

© Copyright 2021

Dawn Sakaguchi-Tang

Understanding and Designing Health Technologies with Older Adults

Dawn Sakaguchi-Tang

A dissertation

submitted in partial fulfillment of the
requirements for the degree of

Doctor of Philosophy

University of Washington

2021

Reading Committee:

Julie A. Kientz, Chair

Leah Findlater

Jason C. Yip

Program Authorized to Offer Degree:

Human Centered Design and Engineering

University of Washington

Abstract

Understanding and Designing Health Technologies with Older Adults

Dawn Sakaguchi-Tang

Chair of the Supervisory Committee:

Julie A. Kientz

Human Centered Design and Engineering

The population of people 60 years and older has been rapidly rising and will continue to grow. This growth has prompted a turn toward innovations to support age-related decline. While these innovations are necessary, the older adult population is large and diverse. Researchers in HCI have recognized opportunities to broaden the design area to include designing for the strengths of aging and to examine the way we perceive aging and older adults in HCI. Some have advocated for methods such as participatory design to involve older adults in the design process. This dissertation focuses on involving older adults in design work and raising awareness of the differences among those in the aging population, especially in their life situations, health goals, and needs. I grounded my work through a systematic review of the use and adoption of patient portals and electronic personal health records (ePHRs). Through this work, I led a team to identify the barriers and facilitators and gained an understanding of the user experience of patient portals and ePHRs.

This review provided a foundation for a study to translate existing study findings into design resources, specifically personas and design guidelines. For this study, I carried out the human centered design approach to create personas and design guidelines that communicate how older adults manage their personal health information (PHIM). We modified the typical persona format and created *connected personas* to show the complexities of PHIM for older adults and emphasize the importance of relationships with family, friends, and providers. I led focus groups with older adults and design workshops with student designers to gather feedback and iterate the design resources. This work led me to reflect on the evaluative role that older adults played in the study. While this was valuable, I realized a need for higher engagement with older adults to understand their needs and goals better.

In my final study, I conducted co-design sessions with older adults and student designers to identify and understand the interactions that contribute to equal collaboration. I also examined the impact of this collaboration on the student designers' perceptions of aging and older adults. The sessions were structured using the human centered design process, and the activities were influenced by the life course perspective. The goal of these sessions was for teams to create a low-tech prototype of a health and well-being technology for older adults. Our work expanded Yip et al. (2017) framework to shift and capture the interactions that occurred in collaborations with older adults. We learned that using the life course perspective for co-design activities led team members to understand each other's perceptions of health and well-being and develop a stronger bond. We found that the life course perspective influenced the teams' design ideas and prototypes. Co-designing with older adults also challenged the assumptions that student designers had about aging and older adults.

Across these three studies, I examined the needs of older adults and advocated for their inclusion

in the design process. I provided considerations in co-designing with older adults to support equal and equitable interactions. This work encourages designers to reflect on their perceptions about the aging population. It demonstrates the value of exploring personal histories in co-design activities to challenge assumptions about older adults and better understand their health and well-being needs.

TABLE OF CONTENTS

Chapter 1. Introduction	15
1.1 Research Questions	18
1.2 Dissertation Overview	19
1.2.1 Chapter 2: Related Literature	20
1.2.2 Chapter 3: Systematic Literature Review	20
1.2.3 Chapter 4: Connected Personas	21
1.2.4 Chapter 5: Co-designing with Older Adults	22
1.2.5 Chapter 6: Life Course Perspective Influence of Design: A Case Study	23
1.3 Contributions.....	23
Chapter 2. Related Literature	25
2.1 Older Adults Use of Technologies.....	25
2.1.1 Technologies for the Aging Population	26
2.1.2 Barriers and Facilitators	27
2.1.3 Broadening Perspectives of Aging.....	29
2.2 Theoretical Foundation	31
2.2.1 Human Centered Design (HCD).....	32
2.2.2 Balance Theory and Work System Model	33
2.2.3 Life Course Perspective	34
2.2.4 Participatory Design and Co-designing with Older Adults	36
2.2.5 Cooperative Inquiry	37
Chapter 3. Patient Portal Use and Experience Among Older Adults: Systematic Review	40
3.1 Systematic Review Objectives.....	41
3.2 Methods.....	42
3.2.1 Revised PRISMA Protocol	42
3.2.2 Literature Search.....	43
3.2.3 Inclusion and Exclusion Criteria.....	43

3.2.4	Quality Review	46
3.3	Results.....	46
3.3.1	Description of Papers	47
3.3.2	Participant Characteristics	49
3.3.3	Quality Review	50
3.3.4	Barriers.....	51
3.3.5	Facilitators.....	53
3.3.6	Changes in Health Information Management and Provider Communication.....	57
3.3.7	Areas to Explore	58
3.3.8	Design Suggestions.....	58
3.4	Discussion.....	59
3.4.1	Overview.....	59
3.4.2	Principal Findings	61
3.4.3	Limitations	67
3.5	Chapter 3 Summary	68
Chapter 4. Connected Personas: Translating the Complexity of Older Adult PHIM for Designers of Health Information Technologies		
		70
4.1	Introduction.....	70
4.2	Background.....	71
4.3	Methods.....	73
4.3.1	HCD 1.1 Persona Process	74
4.3.2	HCD 1.2 Design Guideline Process.....	74
4.3.3	HCD 1.3 Study with Designers.....	76
4.4	Results.....	77
4.4.1	HCD 1.1 Drafting Personas and Emergence of Connected Personas.....	77
4.4.2	HCD 1.2 Development of Design Guidelines.....	80
4.4.3	HCD 1.3 Assessment	83
4.5	Discussion.....	84
4.6	Limitations	86

4.7	Chapter 4 Summary	86
Chapter 5. Co-designing with Older Adults: Examining and Reflecting on Collaboration with Aging Communities		88
5.1	Background	90
5.1.1	Co-designing and Participatory Approaches with Older Adults.....	90
5.1.2	Benefits of Designing with Older Adults.....	91
5.1.3	Power Dynamics and Design Partnerships	92
5.1.4	Reflection in HCI Education.....	93
5.2	Methods.....	94
5.2.1	Context and Participants	94
5.2.2	Data Collection	95
5.2.3	Data Analysis	99
5.3	Part 1: Interactions Present when Co-designing with Intergenerational Teams	102
5.3.1	Facilitation	102
5.3.2	Relationship Building	107
5.3.3	Design-By-Doing.....	109
5.3.4	Elaboration.....	112
5.3.5	Older adults' views of Co-design and Involvement in the Design Process	114
5.4	Part 2: Understanding Student Designers' Perceptions of Co-designing with Older Adults Through Reflection	116
5.4.1	Reflection Activities	116
5.4.2	Broadening Aging Perspectives	117
5.4.3	Balancing Roles	117
5.4.4	Value of Co-design	118
5.5	Discussion.....	119
5.5.1	Part 1: Using the Framework to Understand Interactions When Co-designing with Intergenerational Teams.....	120
5.5.2	Implications for building design partnerships.....	122
5.5.3	Part 2: Co-designing and Reflective Activities on the Learning Experience	123

5.6	Limitations and Future Work	125
5.7	Chapter 5 Summary	126
Chapter 6. Life Course Perspective Influence on Design		128
6.1	Life Course Perspective	128
6.2	Method	129
6.2.1	Participants.....	129
6.2.2	Study Teams.....	130
6.2.3	Co-design Sessions	130
6.2.4	Data Analysis	130
6.2.5	Team Descriptions	131
6.3	Findings.....	146
6.3.1	Turning points.....	146
6.3.2	Linked Lives	148
6.3.3	Independence	150
6.4	Discussion.....	151
6.4.1	Life Course Perspective Contributions	152
6.5	Limitations	154
6.6	Chapter 6 Summary	154
Chapter 7. Discussion		156
7.1	Discovering Complexity	158
7.2	Challenging Aging Perceptions	160
7.3	Considerations for co-designing with Older Adults	162
7.4	Contributions.....	165
7.5	Future Work	166
7.5.1	Design perspectives	166
7.5.2	Community Based Co-design	168
7.5.3	Translating Findings to Practice	168
Chapter 8. Conclusion.....		170

LIST OF FIGURES

Figure 1. Human Centered Design Process	32
Figure 2. Roles that adults and children play in the design process	38
Figure 3. Systematic Review Process	47
Figure 4. Overview of our human centered design approach	74
Figure 5. This set of slides illustrates the video scenario	75
Figure 6. Older adult person, Paula Private and Connected personas	79
Figure 7. Family of connected personas	80
Figure 8. Team’s ideation sketch of their smart-toilet low-tech prototype.....	111
Figure 9. Screens from team’s low-tech prototype.....	114
Figure 10. Photo of Team A	133
Figure 11. Team A's shared understanding of health and well-being poster	134
Figure 12. Team A's timeline of health and well-being events	135
Figure 13. Team A’s persona.....	136
Figure 14. Team A’s prototypes	137
Figure 15. Photo of Team B.....	137
Figure 16. Team B's shared understand of health and well-being poster	139
Figure 17. Team B's timeline of health and well-being events.....	139
Figure 18. Team B’s persona	140
Figure 19. Team B's prototype.....	141
Figure 20. Photo of Team C.....	142
Figure 21. Team C's shared understanding of health and well-being.....	143
Figure 22. Team C's timeline of health and well-being events.....	144
Figure 23. Team C's persona.....	145
Figure 24. Team C’s prototype	146

LIST OF TABLES

Table 1. Alignment of Research Questions to Dissertation Studies	21
Table 2. Searches Used in Each Database	45
Table 3. Inclusion Criteria	45
Table 4. Demographics of Older Adults	97
Table 5. Demographics of Student Designers.....	97
Table 6. Summary of Session Activities.....	99
Table 7. Student Designers Reflection Activities	100
Table 8. Summary of Activities	132

ACKNOWLEDGEMENTS

I am so grateful to my advisor, Julie A. Kientz, for always being the person in my corner, supporting and believing in me, especially when I was less than sure of myself. I feel lucky to have an advisor that understands the demands of being a parent and encourages a work/life balance. I also want to thank my wonderful committee, Leah Findlater and Jason Yip. I am thankful to Leah for her guidance throughout the years and for introducing me to the life course perspective. I want to thank Jason for collaborating with me and asking questions that challenged me to identify unique contributions in my work. I am grateful to Anne M. Turner for her mentorship and for bringing me onto the SOARING project. I learned so much about older adults and the complexities of health information management.

I could not have done the work in this dissertation alone. I am thankful to have been on the SOARING team with Andrea Civan Hartzler, George Demiris, Elizabeth Phelan, Ian Painter, Katie Osterhage, Shih-Yin Lin, and Andrew Teng. I am especially thankful to have worked with Jean O. Taylor, Alyssa Bosold, Selena Xu, and Yong Choi. I am also grateful to my fellow collaborators on the co-designing with older adults study, Jay Cunningham and Wendy Roland, for brainstorming with me and for their insights to make it a great study.

