and adopted by older adults. The implications of our findings for designers are summarized in the design book entitled, The Essential Guide to Older Adult-Centered Design: Supporting Personal Health Information Management, UW SOARING, which will be made publicly available at the end of 2019.

D.4 PUBLICATIONS/PRESENTATIONS/PRODUCTS

D.4a Publications:

Sakaguchi-Tang D, Turner AM, Taylor JO, Kientz J. Connected Personas: Translating the Complexity of Older Adult Personal Health Information Management for Designers of Health Information Technologies. AMIA Annu Symp Proc. 2019. (in press). – Selected as a finalist for the best student paper award

Sakaguchi-Tang D, Taylor, J, Kumari K, Takano A, Wu Y, Turner AM, Kientz, JA. Connected Personas: Using a Network of Personas to Translate the Complexity of Stakeholder Needs. (Submitted to CHI 9/19, under review)

D.4b Presentations:

Sakaguchi-Tang D, Turner AM, Taylor JO, Kientz J. Health Information Technology for Older Adults: A Human-Centered Design Perspective. Presented at Washington State Public Health Association Annual Conference. Wenatchee, WA. 2018.

D.4c Products:

Design Book/Personas

SOARING Team (PI) Guidebook: The Essential Guide to Older Adult-Centered Design: Supporting Personal Health Information Management
URL: http://www.soaringstudy.org/content/3-news/amia-2019/Design-Book-0905.pdf
Accessed 11/24/19.