I am grateful for the support from fellow students in the PhD program. I want to thank Arpita B, Jay Cunningham, Wendy Roldan, Saba Kawas, Calvin Liang, Akeiyah DeWitt, Rebecca Michelson, Susanne Kirchner, Elena Agapie, Lucas Colusso, Kai Lukoff, Sam Kolovson, Mia Minhyang Suh, Meg Drouhard, Kathryn Shroyer, Spencer Williams, Keri Mallari, Hyewon Suh, Kiley Sobel, Alexis Hiniker, Jared Bauer, John Porter and Eun Kyoung

Choe for their friendship throughout the years. Since working this past year remotely, I have truly missed the informal chats we used to have in the lab and in the hallways. I am grateful to all the students and sites that have worked with me to conduct my studies. I am also very thankful to the older adult participants who shared their experiences and insights.

I want to thank my family for their support, especially my aunt, Gail Nomura, who has been a source of advice, support, and encouragement. I want to thank my friends for constantly cheering me on, making me laugh, and reminding me to take breaks.

I could not have pursued this journey without the full support of my husband, Harry. Even though he didn't have a complete understanding of my work or what being a PhD student was like, he stood by me through the ups and downs of this experience. He often whisked the kids to the park or store and stayed on daddy duty for many bath and bedtimes, so I could focus on getting work done. I don't have all the words to express my gratitude and love, but I'm very thankful to have him by my side and look forward to the new adventures we will go on.

When I entered the PhD program, we were a family of three, and now, as I exit, we have grown into a family of four. Evan is seven, and Adam is three years old. I am so grateful to have had them on this journey for making it a fun and colorful ride. I could always count on them for hugs and "I love you, mama," which always perked me when I felt exhausted. I thank them for being the motor behind my drive to get to the end. I am looking forward to supporting them in their journey in life.

DEDICATION

To my children, Evan and Adam for being the joy and light in my life.

To my husband, Harry Tang for his patience, support and love.

Chapter 1. Introduction

The population of people 60 years and older has been rapidly rising and will continue to grow. By 2050, it is estimated that 2 billion people will be 60 years or older, doubling the proportion in 2015, from 12% to 22% of the global population (World Health Organization, 2018). The rise in our aging population has prompted researchers to investigate its impact on society and sparked innovations to support older adults as they age (Vines, Pritchard, Wright, Olivier, & Brittain, 2015), for example, smart home technologies (G. Demiris & Hensel, 2008) and technologies for social communication (Raffle et al., 2011) and medication management (Haverhals et al., 2011; Siek et al., 2011).

While these technologies are essential to supporting the aging population, Human Computer Interaction (HCI) researchers also recognized that the focus of these innovations was on the decline of aging, referred to as **deficit-driven design** (Carroll, Convertino, Farooq, & Rosson, 2012; Vines, Pritchard, et al., 2015). Some researchers argued that technologies are developed with a younger user in mind and are typically created by people younger than those in the older adult population (Culter, 2005; Joyce, Williamson, & Mamo, 2007). In an editorial, Don Norman (Norman, 2019) expressed his dismay at the lack of considerations for older adults, for example, hard to open containers and small font on printed labels. He noted, “*when companies do design things specifically for the elderly, they tend to be ugly devices that shout out to the world “I’m old and can’t function!” We can do better.*”

Researchers have called for ways to counter these perceptions by advocating to reframe aging in HCI and encourage older adult participation in the design process. Carroll et al. (2012) suggested broadening the design space to include innovations that support and leverage the

strengths of aging, or **positive design**. Some have called for methods that give older adults more agency in the design process (Y. Rogers & Marsden, 2013; Y. Rogers, Paay, & Brereton, 2014; E. B. N. Sanders, Brandt, & Binder, 2010) and let them participate in design activities based on shared interests or everyday practices and not based solely on age (Righi, Sayago, & Blat, 2017; E. B. N. Sanders et al., 2010).

These perspectives are essential to consider in health and well-being design spaces, where a slower adoption of health technologies by older adults have been observed compared to technologies such as, cell phones, computers, and the internet (Levine, Lipsitz, & Linder, 2016). This lag could be in part due to barriers such as socioeconomic disparities, physical challenges, perceived ability to use technologies, and usability issues (Anderson & Perrin, 2017; Sakaguchi-Tang, Bosold, Choi, & Turner, 2017; Vines, Pritchard, et al., 2015).

These barriers have become more pronounced since the COVID-19 pandemic (K. Lam, Lu, Shi, & Covinsky, 2020). Lam et al. (2020) estimated that 13 million older adults in the United States were not ready to switch to video telehealth visits at the start of the COVID-19 pandemic and suggested that telephone visits would reach more older adults. However, studies also found that older adults are more willing to turn to digital or online resources because of limited in-person health services (D. R. Lee, Lo, Ramalingam, & Gordon, 2020). Chen et al.(2020) reported that older adults have been using technologies including telephone, internet, and email during the pandemic and are willing to use telehealth for health services such as, follow-up appointments and refilling prescriptions. Although older adults may agree to try digital solutions to maintain their health and well-being, contextual factors can make it difficult or impossible for some to attempt to do so. These are obstacles that leave many older adults in a digital divide that has been exacerbated by the COVID-19 pandemic, which limited the typical

means of receiving health services.

My work focused on involving older adults in design work and raising awareness of the differences among those in the aging population, especially in their life situations, health goals, and needs. The studies in this dissertation were completed before the COVID-19 pandemic but are consistent with the recent findings of the impact on older adults' willingness and readiness to use health technologies.

A large part of my work has been within a project called Studying Older Adults & Researching Needs & Goals (SOARING). SOARING was a 5-year project funded by the Agency for Healthcare Research and Quality (AHRQ). The project aimed to deepen the understanding of older adults' personal health information management (PHIM) and the role that family, friends, and providers play in that process. In this dissertation, I discuss how I led the human centered design process to translate study findings into design materials (i.e., personas and design guidelines) that illustrated the complexity of older adults' PHIM practices, living situations, and social support. The complexity and variability among the older adults in this project highlighted the need to broaden the design space to consider older adults' contextual, situational, and social factors. Also, it heightened the need for deeper participation of older adults in the design process.

Prior work in participatory design (PD) approaches and co-design have been a way to ensure that technologies better meet the needs of older adults (Y. Rogers et al., 2014; Uzor, Baillie, & Skelton, 2012). PD approaches have also been used to challenge stereotypes of older adults that question their abilities to contribute novel and creative ideas to technology design (Davidson & Jensen, 2013a; Y. Rogers et al., 2014). Researchers have included older adults in a range of design activities, including expressing their needs (Davidson & Jensen, 2013b;

Harrington, Wilcox, Connelly, Rogers, & Sanford, 2018) and creating and evaluating prototypes (George Demiris, Oliver, Dickey, Skubic, & Rantz, 2008; Ellis & Kurniawan, 2000; Hakobyan, Lumsden, O’Sullivan, & Bartlett, 2013; Iacono & Marti, 2014; Massimi, Baecker, & Wu, 2007). Sharing the design process with people who may use technology is essential to the co-design approach. Researchers have provided frameworks, guidelines, and lessons learned to facilitate successful collaborations with older adults (Davidson & Jensen, 2013a; Kopec, Nielek, & Wierzbicki, 2018; Lindsay, Jackson, Schofield, & Olivier, 2012; Massimi et al., 2007; Petsani et al., 2019). However, understanding participation and collaboration between older adults and designers remained an area of need to facilitate equal and equitable collaboration during design activities. My work also aimed to understand the co-design collaboration between older adults and student designers by examining their interactions and by adapting a framework to understand the child-adult design partnership (Yip et al., 2017). Also, we demonstrate that using a life course perspective in design activities facilitated sharing life stories that impacted team bonding, influenced design decisions, and broadened aging views (Brown & De Schutter, 2016).

1.1 RESEARCH QUESTIONS

My dissertation explores the approaches and applications of involving older adults in designing technologies for health and well-being and its impact on designers’ perceptions of the aging and the older adult population. Specifically, my dissertation aims to answer five research questions.

RQ1. What are older adults’ use and experiences with health technologies?

RQ2. How do designers and older adults perceive and/or use design resources (e.g., personas, scenarios, design guidelines)?

RQ3. What interactions occur in co-design sessions with older adults and student

designers to create health and well-being technologies?

RQ4. How do co-design sessions impact student designers' perceptions of the aging population and of designing with older adults?

RQ5. How does the life course perspective influence design ideas of intergenerational co-design teams?

1.2 DISSERTATION OVERVIEW

This dissertation encompasses three studies. The first was a systematic review to understand the barriers, facilitators, and experience of older adults with health technologies, specifically patient portals and electronic personal health records (ePHRs) (RQ1). These findings provided foundational knowledge going into the human centered design process where we translated existing study findings of PHIM of older adults into resources that designers could use to develop health information technologies (RQ2). Through this process, I triangulated existing study findings with feedback we received from older adults in focus groups, designers through workshops, and subject matter experts through meetings. Involving these voices led us to modify the typical persona method to create what we called connected personas to represent better the role that the social and professional connections have on older adults' PHIM.

In these studies, older adults took on informative (existing study interviews) and evaluative roles (focus groups), demonstrating the complexity of health information management across the older adult population. My experience from the SOARING project and recent work advocating for a shift of aging views in HCI led me to reflect on the role that older adults played in our studies and the need for higher engagement with older adults, such as, in co-design methods, which has resulted in a greater understanding of older adults' needs and goals.

At its core, co-design seeks to create an equal and equitable collaboration between older

adults and designers. Prior work has provided models, guidelines, and lessons learned to participatory design with older adults. There has been little research done to examine the interactions between older adults and designers that contribute to or distract from equal and equitable collaborations. I set out to address this gap by conducting co-design sessions with older adults and student designers to create a low-tech prototype of new health and well-being technology (RQ3, RQ5). A life course perspective was incorporated, acknowledging that contextual, historical, and social factors influence an individual's health and well-being, as well as their design decisions (RQ5). Student designers experienced designing alongside people who were different from them and who are often characterized by negative stereotypes. So, students engaged in weekly reflection activities to consider and make sense of their experiences (RQ4). Table 1 shows how each study addresses my research questions.

1.2.1 *Chapter 2: Related Literature*

This section summarizes the current understandings of technology use by older adults and the barriers and facilitators to adoption. I also describe the studies that created awareness and advocated for the need to re-frame aging in HCI. After setting up this context, I summarize my work's theoretical underpinnings and how it guided my study design and analyses. The theories and approaches encouraged users' consideration and involvement, and they include human centered design, the Balance Theory, Work System Model, co-design, and Cooperative Inquiry.

1.2.2 *Chapter 3: Systematic Literature Review*

In this chapter, I discuss the systematic literature review on the use of patient portals and electronic personal health records (ePHR) by older adults. This research aimed to understand prior work on the use, adoption, and experiences that older adults have with patient portals and

ePHRs (RQ1). This research supported the work we did to create design resources using the human-centered design approach. It informed the content that went into personas and design guidelines that we created for designers of health technologies for older adults.

Table 1. Alignment of Research Questions to Dissertation Studies

	Study 1 Systematic Literature Review	Study 2 Connected personas	Study 3 Co-designing with older adults
RQ1. What are older adults’ use and experiences with health technologies?	X	X	X
RQ2. How do designers and older adults perceive and/or use design resources (e.g., personas, scenarios, design guidelines)?		X	X
RQ3. What interactions occur in co-design sessions with older adults and student designers to create health and well-being technologies?			X
RQ4. How do co-design sessions impact student designers’ perceptions of the aging population and of designing with older adults?			X
RQ5. How does the life course perspective influence design ideas of intergenerational co-design teams?			X

1.2.3 Chapter 4: Connected Personas

In this chapter, I describe how we used the human centered design process to take findings from that prior work to inform the creation of personas and design guidelines for health information technologies designers. The process included feedback from subject-matter experts in nursing, medicine, biostatistics, health informatics, and human-computer interaction. It also included involving older adults and designers throughout the process to create and iterate the design resources. I led a group of students from the Human Centered Design and Engineering (HCDE) department to develop the design guidelines and to conduct three focus groups with older adults in senior living communities.

I also ran a two-part study with student designers to evaluate our design resources' accuracy and usefulness. This process led to personas and design guidelines that illustrated the intricacies of the PHIM of older adults and the importance of the social connections they have with family, friends, and providers. Through our evaluation with student designers, we learned that the connected personas and design guidelines were comprehensive and provided a holistic picture of the differing contexts that impact how older adults manage their health and health information (RQ2).

1.2.4 *Chapter 5: Co-designing with Older Adults*

In this study, I aimed to understand how the co-design approach facilitated collaboration between older adults and student designers. I also examined the impact of this collaboration on the student designers' perceptions of aging and older adults. This chapter will describe a six-week co-design study at two sites where older adults and student designers team up to create a new health and wellness technology.

The co-design sessions were structured using the human centered design process and the life course perspective influenced the activities. The teams engaged in activities that explored their perceptions of health and well-being across their life span. These activities helped them narrow in on a design area and user, brainstorm design ideas, and build a low-tech prototype. I led the analysis to identify interactions in co-design collaboration across the two sites. We utilized the framework by Yip et al. (2017) to understand the interactions in co-design between children and adult designers to guide our analysis. Also, I analyzed the audio transcripts and artifacts from student reflections about their experience with their older adult teammates and in this study.

Our work extended the Yip et al. (2017) framework to shift and capture the interactions

that occurred in collaborations with older adults (RQ3). We learned that the life course perspective increased team bonds and challenged student perceptions' of older adults (RQ4). We recommended that HCI education incorporate co-designing with a different population from student designers, such as, older adults, as having a positive professional and personal impact (RQ4).

1.2.5 Chapter 6: Life Course Perspective Influence of Design: A Case Study

In this chapter, we extended the co-design study introduced in chapter 5 by presenting a case study of three teams who created prototypes that show the influence of the life course principles and key concepts. In this chapter we describe each team in detail and the artifacts they created throughout the sessions, as well as how they were represented in their prototypes. I discovered three themes across the prototypes; they were *turning points*, *independence* and *linked lives*. Through these themes I was able to spotlight the variety of ideas and health and well-being needs of the older adults on the teams.

1.3 CONTRIBUTIONS

This dissertation presents three types of contributions: survey contribution, empirical findings and methodological. These specific contributions are as follows:

- **Survey contribution:** I led a synthesis of a decade of prior work on using and adopting patient portals and electronic personal health records among older adults. We identified the barriers and facilitators to adoption and suggested design opportunities for addressing the barriers (RQ1).
- **Empirical findings:** To address RQ2, I implemented the human centered design by facilitating subject matter expert meetings, conducting focus groups with older adults,

and design workshops with student designers. These activities led to a deeper understanding of how older adults manage their health information and informed the development of personas and design guidelines representing older adults' different life situations. Also, subject matter expert meetings during the early stages of persona building led us to modify the typical persona process to create a network of connected personas that better reflect family, friends, and providers' influence on older adults' PHIM. To investigate RQ 3 and 4, I conducted co-design sessions that led us to examine and understand the interactions between older adults and student designers. We learned that the co-design activities that were influenced by the life course perspective impacted the team's bond and a broader understanding of how their histories contributed to their perception of health and well-being (RQ5).

- **Methodological contributions:** Prior work has focused on the importance of engaging older adults in PD and has provided guidelines and frameworks to support successful collaborations. We took a different approach to investigate factors that contributed to the equal intergenerational collaboration between older adults and student designers in co-design by adapting Yip et al.'s (2017) framework of dimensions used to understand the child-adult design partnership (RQ4).

Chapter 2. Related Literature

2.1 OLDER ADULTS USE OF TECHNOLOGIES

Older adults are increasingly using and adopting technologies. The Pew Research Center (2017) reported that 4 in 10 older adults own a smartphone, a 24% increase of ownership since 2013. Internet use, social media, broadband at home, and tablet ownership have all increased too. However, these trends lag behind adults 18-64 years old (Anderson & Perrin, 2017).

Differences also exist across technologies. While there has been a dramatic rise in older adults using everyday technologies for example, cell phones and the internet, the uptake of health technologies among older adults is much slower (Hung, Lyons, & Wu, 2020; Levine et al., 2016). Levine et al. (2016) analyzed the National Health and Aging Trends (NHATS) annual survey of Medicare beneficiaries 65 years or older. They found that while 63% of older adults had a computer, and 43% used the internet, only 16% searched for health information online, and 10% refill their prescriptions online. Hung et al. (2020) examined the U.S. National Health Interview Survey (NHIS) from 2009-2018 and found that older adults are increasingly using health information technologies, particularly seeking health information online; however, they noted the digital divide between the young and older generations. They urged healthcare providers to inquire about older adults' health information technology use and offer guidance on health management (Hung et al., 2020). The slow but rising technology use is significant because government agencies have recognized health technologies to support the rapidly growing aging population to manage their health and to live independently (National Science and Technology Council, 2019). In this dissertation, I further investigate the use and adoption of health technologies, specifically patient portals and electronic personal health records (ePHRs), through

a systematic literature review.

2.1.1 *Technologies for the Aging population*

Researchers in HCI have explored technologies to support the autonomy and quality of life of older adults. For example, one study facilitated social communication with older adults. They have sought ways grandparents and grandchildren can keep in touch and have rich conversations through reading stories through video communications (Raffle et al., 2011). Through virtual reality, older adults were able to recall and share memories with other older adults (Baker, Waycott, Carrasco, Hoang, & Vetere, 2019).

Researchers in HCI have also explored technologies that support older adults to live independently longer by monitoring their daily activities and communicating it to loved ones through a digital photo frame called, the Digital Family Portrait (Rowan & Mynatt, 2005), DigiSwitch (Caine et al., 2010) and CareNet Display (Consolvo et al., 2004). These technologies help to share information across an older adults' care network, support aging in place and allow network members to continue their daily activities (Consolvo et al., 2004). However, monitoring these activities raises privacy concerns about identifying information including their home and health conditions (Caine, Fisk, & Rogers, 2006; Caine et al., 2010). Prior work has examined different visualizations to explore older adults' perception of privacy and found that concerns depended on the type of need (Caine et al., 2006) and also found that older adults want to have control over when the device is collecting information on them (Caine et al., 2010). The work in this dissertation also explores considerations in designing for the complexity that represents that balance between autonomy and a network of loved ones in managing the older adults' personal health information.

2.1.2 *Barriers and Facilitators*

Prior work has shown factors that influence the use and adoption of general technologies (i.e., internet, cell phones, and computers) also affect health technologies. Socioeconomic and demographic factors, in particular age, education, race, and income, influence use. Pew Research Center (2017) found that twice as many older adults who are 65-69 years old use the internet than older adults 80 years or older. Regarding race and ethnicity, non-Hispanic Blacks and Hispanic older adults used health information technologies less than non-Hispanic Whites (Hung et al., 2020). Other factors such as, health literacy and living with chronic illnesses also influence the ability to use health information technologies (Hung et al., 2020).

Age-related changes in physical and cognitive abilities can limit the capacity to use technologies (Anderson & Perrin, 2017). Studies have noticed that older adults lack comfort and confidence with technologies (Anderson & Perrin, 2017; Knowles & Hanson, 2018; C. C. Lee et al., 2019; C. Lee & Coughlin, 2015; Neves & Amaro, 2012). Researchers emphasized that perceived benefits and usefulness are essential elements to the adoption of health and general technologies (Coleman, Gibson, Hanson, Bobrowicz, & McKay, 2010; Jimison et al., 2008; Kavandi & Jaana, 2020; S. Kim, Gajos, Muller, & Grosz, 2016; Knowles & Hanson, 2018; Mitzner et al., 2010). Also, older adults' values about the role and impact that technology may have on their social interaction with others or their time were considerations (Jimison et al., 2008; Quan-Haase, Williams, Kicevski, Elueze, & Wellman, 2018). A couple of studies noted that older adults were satisfied with their current situation, and using technology did not come to mind (Heinz, Margrett, Franke, Wong, & Chang, 2013; S. Kim et al., 2016). Designers need to consider ways technologies can easily fit into older adults' lives (Kavandi & Jaana, 2020; W. A. Rogers & Mitzner, 2017).

Social support was noted as a facilitator, such as family members encouraging the use of technologies (Friemel, 2016) or grandchildren helping their grandparents get started with new technologies (Neves & Amaro, 2012), or peers who are using technologies (S. Kim et al., 2016). Health care providers can also play a supportive role in creating awareness of health technologies, guide older adults to reliable sources and share ways health technologies can benefit them (Hung et al., 2020; Jimison et al., 2008). Kampmijer et al. (2016) found that if older adults received social support and feedback from e-tools or m-health tools to help them progress toward their goals, they are likely to keep using them.

The barriers and facilitators provide context for designers to consider as they design health technologies for an aging population. Researchers have furthered understanding of the use and adoption of technologies among older adults by examining them in different ways, including age range within the aging population (Anderson & Perrin, 2017; C. C. Lee et al., 2019; Loe, 2010). They also examined where they lived, such as older adults living in rural areas compared to those living in urban areas (Heinz et al., 2013) or by use of and skill with digital technologies (Quan-Haase et al., 2018). These efforts offer insights into the contextual factors that matter and affect older adults' experiences with technologies. Researchers encourage work that investigates the current ways that older adults use and value technologies to support independent living (Brereton, 2013; Loe, 2010). Loe (2010) found that radio and television are ways that nonagenarians stay connected. The aging population is heterogeneous, and it is essential for designers to consider the complexity of their needs and wants in the design process (Friemel, 2016; C. C. Lee et al., 2019; Mitzner et al., 2010; Neves & Amaro, 2012; Ostlund, 2005; W. A. Rogers & Mitzner, 2017; Vines, Wright, Silver, Winchcombe, & Olivier, 2015).

2.1.3 *Broadening Perspectives of Aging*

Ageism is widespread and an enduring influence across the globe. It is "negative or positive stereotypes, prejudice and/or discrimination against (or to the advantage of) elderly people on the basis of their chronological age or on the basis of a perception of them as being 'old' or 'elderly'" (p. 15) (Iversen, Larsen, & Solem, 2009). The assumptions applied to the aging population, such as older adults are frail, have implications on public policies and the older adults' potential to decide their futures and make continued contributions to society (World Health Organization, n.d.).

Assumptions about older adults have impacted technology design. All too often, considerations for older adults' needs are not included in the design process and are designed by people who are much younger and are at a different stage and time in their lives (Joyce et al., 2007). Even when the design's focus is the older adult, it can lack pleasing aesthetics or lead older adults to feel old or frail (Light et al., 2016; Norman, 2019).

Researchers and designers across different fields, including Human Computer Interaction (HCI), have critically reflected how aging and older adults have been framed in their areas. In HCI, researchers have examined prior literature to investigate ways aging and older adults are discussed (Cozza, De Angeli, & Tonolli, 2017; Durick, Robertson, Brereton, Vetere, & Nansen, 2013; Vines, Pritchard, et al., 2015).

Technology has been seen as the solution to the issues expected from the rising aging population by supporting older adults to live independently, mitigate health costs, and reduce social isolation (Durick et al., 2013; Light et al., 2016; Vines, Pritchard, et al., 2015). These technologies are essential; for example, older adults are at a higher risk for social isolation due to living alone, having limited mobility, or moving into residential care (Vines, Pritchard, et al.,

2015). They also experience loss of relationships to illness and mortality (Lindley, Harper, & Sellen, 2008). However, these technologies center on the losses incurred by aging and have become a dominant voice in HCI (Ferri, Bardzell, & Bardzell, 2017; Vines, Pritchard, et al., 2015). This narrative ignores the vast diversity in the aging population and perpetuates aging assumptions (Durick et al., 2013; Ferri et al., 2017; Vines, Pritchard, et al., 2015).

Typically held assumptions such as, loneliness among older adults are not true for all of the aging population. A closer examination of later in life relationships reveals that social connections are more complex. Some older adults prefer a smaller social network, maintaining meaningful relationships with people closer to them (Durick et al., 2013; Lindley et al., 2008). Lindley et al. (2008) challenged assumptions about older adults and loneliness, pointing out that many older adults are happily living alone. They also noted the differences of symmetry in relationships, specifically older adults had more balanced relationships with friends and an asymmetric or more of a give and take relationship with family members (Lindley et al., 2008). Designing to increase social connectedness for older adults requires a more in-depth understanding of their relationships. While there are older adults who are at risk for social isolation, many have made purposeful choices in their relationships. Designers need to recognize that the differences within the aging population are varied and dynamic.

HCI researchers have called for broadening the design space to include ideas that consider the varying interests, range of abilities, and diverse lived experiences among older adults (Durick et al., 2013; Oudshoorn, Neven, & Stienstra, 2016; Subasi, Malmborg, Fitzpatrick, & Östlund, 2014; Vines, Pritchard, et al., 2015). Carroll et al. (2012) suggested *positive design*, an approach that focuses on people's strengths instead of problems (*deficit-driven design*), specifically the issues related to aging. Centering on strengths can reveal

older adults' opportunities to contribute to the community (Carroll et al., 2012).

Researchers have suggested involving older adults in the design process to understand their goals and needs better. At the same time, they also need to challenge and reflect upon their motivations for pursuing aging topics and challenge their presumed assumptions about the older adult population (Subasi et al., 2014; Vines, Pritchard, et al., 2015). Oudshoorn et al. (2016) observed the design process for an assistive robot for older adults. They explained that the design team acknowledged the aging population's diversity and invited older adults to provide feedback about the robot. However, they ignored the feedback that most participants said they would not use the robot because they were able and independent. The researchers attributed that response to their study set up and believed that older adults would benefit from the robot and eventually like it (Oudshoorn et al., 2016). This example illustrates the need for reflection and for confronting assumptions about aging and older adults. It also stresses the value of involving older adults in the design process.

2.2 THEORETICAL FOUNDATION

My work has been grounded in theoretical frameworks and approaches from HCI, social sciences, and health informatics. They include Human Centered Design, Balance Theory Model, Life Course Perspective, Participatory Design, and Cooperative Inquiry. Each of these frameworks emphasizes including the person you are designing for in the design process. They also highlight the importance of considering contextual and societal factors that could impact choices, perceptions, and accessibility to using technologies.

2.2.1 Human Centered Design (HCD)

The main principle of the Human Centered Design (HCD) approach is that it actively involves end-users throughout the design process, considering their perspectives and context to heighten acceptance of the technology (Giacomin, 2016; Maguire, 2001). HCD encourages multidisciplinary collaboration, including technical experts, designers, subject matter experts, and other stakeholders in the technology design (Giacomin, 2016; Maguire, 2001). HCD is an iterative process (Giacomin, 2016; Maguire, 2001) that typically includes planning the process, conducting activities that lead to understanding users and their context, identifying and defining design requirements, brainstorming design ideas, and evaluating concepts (Dubberly, 2004) (see Figure 1).

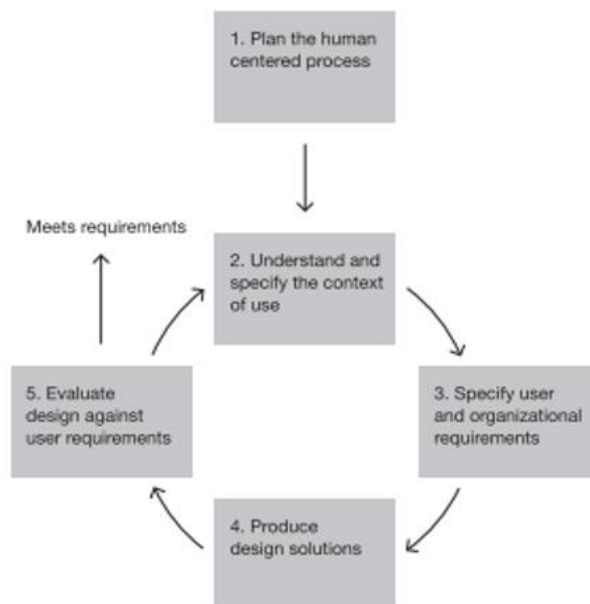


Figure 1. Human Centered Design Process (Dubberly, 2004)

Each phase can utilize various methods, such as interviews, observations, surveys, prototype testing, and usability testing. Researchers used the HCD approach with older adults to create a mobile application that supports detecting the risk of falls (Harte et al., 2017). The HCD

approach has also created technologies such as, exergames to encourage fitness training among older adults (Muñoz, Gonçalves, Rúbio Gouveia, Cameirão, & BermúdezBadia, 2019) and engage older adults in making decisions about their health care (Kumar, Maskara, & Chiang, 2014). Older adults were included in the design process to get a clear understanding of their needs and wants and to ensure good usability and a positive user experience with their technologies (Harte et al., 2017; Kumar et al., 2014; Muñoz et al., 2019).

I have used the HCD approach to translate study findings into design resources, specifically personas, scenarios, and design guidelines for health information technology designers. Using this approach led us to create resources that illustrated how older adults manage their health information, their needs, and differences in context. I also used HCD to guide co-design sessions with older adults and student designers. It provided a structure to introduce the design process to the teams and for student designers to apply their knowledge outside of the classroom.

2.2.2 Balance Theory and Work System Model

A large portion of my work has been with the SOARING project, which aimed to understand older adults' personal health information management (PHIM) practices. The Balance Theory and Work System Model guided the exploration and understanding of those practices. This model brings together three areas; organizational design, job stress and human factors, and ergonomics. The Work System Model describes aspects of work, including the technologies and the physical environment that a worker needs to complete a job (Carayon, 2009). Balance Theory extends the model by understanding how these aspects can have a psychosocial, cognitive, and physical impact on individuals and their work outcomes such as job satisfaction, stress, safety, health, and well-being (Carayon, 2009). The SOARING project

<https://www.nwcphp.org/research/projects/health-information-management-older-adults>)

described this model as the Balance Model. It was a useful framework because it considered contextual factors, for example, potential environmental and social changes that can happen as people age to understand how older adults manage to maintain their personal health information.

The Balance model is shown clearly through our translation of study findings into personas. In this dissertation, I describe how we modified the persona process to create what we termed as connected personas, sets of personas where the older adult persona is "connected" to a family and/or friend persona and a provider. We called them connected because understanding these relationships are necessary to have a full picture of an older adult's PHIM.

2.2.3 *Life Course Perspective*

The Balance Theory Model and HCD approach focus on individual and situational factors that contribute to perceptions and decision-making. However, these approaches tend to center on current experiences. HCI researchers have advocated for a broader perspective to understand the needs and the dynamics of aging better. Some have suggested a Life Course perspective (Brown & De Schutter, 2016; Foong, 2016; Franz, Findlater, & Wobbrock, 2018; Mennicken et al., 2015; Vines, Pritchard, et al., 2015). The Life Course perspective focuses on the changes that occur across a person's lifetime, including life transitions, historical events, relationships, choices made, and timing (Elder, Johnson, & Crosnoe, 2003). This perspective encourages researchers and designers to reflect on their motivation in their work with older adults and to have a heightened awareness of the differences and nuances between older adults (Foong, 2016; Franz et al., 2018; Vines, Pritchard, et al., 2015).

The Life Course approach was introduced in the 1950s, but it was not until the 1960s, in light of the influence of historical events, for example, World War II, that it was used to

understand the role that contextual factors played in the ways that people lived their lives (Elder et al., 2003). There are five principles that Elder et al. (2003) provide as a framework to guide researchers. They are "(1) *The Principle of Life-Span Development: Human development and aging are lifelong processes*, (2) *The Principle of Agency: Individuals construct their own life course through the choices and actions they take within the opportunities and constraints of history and social circumstance*, (3) *The Principle of Time and Place: The life course of individuals is embedded and shaped by the historical times and place they experience over their lifetime*, (4) *The Principle of Timing: The development antecedents and consequences of life transitions, events, and behavioral patterns vary according to their timing in a person's life*, (5) *The Principle of Linked Lives: Lives are lived interdependently, and socio-historical influences are expressed through this network of shared relationships.*" (Elder et al., 2003) (p.12-13)

The life course approach has been advocated in aging studies to better understand health determinants and healthy aging (Hardy, Lawlor, & Kuh, 2015; Kuh, 2007). There has also been a call to expand Rowe and Kahn's successful aging model to include a life course perspective because it would emphasize the dynamics of aging and recognize the micro and macro societal and environmental issues that impact life experiences and decisions (Stowe & Cooney, 2015). In HCI, the life course perspective helped show that game preferences were established at a young age and influenced gameplay choices later in life, suggesting that these insights about the past have design implications to making games more meaningful or easier to use (Brown & De Schutter, 2016). Researchers have used the life course perspective as a way to identify new mobile technology opportunities for older adults (Foong, 2016) and structure workshops to guide designers and researchers in a discussion about smart home technologies to evolve across a lifetime (Mennicken et al., 2015). The life course perspective influenced the co-design activities

for intergenerational teams in my study. The goal was for younger adults and older adults to gain a fuller understanding of each other's perception of health and well-being through exploring their histories. The co-design activities led to a better understanding of each other, surfaced potential user needs, and facilitated team bonding.

2.2.4 *Participatory Design and Co-designing with Older Adults*

Central to HCD is the principle that people you are designing for should influence the design. It is also essential to a practice of participatory design (PD) to include users throughout the entire process. PD was introduced in the 1970s and 1980s through a political movement in Scandinavia to democratize the workplace. The movement empowered workers' voices to design the tools and technologies they would be using (Spinuzzi, 2005). PD gained popularity in the United States when computer-based systems became more prevalent in the workplace. The realization that involving workers in the design process led to higher quality systems (Schuler & Namioka, 1993). In 1990, the first participatory design conference in Seattle, Washington, created an awareness of the approach and shared how to use participatory design for "off-the-shelf" applications (Schuler & Namioka, 1993).

Researchers can use various methods to carry out PD, which can vary users' participation level (Kuhn & Muller, 1993; Merkel & Kucharski, 2019). For example, early in the design process, researchers seeking to understand their users' needs might choose various methods such as interviews, surveys, or co-design sessions. All PD methods involve users but at different levels of engagement. Several researchers have described levels of participation in the design process. There is low-level participation, where participants are using technologies and are observed by researchers. There is a medium level where participants evaluate design ideas or testing artifacts such as, a prototype. A high level of participation is when users are an equal

partner in the design process and influence design decisions (Damodaran, 1996; Druin, 1999; Merkel & Kucharski, 2019).

HCI researchers have advocated for methods that give older adults agency in the design process (Y. Rogers & Marsden, 2013; Y. Rogers et al., 2014; E. B. N. Sanders et al., 2010). One approach that has gained popularity is co-designing with older adults. Co-design is an approach that involves a high level of participation; designers and users collaborate in the design and development process of technologies (E. B.-N. Sanders & Stappers, 2008). Prior work has shown that participatory design approaches have led to a better understanding of older adults' needs (Davidson & Jensen, 2013b; Massimi et al., 2007; Uzor et al., 2012). It has also challenged assumptions about the aging population, such as, the perception that older adults lack technology experience to contribute creative or novel ideas (Davidson & Jensen, 2013a; Harrington et al., 2018; Y. Rogers et al., 2014).

Researchers encouraged others to utilize these co-design and participatory approaches with older adults by offering lessons learned and guidelines to working with older adults (Davidson & Jensen, 2013a; Harrington et al., 2018; Iacono & Marti, 2014; Lindsay, Jackson, Ladha, et al., 2012; Massimi et al., 2007). Some researchers have created models to ensure successful engagement with older adults in participatory design (Kopeć et al., 2018; Lindsay, Jackson, Ladha, et al., 2012). Involving older adults in the design process highlights the value of their contributions and promotes their continued participation. This advocacy is essential mainly because older adults have often been left out of the design process.

2.2.5 *Cooperative Inquiry*

In Cooperative Inquiry, Druin (2002) illustrated the four roles a child could have in designing technologies with concentric circles. The roles are user, tester, informant, and design

partner (Druin, 2002). A child in the role of the *user* is observed by adults interacting with technology. As a *tester*, the child tries out technology and provides feedback to the adults about their technology experience. As an *informant*, the child participates in multiple stages of the design process and influences the design differently, such as working with adults to provide feedback, sketch ideas, or create low-tech prototypes. Finally, as a *design partner*, the child is involved in the entire design process and is considered an equal stakeholder in developing technologies (Druin, 2002).

Yip et al. (2017) expanded upon Druin's (2002) description of a child's role in the design process by adding corresponding roles for designers, including observer, test facilitator, interpreter, and design partner. The roles are sets of concentric circles, one for the child's role and one for the adult's part (Figure 2). The circles also represented the child's level of interaction as user and adult as an observer as the smallest and most distant circles, with design partners as the largest and closest circles (Yip et al., 2017).

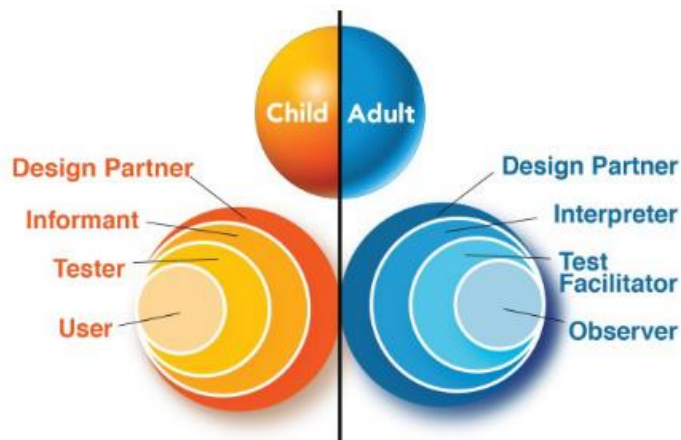


Figure 2. Roles that adults and children play in the design process (Yip et al., 2017)

Both Druin (1999;2002) and Yip et al. (2017) have implemented Cooperative Inquiry sessions over more extended periods, from months to years, to develop design partnerships

between children and adults. However, time and resources are often typical constraints for projects. Large et al.(2006) faced similar obstacles in co-designing with children and developed a bonded design methodology. It established that intergenerational collaborations have meaningful impacts on technologies' design, and participants created a bond with each other (Large, Nessel, Beheshti, & Bowler, 2006).

Building toward a partnership between designers and older adults is essential to equal collaboration and the center of Cooperative Inquiry (Druin, 1999). There has been little work examining the interactions between older adults and designers that contribute to understanding design relationships. In this dissertation, my work fills this gap by investigating factors that lead to balanced or unbalanced interactions between older adults and student designers through a six-week co-design collaboration.

Chapter 3. Patient Portal Use and Experience Among Older Adults: Systematic Review

In this chapter, I address **RQ1, What are older adults' use and experiences with health technologies?** This is a systematic literature review aimed to assess the existing research landscape related to patient portals and electronic personal health records (ePHRs). There are several definitions of ePHRs and patient portals within the literature, and patient portals are sometimes described as a type of ePHR. In my dissertation, patient portals are defined as systems for health information management that are linked, or tethered, to a patient's electronic health record (EHR) (Taha, Sharit, & Czaja, 2014; Turner et al., 2015). For example, the US Department of Veterans Affairs offers patients access to My Health e Vet (US Department of Veterans Affairs, n.d.), and several hospitals in the United States use Epic's MyChart portal (Epic, 2016).

Both portals give patients access to their health information and include features such as the ability to schedule appointments, view test results, request prescription renewals, and send messages to health care providers. In addition to tethered patient portals, there are ePHRs that are not connected to EHRs, such as Microsoft HealthVault and the Health app on Apple devices. In these systems, the individual is responsible for entering their own health information. ePHR systems often include features such as health tracking or medication lists. Other features of these systems include the ability to share health information with others and track fitness and personal health goals. The major distinction between ePHRs and patient portals is that patient portals are tethered (to EHRs) and ePHRs are not. Both offer a centralized location for storing and organizing electronic health information.

Interest in electronic health records (EHRs), patient portals, and electronic personal

health records has increased in recent years (Ancker, Hafeez, & Kaushal, 2016; Ford, Hesse, & Huerta, 2016; Zhang, Fleischmann, Gao, & Xie, 2015). Ancker et al (2016) conducted a survey of New York State residents to understand the rate of patient portal and personal health records (PHRs) adoption over time. They found that use of PHRs by New Yorkers increased from 11% in 2012 to 27.1% in 2015. Ford et al (2016) forecasted the adoption of PHRs based on the 2008, 2011, and 2013 Health Information National Trends Surveys. They anticipated that PHR adoption will grow beyond 75% by 2020. These studies show that the use of patient portals and PHRs will likely continue to grow.

3.1 SYSTEMATIC REVIEW OBJECTIVES

Although much has been written about the use of patient portals and ePHRs in general, there is less material focused on the use of patient portals by older adults. Technologies such as patient portals and ePHRs have the potential to help older adults by strengthening their ability to manage, understand, and control their health information. However, it is a leap to assume that patient portals and ePHRs, as they are currently designed and used, will effectively address the health information needs of the older adult population. It is important to first understand the facilitators of and barriers to older adult use and adoption of health-related technology. It is also important to understand their experiences with ePHRs and patient portals and how these experiences have influenced or changed their personal health information management. Understanding the facilitators and barriers will provide insights to why older adults decide to use or adopt patient portals and ePHRs. Similarly, learning about older adults' experiences with these systems and their impact on health information management can provide guidance on how to improve their design and ensure their effective use and adoption. Finally, it is important to understand what design recommendations have been proposed, and what is important to older

adults. Considering these objectives, the goal of this systematic review was to investigate the existing research landscape with a focus on answering the following questions:

1. In the literature, what barriers and facilitators to older adults' use and adoption of patient portals and ePHRs have been described? What is the evidence that these barriers and facilitators exist?
2. How do older adults describe their experience using patient portals and ePHRs?
3. What design recommendations have been proposed to help overcome barriers and enhance facilitators of older adults' experience, use, and adoption of patient portals or ePHRs?

3.2 METHODS

3.2.1 *Revised PRISMA Protocol*

I led the team in adapting the preferred reporting items for systematic reviews and meta-analyses (PRISMA) 2009 checklist to guide our systematic review of the use of patient portals and ePHRs among older adults (Moher et al., 2009). As PRISMA is positioned toward standardized study designs, such as clinical trials that aim to support universal interpretation of results, we¹ modified the PRISMA protocol to accommodate the study methodologies in this review more common to information sciences, specifically qualitative and mixed-method studies. Thus, we reviewed the methods and metrics used in the studies rather than the standardized outcome variables one would typically see in traditional systematic reviews of controlled trials. Our protocol included a systematic search, a study selection, and a qualitative review of the findings.

¹ In Chapter 3 (this chapter), “we” refers to co-authors on this work, specifically, Alyssa L. Bosold, Yong K Choi and Anne M. Turner.

3.2.2 *Literature Search*

I conducted searches in six databases that spanned the medical, nursing, and engineering literature. These databases were PubMed, EMBASE, CINAHL Complete, Compendex (includes ACM digital library and IEEE Xplore), and Inspec. I consulted with librarians in the University of Washington Health Sciences and Engineering libraries on the selection of databases and the mechanics of using them (e.g. controlled vocabulary, using filters, and syntax). I also received assistance narrowing down keywords to use.

I searched all databases with the keywords “older adult,” “seniors,” or “elders,” and “patient portal,” “electronic medical record,” or “personal health record” (see **Error! Reference source not found.**). I did a general search in Google Scholar to find potential papers that did not result from our searches in the other databases. In PubMed and EMBASE, I used additional keywords such as “usage,” “utilization,” “adoption,” and “patient satisfaction”. I did not use the additional keywords in CINAHL Complete, Compendex, and Inspec because it narrowed rather than broadened our search results. I limited our search to papers published within a 10-year period (January 2006-November 2016). Although we recognize that a 10-year period is a broad timeline given the fast pace of advancement in technology, we selected this time range to get an expanded view about needs and experiences of older adults related to health information technology, and included commentary on changes in technology and findings over time.

3.2.3 *Inclusion and Exclusion Criteria*

Papers were selected based on the inclusion criteria in (**Error! Reference source not found.**) and exclusion criteria provided here. Our team excluded studies that were not focused on older adults’ use, experience, or adoption of patient portals, ePHRs, or features of those systems. Although studies do not consistently report clear definitions of use and adoption, we chose to

differentiate between these two terms for this review. Specifically, we refer to use as short-term activity within a patient portal for a period of less than 1 year, whereas we define adoption as a commitment to continued use of systems beyond 1 year. We defined experience as a person's perceptions of their interactions with patient portals or ePHRs. We also included formative studies that were focused on information gathering for design, including user testing of new systems and assessments to inform development of systems or test the acceptability of particular systems. Formative studies were not focused on adoption or use or factors influencing the initial use of a particular developed system.

The types of papers that were excluded were studies focused on patient online communities or the provider experience using patient portals or ePHRs. Papers that solely recorded log-in data and demographics were also not considered to be focused on use and were excluded from this review. In addition, we excluded nonempirical studies such as commentaries, letters to the editors, notes, books, reviews, and conceptual papers.

I (DST) conducted an initial screening of the paper titles and abstracts, removing records that were irrelevant such as those focused on provider experience, implementation of EHRs, and using EHRs to recruit participants. Then 3 researchers applied the inclusion and exclusion criteria to the abstract of each paper using the Covidence (Melbourne, Victoria) software (Covidence, 2017). Each paper was reviewed by at least 2 of the 3 researchers (DST, AB, and YC), and any disagreements were discussed. In cases where a resolution could not be reached, a third researcher made the final decision. After excluding an initial set of papers, the same 3 researchers applied the inclusion and exclusion criteria to the full text of the papers using the same process described above to resolve disagreements.

Table 2. Searches Used in Each Database

Database	Description	Citations
PubMed	older adult OR seniors OR elderly OR aged AND patient portal OR electronic health record OR personal medical record OR personal health record AND usage OR using OR utilization OR utilize OR adopt OR adoption OR preferences OR patient access to records OR patient satisfaction AND english NOT letter OR editorial AND last 10 years	885
EMBASE	older adult OR older adults OR seniors OR elderly OR aged OR aged AND patient portal OR electronic medical record OR personal medical record OR personal health record AND usage OR utilization OR utilize OR adopt OR adoption OR preference OR patient access to records OR patient attitude AND english AND [embase]/lim NOT [medline]/lim AND (2006-2016)/py	409
CINAHL	patient portal OR electronic health record OR personal health record older adult OR senior OR elder Limiters: published date: 2006-01-01-2016-12-31; English language	129
Compendex and Inspec	older adult OR senior OR elder AND electronic health record OR personal health record AND 2006-2016 AND english	484

Table 3. Inclusion Criteria

Inclusion Criteria
<ul style="list-style-type: none"> • Include participation of adults who were 60 years or older. These older adults could be the sole focus of the study or be a group of adults who were part of a larger study. Typically, older adults are characterized as 65 years and older; however, we decided to use a wider age range to include a broader set of papers. • Focus on patient portals or ePHRs • Discuss use, adoption, or experience with patient portals and ePHRs or features of those systems (eg, studies that evaluated patient experiences using secure messaging with providers, or having electronic access to medical records) • Examine features of patient portals and ePHRs to inform design • Published from 2006 to 2016 • Written in English

After applying the inclusion and exclusion criteria, we conducted a thematic analysis of the papers. Two researchers (DST and AB) created codes using an inductive process. They

summarized each of the papers and collectively came up with a list of key points from the summaries and from the papers themselves.

These key points were then grouped into codes. The groups of codes were then further refined into themes, and the final list of themes was informed by the project's research questions and decided collectively in a meeting with the team researchers.

3.2.4 *Quality Review*

We reviewed the papers using the top two guidelines from the mini Statement on the Reporting of Evaluation studies in Health Informatics (STARE-HI), ranked as essential by professionals in health informatics for reporting studies (De Keizer et al., 2010). They were “Interpret the data and an answer to the study question” and “Description of the outcome measure or evaluation criteria.” We added two additional guidelines because they provided key information related to our study questions: “Provides a description of system and its functionalities” (Talmon et al., 2009) and “Provides clear description of how results impact design recommendations.” We gave the papers a score for each of the four guidelines outlined above. The score ranged between 0 (does not meet the criteria) and 2 (fully meets the criteria), for a total score of 8.

3.3 RESULTS

The search returned 1907 papers in total after removing duplicates. An initial screening of paper titles and abstracts resulted in 199 papers. Abstract review, described above, resulted in 46 papers for full-text review. The full-text review resulted in a final set of 17 papers (see **Error! Reference source not found.**).

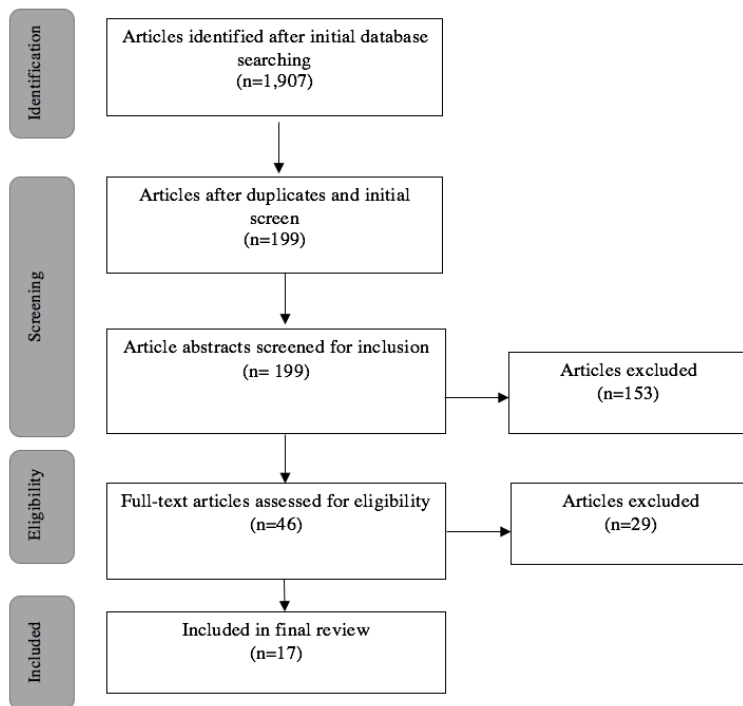


Figure 3. Systematic Review Process

3.3.1 Description of Papers

The final set of 17 papers focused on 15 separate projects. Papers spanned the 10-year period from 2006 to 2016. All papers published before 2014 examined ePHRs, whereas those papers published from 2014 to 2016, with the exception of one (Zettel-Watson & Tsukerman, 2016), looked at patient portals. Of the 17 papers, 7 (41%) were conference proceedings. All conference proceedings were peer-reviewed. Authors used a range of research methods in the final set of papers: 10 of 17 (59%) were interviews, observations, focus groups, design sessions, and user studies; 9 of 17 (53%) were surveys or questionnaires; and 4 of 17 (24%) were mixed-methods studies. The sample size of the papers ranged from 16 participants in a user study to 231,082 participants in a survey. Six papers focused on patient portals (Barron, Bedra, Wood, & Finkelstein, 2014; Gordon & Hornbrook, 2016; Kerai, Wood, & Martin, 2014; Latulipe et al.,

2015; Taha et al., 2014; Turner et al., 2015), 8 papers focused on ePHRs (Hourcade et al., 2011; E. H. Kim et al., 2009; R. Lam et al., 2013; Lober et al., 2006; Logue & Effken, 2012; Price, Pak, Müller, & Stronge, 2013; Sack, Pak, & Ziefle, 2011; Siek et al., 2011), and 2 papers looked at other similar systems, specifically a personal health application and the Swedish medication registry (Haverhals et al., 2011; Montelius, Åstrand, Hovstadius, & Petersson, 2008). Half (8/17) of the papers evaluated patient portals or ePHR systems overall (Barron et al., 2014; Gordon & Hornbrook, 2016; Kerai et al., 2014; E. H. Kim et al., 2009; Lober et al., 2006; Sack et al., 2011; Siek et al., 2011; Taha et al., 2014); others focused on specific features such as messaging systems (R. Lam et al., 2013) or medication management tools (Haverhals et al., 2011; Hourcade et al., 2011; Montelius et al., 2008; Siek et al., 2011).

Seven papers focused on short-term use or factors influencing the initial use of a system. Nine papers were primarily formative, collecting information related to system design, development, or usability. Formative papers collected information to inform design of systems generally (Haverhals et al., 2011; Kerai et al., 2014; Latulipe et al., 2015; Price et al., 2013; Taha et al., 2014; Turner et al., 2015) or focused on developing specific systems (Barron et al., 2014; Hourcade et al., 2011; Siek et al., 2011). Only 3 papers compared short-term use and long-term adoption (E. H. Kim et al., 2009; R. Lam et al., 2013; Zettel-Watson & Tsukerman, 2016). In 2 cross-sectional papers, Lam et al (2013) and Zettel-Watson and Tsukerman (2016), participants most commonly reported using systems anywhere from 1 month to 1 year and reported an average period of use of over 3 years, respectively. In the Kim et al (2009) paper that looked at patterns of use longitudinally, 51% of the participants only used the system once during the first year of the study period.

Qualitative and cross-sectional papers provided insight into both specific systems and

general experience. In 3 of the 17 papers (18%), participants used a system and were given a survey or questionnaire to gain feedback on their experience (Gordon & Hornbrook, 2016; R. Lam et al., 2013; Montelius et al., 2008). There were 2 papers (12%) that evaluated a system in a lab setting (Barron et al., 2014; Taha et al., 2014) and 3 papers, focused on two projects, (18%) (E. H. Kim et al., 2009; Lober et al., 2006) where participants used a system in a community setting such as a retirement or housing facility (Hourcade et al., 2011; E. H. Kim et al., 2009; Lober et al., 2006). Four papers (24%,) did not focus on a specific system but instead asked participants to reflect on their experiences with patient portals or ePHRs in general (Latulipe et al., 2015; Logue & Effken, 2012; Turner et al., 2015; Zettel-Watson & Tsukerman, 2016). Two papers (12%, 2/17) focused on developing a personal health application with participants (Haverhals et al., 2011; Siek et al., 2011). Another approach that 3 papers (18%, 3/17) took was to gather information needs from participants through qualitative methods such as interviews, design sessions, and a diary method to inform design of a system (Hourcade et al., 2011; Latulipe et al., 2015; Price et al., 2013) (see Multimedia Appendix 2).

3.3.2 *Participant Characteristics*

All papers had participants who were 65 years or older (Barron et al., 2014; Gordon & Hornbrook, 2016; Haverhals et al., 2011; Hourcade et al., 2011; Kerai et al., 2014; E. H. Kim et al., 2009; R. Lam et al., 2013; Latulipe et al., 2015; Lober et al., 2006; Logue & Effken, 2012; Montelius et al., 2008; Price et al., 2013; Sack et al., 2011; Siek et al., 2011; Taha et al., 2014; Turner et al., 2015; Zettel-Watson & Tsukerman, 2016). Two papers (Gordon & Hornbrook, 2016; Montelius et al., 2008) analyzed differences between age categories within the older adult group. In all other papers, the older adults were reported as one group. Of the 13 studies that reported gender, 11 had more female than male participants (Gordon & Hornbrook, 2016;

Haverhals et al., 2011; Kerai et al., 2014; E. H. Kim et al., 2009; Latulipe et al., 2015; Lober et al., 2006; Logue & Effken, 2012; Montelius et al., 2008; Taha et al., 2014; Turner et al., 2015; Zettel-Watson & Tsukerman, 2016).

3.3.3 *Quality Review*

All of the papers met the criteria “Interpret the data and an answer to the study question,” and almost all (14 of 17) met the criteria “Description of the outcome measure or evaluation criteria.” The last two criteria were more varied. There were 7 papers that did not provide enough detail about a system and its functionalities (Barron et al., 2014; Gordon & Hornbrook, 2016; Haverhals et al., 2011; Hourcade et al., 2011; Latulipe et al., 2015; Sack et al., 2011; Zettel-Watson & Tsukerman, 2016). For example, Sack et al (2011) evaluated PHR technologies using Web and mobile-based Google Health. In discussing the technologies, they did not provide details about the features or functions of the system beyond it being Web or mobile-based. Papers were given full points if they provided a definition including functionality for a patient portal or an ePHR. Descriptions of the system provide a context for results and recommendations. It also provides a status of the technology at that time.

The other criterion that papers were varied on was “Provide clear description of how results impact design recommendations.” Although a majority of papers did not aim to provide design recommendations, one of our research questions was to learn about design recommendations that have been proposed to address the barriers and facilitators to use, adoption, and experience. We did find that 15 of 17 papers connected their findings to design considerations or suggestions for improving use of systems (Barron et al., 2014; Gordon & Hornbrook, 2016; Haverhals et al., 2011; Hourcade et al., 2011; Kerai et al., 2014; R. Lam et al., 2013; Latulipe et al., 2015; Logue & Effken, 2012; Montelius et al., 2008; Price et al., 2013;

Sack et al., 2011; Siek et al., 2011; Taha et al., 2014; Turner et al., 2015; Zettel-Watson & Tsukerman, 2016), for example, training to increase adoption (Logue & Effken, 2012). Papers were given a partial score if their recommendations were brief and vague. Papers received full points if authors offered clear considerations for design and gave detailed recommendations.

3.3.4 *Barriers*

We found commonalities among all papers concerning barriers and facilitators to the use and adoption of patient portals or ePHRs by older adults. We identified two main barriers across studies: (1) privacy and security and (2) access and ability to use technology and the Internet.

3.3.4.1 Privacy and Security

In 7 papers, older adults expressed a concern about the privacy and security of their information when using patient portals, ePHRs, or Web-based health management tools (Hourcade et al., 2011; Kerai et al., 2014; Latulipe et al., 2015; Lober et al., 2006; Price et al., 2013; Turner et al., 2015; Zettel-Watson & Tsukerman, 2016). Privacy and security concerns were linked to the storage and use of data collected in patient portals. Hourcade et al (2011) reported that participants were worried about pharmaceutical or drug companies accessing and misusing their data. Despite reassurance that the research was confidential and for academic purposes, participants expressed worry that researchers might not fully disclose partnerships with government institutions or drug companies. In the Kerai et al (2014) paper, 63% of participants were concerned about security. Participants in the Latulipe et al (2015) paper were concerned that the government or insurance companies would access their records without their permission. In the Lober et al (2006) paper, participants were living in a government housing authority and had to be able to live independently to stay there. They were protective of their health information because they did not want to be evicted if their physical health limited their ability to

remain independent.

3.3.4.2 Access and Abilities

Lack of access to technology and the Internet was mentioned as a barrier in 5 papers. However, the results from these papers are based on small sample sizes, and two of them were focused on lower income communities. In the papers we reviewed, disparities in age, race, and ability to pay for the Internet were mentioned. Turner et al (2015) reported that some of their participants had difficulty accessing the Internet because of its cost. Logue and Effken (2012) identified that older and younger seniors had similar access to computers but differed in Internet access. Seniors over the median age of 78 years had less access to and familiarity with the Internet than seniors aged under 78 years (Logue & Effken, 2012). Of the 38 participants in the Lober et al (2006) study, 27 (71%) did not own computers. Latulipe et al (2015) reported that older adults were aware of Internet access in their communities, and over half had a digital device such as a computer, laptop, or tablet. However, some participants did not have access to the Internet at home, suggesting that the devices were not being used (Latulipe et al., 2015). Two papers noted gendered differences in Internet access, but results were mixed (Kerai et al., 2014; Logue & Effken, 2012).

Seven papers defined computer and Internet skills as a barrier, and papers focused on both actual and perceived abilities. Lober et al (2006) reported that major barriers to use of their portal system were computer literacy and computer anxiety. They described computer literacy as instances where participants were unable to do tasks on their own, such as turning on the computer or using a mouse or keyboard. Computer anxiety was a refusal to complete tasks on the computer, despite having the cognitive or physical abilities to accomplish the tasks. Turner et al (2015) also identified that confidence in the ability to use computers and computer anxiety

impacted the use of patient portals. Turner et al (2015) found that of the 59 participants who were nonusers of patient portals, 19% (11/59) had never learned how to use a computer. Disparities in age and race were also mentioned. Logue and Effken (2012) found that older seniors were less confident than younger seniors in their ability to use an Internet-based PHR. Older seniors (older than 78 years) were also less likely to know how to find health resources on the Internet and less interested in using PHRs (Siek et al., 2011). Gordon and Hornbrook (2016) reported that 10.09% (260/2602) of seniors surveyed received help from someone to go on the Web or had someone go on the Web for them. They also found Chinese, non-Hispanic whites, and younger seniors (aged 65-69 years) were more likely to use the Internet for email and health-related tasks than black, Latino, and Filipino seniors and those who were aged 75 years and older (Gordon & Hornbrook, 2016).

Some studies also mentioned disparities based on physical and cognitive ability (Gordon & Hornbrook, 2016; Lober et al., 2006). Lober et al (2006) found that 13 of 38 participants had cognitive issues that impacted their use of a computer, presenting problems specifically when remembering the URL of the system, usernames, and passwords. Older adults with vision, hearing, and physical limitations leading to decreased mobility had difficulty using the system on their own (Lober et al., 2006). Gordon and Hornbrook (2016) also reported that physical issues inhibit use of a computer or the Internet. They noted that this posed more of a problem to seniors in the oldest age group (75-79 years).

3.3.5 *Facilitators*

We identified two major factors that facilitated older adults' use and adoption of patient portals and ePHRs: (1) technical assistance and (2) the advice of family and providers.

3.3.5.1 Technical Assistance

Three papers mentioned the role of technical assistance in initially facilitating portal use (Gordon & Hornbrook, 2016; Hourcade et al., 2011; E. H. Kim et al., 2009). Hourcade et al (2011) described a video to help present the ePHR that they were testing among older adults. They also explained that they saw a benefit in working with older adults over several weeks, which allowed them to introduce older adults to the ePHR concept, assist with system navigation, and ultimately gather more meaningful feedback from a group that was informed about the ePHR tool (Hourcade et al., 2011). In their paper, Gordon and Hornbrook (2016) found that participants wanted technical assistance with using a portal and preferred help from a person rather than a Web video (Gordon & Hornbrook, 2016). Kim et al (2009) had graduate nursing students available to assist participants with using a patient health information management system (PHIMS) portal. They noted that the most frequent use of PHIMS coincided with the days when the nursing students were onsite (E. H. Kim et al., 2009).

3.3.5.2 Family and Provider Advice

Other papers noted family and provider advice as facilitators to portal use. Lam et al (2013) found that participants were significantly more likely to be introduced to a portal messaging system by their providers than were nonusers. Similarly, Zettel-Watson and Tsukerman (2016) reported that patients cited their doctor's recommendation as being important when initially using the portal but not for adoption or continued use. Logue and Effken (2012) found that Hispanic women, in particular, were likely to be influenced to use a PHR based on a family member's recommendation. Forty-six percent of Hispanic women stated that this was the case. They also reported that older adults who felt they were a part of a team with their health care provider were more motivated to try a PHR, to believe that an Internet-based PHR would

give them their desired health outcomes, and to select a particular practice because PHRs were a part of care (Logue & Effken, 2012).

3.3.5.3 User Experience

The papers that were reviewed spanned a 10-year period. This is considerable, as technology tends to rapidly change over time. It is likely that experiences with newer technologies are different from older technologies. In the papers that we reviewed, we found 10 papers from 2006 to 2013 that focused on ePHRs, whereas 6 papers from 2014 to 2016 focused on patient portals.

There were several papers that evaluated participants' use of patient portals, ePHRs, or Web-based health management tools (Barron et al., 2014; Gordon & Hornbrook, 2016; Kerai et al., 2014; E. H. Kim et al., 2009; Latulipe et al., 2015; Lober et al., 2006; Logue & Effken, 2012; Montelius et al., 2008; Sack et al., 2011; Taha et al., 2014; Turner et al., 2015; Zettel-Watson & Tsukerman, 2016). Participants reported an overall satisfaction with the system they used (E. H. Kim et al., 2009; R. Lam et al., 2013). In addition to participants' satisfaction with the system, they reported that the system was useful and it improved the quality of the health care they received (E. H. Kim et al., 2009; Lober et al., 2006). Sack et al (2011) conducted focus groups to evaluate mobile PHRs versus Web-based PHRs. They used a cost (negative comments) versus benefit (positive comments) analysis as a strategy to interpret their findings. They found that overall there were more benefit comments than cost comments for Web-based PHRs (Sack et al., 2011).

3.3.5.4 Features

In several papers, participants reported features of systems that they frequently used and liked. They appreciated the health information management tasks such as checking lab results,

learning about health conditions (Zettel-Watson & Tsukerman, 2016), preparing for appointments through medication list management (Montelius et al., 2008; Siek et al., 2011), and record management (Zettel-Watson & Tsukerman, 2016). Participants also appreciated the ability to communicate directly with providers through secure messaging (Gordon & Hornbrook, 2016; Turner et al., 2015).

Six papers identified features that participants wanted from a patient portal or an ePHR system. Two mentioned that participants wanted to share health information, such as medication lists, with others or share different views of their health information depending on the person or situation (Haverhals et al., 2011; Price et al., 2013). Participants in the Sack et al (2011) paper suggested that medical personnel should have a security password for record access in emergency situations.

Several papers indicated participants' desire for systems with further health management capacity and those that offered more contextual health information. Two papers reported that participants wanted the system to provide reminders for upcoming appointments, remind them when to refill medications, and help them manage their bills and health status over time (Price et al., 2013; Zettel-Watson & Tsukerman, 2016). In 3 papers, participants wanted the system to provide lifestyle advice and tips or a dictionary of medical terms (Hourcade et al., 2011; Sack et al., 2011; Zettel-Watson & Tsukerman, 2016). Participants in 2 papers wanted the system to provide a diagnosis and prognosis (Price et al., 2013; Sack et al., 2011).

Other participants requested features specific to medication such as warnings about medication interactions and the ability to make changes to their medication lists (Haverhals et al., 2011; Sack et al., 2011). Hourcade et al (2011) suggested that medication information and warnings should be layered from basic to advanced information.

Other desired features included the ability to print information, access to complete medical records, having good technical support, and the ability to take voice commands (Latulipe et al., 2015; Sack et al., 2011).

3.3.6 *Changes in Health Information Management and Provider Communication*

Five papers described the impact of patient portals on health information management, focusing on increased access to records and improved storage of health information (Kerai et al., 2014; E. H. Kim et al., 2009; Latulipe et al., 2015; Turner et al., 2015; Zettel-Watson & Tsukerman, 2016). Zettel-Wattson and Tsukerman (2016) explained that 90.6% of portal users (56/62) thought a portal helped them better manage health, and 89.7% (55/62) reported that health management tools allowed them to keep all of their records in one place. Additionally, 80.4% (50/62) explained that health information tools gave them a sense of control over their health.

In one paper, findings regarding older adult views on record access and management were mixed: 86% of participants (69/80) wanted access to their records in one place but did not necessarily want to be responsible for managing records, and 84% of participants (67/80) preferred that their records continue to be managed by primary care providers (Kerai et al., 2014).

Papers also described changes in patient-provider communication. In one paper, participants expressed that having access to patient portals made them feel more prepared for emergencies and made visits with providers more efficient (E. H. Kim et al., 2009). However, physicians thought that giving patients access to records may increase their worry (Kerai et al., 2014), and some patients were concerned about a loss of face time with providers (Latulipe et al., 2015).

3.3.7 *Areas to Explore*

Health literacy, defined as the ability to collect, interpret, and process basic health information (Centers for Disease Control Prevention CDC, 2016), was mentioned in 4 papers as a barrier. However, these papers measured and defined health literacy differently (Lober et al., 2006; Logue & Effken, 2012; Taha et al., 2014), making it difficult to categorize health literacy as a barrier in this review but highlighting it as an area for future research. Of those papers that mentioned health literacy, one defined and measured health literacy by looking at participant questions related to the content of patient portals, particular diseases, and interpreting medical terminology (Lober et al., 2006). This paper found that health literacy was a barrier for 29% of participants (11/38) who had questions about these issues (Lober et al., 2006). Logue and Effken (2012) defined and measured health literacy using the eHealth Literacy Scale (eHEALS) and criteria that looks specifically at the ability to identify, evaluate, and synthesize health information delivered electronically. They found that all three eHealth literacy indicators from the eHEALS were positively correlated with confidence in communicating with others on the Internet, ability to express oneself in writing, and using an Internet-based PHR. Taha et al (2014) measured health numeracy or the ability to interpret health information reported as numbers. They found that 52.9% of their participants (27/51) correctly answered only 5 or fewer objective numeracy questions on an 11-question measure. However, on a Subjective Numeracy Scale, which measures perceived health numeracy, several participants gave themselves a high rating, indicating that many had overestimated their health numeracy skills (Taha et al., 2014).

3.3.8 *Design Suggestions*

Several papers provided guidance about features and functions of patient portals and ePHRs (Price et al., 2013; Siek et al., 2011; Taha et al., 2014). At a basic level, these systems

should provide health information, including medical history, test results, and medication information (Price et al., 2013). Information should be provided in a way that does not overwhelm the user (Price et al., 2013; Siek et al., 2011). Tools and aids were suggested to help users gain an understanding of health information and complete health management tasks (Taha et al., 2014). Price et al (2013) suggested that an ePHR should provide memory support to patients. For example, it should store a patient's health history and help them remember daily tasks (Price et al., 2013). Khan et al (2010) mentioned a need for clear communication between experts, designers, and patients regarding their understanding of personal health information. This would guard against the bias of one group impacting system design (Siek et al., 2011).

3.4 DISCUSSION

3.4.1 *Overview*

With this review that I led, we set out to identify and assess the evidence of barriers and facilitators to the use and adoption of patient portals and ePHRs by older adults. We also wanted to gain an understanding of older adults' experiences with these systems and learn about the design recommendations resulting from study findings.

Through our systematic review, we identified two barriers (privacy and security, and access and abilities) and two facilitators (technical assistance, and family and provider advice) to the use and adoption of patient portals and ePHRs. We also gained an understanding of older adults' experiences with these systems, specifically perceived benefits, satisfaction, and desired features. Some of the papers did not present specific design recommendations, making it difficult to translate findings to improve the design of patient portals and ePHRs. We also found that some papers lacked a detailed description of patient portals or ePHRs; this is an issue because

systems are not static and likely changed over time. Having a detailed description of the system would provide context to study results.

Overall, even though we were able to identify barriers and facilitators, the evidence lacked strength. There were several reasons for this, including the fact that many of the studies had a small sample size and were a convenience sample. In addition, our search results included a diversity of studies, making it difficult to draw firm conclusions related to our research questions.

It should also be noted that, throughout our analysis, we reported themes by grouping papers on ePHRs and patient portals together. It could be argued that the type of technology used (ePHR vs patient portal) would influence results related to user experience, barriers, and facilitators. When it came to barriers and facilitators, we noticed no clear trends in terms of concerns about privacy and security but found that the barrier of access to the Internet was more often mentioned in papers about patient portals (Kerai et al., 2014; Latulipe et al., 2015; Turner et al., 2015), whereas facilitators were mostly mentioned in papers that focused on ePHRs (Hourcade et al., 2011; E. H. Kim et al., 2009; R. Lam et al., 2013; Logue & Effken, 2012). However, this could be because there were very few papers focused on facilitators in general, and the majority of those that mentioned facilitators were also looking at initial use (Gordon & Hornbrook, 2016; E. H. Kim et al., 2009; R. Lam et al., 2013; Logue & Effken, 2012; Zettel-Watson & Tsukerman, 2016). In contrast, the papers on patient portals that mentioned barriers were all formative in nature (Kerai et al., 2014; Latulipe et al., 2015; Turner et al., 2015). This difference in paper topic (formative vs initial use) may have accounted more for the patterns in results related to barriers and facilitators than the technology itself. In terms of user experience, there were no overall trends demonstrating differences between ePHRs and patient portals.

However, log-in issues were reported only from formative papers involving patient portals (Latulipe et al., 2015; Turner et al., 2015), and suggestions for added features (discussed in detail under experience and design) came mainly from papers involving ePHRs (Hourcade et al., 2011; R. Lam et al., 2013; Price et al., 2013; Sack et al., 2011; Siek et al., 2011).

On the basis of our review, we identified a need for more longitudinal evaluation of patient experience and use, more nuanced understanding of older adult subgroups, and further discussion of barriers and facilitators to inform design recommendations. There were 2 papers (Gordon & Hornbrook, 2016; E. H. Kim et al., 2009) that looked at older adult portal use through a cohort study design, examining log-in data and uses of the portal over the course of a year (Gordon & Hornbrook, 2016) and almost 3 years (R. Lam et al., 2013). However, other papers examined average length of use of the portals. One paper found that several participants used the portal for longer than a year (R. Lam et al., 2013) and in another paper several participants used the portal for an average of 3 years (Zettel-Watson & Tsukerman, 2016). Further research with longitudinal studies could help to show how use evolves into adoption and why. It could also help to better identify barriers and facilitators to adoption of patient portals or ePHRs. Papers used different approaches to evaluate patient portals or ePHRs. Although common themes emerged across papers, the variety of approaches made drawing conclusions difficult. It would be helpful to have more research on specific and widely used systems to produce results that are comparable and generalizable.

3.4.2 *Principal Findings*

3.4.2.1 Barriers and Facilitators

Overall, it was more common for papers to describe barriers than facilitators to patient portal use. Concerns about privacy and security and lack of access or ability to use computers

and technology were all commonly identified as barriers. These barriers are consistent with what has been identified in related literature. Some barriers were explained in more detail than others, and very few papers offered concrete solutions for addressing barriers, particularly among older adult populations.

Papers consistently described privacy and security issues. However, there were not many specific suggestions for making older adults feel secure, and there were no design suggestions from older adults about what would make them trust the security of a system.

Other papers more specific to privacy and security concerns found that although unauthorized access to records was an issue for older adults, it was also a concern for the general population (Le, Thompson, & Demiris, 2013). In fact, older adults were significantly more willing than the general population to share health information with a provider (Le et al., 2013). Privacy and security concerns about patient portals are warranted, especially in today's climate where breaches to data are often in current news. For example, in 2016, Molina Healthcare shut down its patient portal because of a security flaw that allowed patients to access other patient's claims without authentication (Davis, 2017a). In 2017, there was a breach of UC Davis Health patient health records when an employee responded to a phishing email that allowed the hacker to access the employee's emails and personal health information of patients. Fifteen thousand patients were impacted by this incident (Davis, 2017b).

Authors of security-specific literature offered design suggestions to alleviate privacy concerns such as allowing patients to restrict access and sharing within a portal, and providing patients with an access log and list of any changes to medical information (Le et al., 2013). More research should be done to determine whether these and other design suggestions can work to mitigate security concerns, while still providing a positive user experience. Addressing security

concerns could affect usability of a system. For example, users required to go through a 2-step log-in may perceive it as being cumbersome (Tjora, Tran, & Faxvaag, 2005).

In patient portal research in general, there is recognition of systematic gaps in technology access and portal use (Czaja et al., 2015; Graetz, Gordon, Fung, Hamity, & Reed, 2016; Wallace et al., 2016; Weppner et al., 2010). Similar gaps in access have been identified in this literature review. Gordon and Hornbrook's (2016) paper was an exemplary publication with a large sample size that identified differences in portal use and technology access within subpopulations of older adults based on age and race and asked critical questions about physical ability. However, among the papers reviewed, there was not enough evidence to understand whether there are inequities in access to technology that in turn influence older adults' portal use, skill, and quality of health care at a broader level. As noted by Kneale and Demiris (2017), evaluations of patient portals often lack diversity or fail to report differences based on race, ethnicity, and gender. Generally, evaluations that report demographics conduct evaluations primarily with younger, white, non-Hispanic males who are highly educated (Kneale & Demiris, 2017). Further evaluation of socioeconomic, racial, and gender disparities is necessary. Only a few papers drew explicit connections between access and its impact on perceived computer and Internet skills (Lober et al., 2006; Turner et al., 2015). These papers generally did not examine the reasons behind computer anxiety or lack of confidence. Understanding and overcoming perceived barriers may be key to encouraging use and adoption of portals, but more research is necessary to identify why these perceived barriers exist.

A more in-depth discussion of facilitators, particularly among different cultural, social, and economic groups of older adults, may also be an important step toward creating a supportive system for older adults. Mention of facilitators in the literature is mainly limited to providing

technical assistance (E. H. Kim et al., 2009; Latulipe et al., 2015; Lober et al., 2006; Zettel-Watson & Tsukerman, 2016). Only Gordon and Hornbrook offer suggestions for large-scale assistance programs, including user handbooks, a hotline, and workshops. Another facilitator described in the literature was provider advice. Although provider perspective was not the focus of our review, other studies suggest that provider EHR use has an impact on whether patients adopt portal technology (Archer, Fevrier-Thomas, Lokker, McKibbon, & Straus, 2011; Irani, Middleton, Marfatia, Omana, & D'Amico, 2009). Overall, additional research should focus on what facilitators are important to older adults and how these facilitators can be incorporated into the patient portal experience and implementation.

3.4.2.2 Health Literacy

Low health literacy and technology have been identified as barriers for adoption of patient portals among underserved adult populations (Czaja et al., 2015; Goldzweig et al., 2013), and privacy and technological concerns are common barriers to older adults adopting technology in general (Young, Willis, Cameron, & Geana, 2014). In this review, the papers varied in the way they defined and measured health literacy. One looked at health literacy by focusing on numeracy (Taha et al., 2014), another used eHEALS (Logue & Effken, 2012), and another measured health literacy by the number of questions that were asked about the content in the patient portal (Lober et al., 2006). More research is needed to measure this barrier using a uniform method to identify how it affects portal use for older adults and to find design or implementation solutions that can be used to support health literacy among different subgroups of the older adult population.

3.4.2.3 Experience and Design

The papers in this review have used exploratory and evaluative methods to understand

the factors that impact the use and experience of patient portals and ePHRs. However, there are opportunities to apply a design framework to developing patient portals and ePHRs. Nath and Sharp (2015) proposed building on existing research methods, such as those that identify patient needs and preferences, using approaches such as user-centered design. Doing so will bridge the gap between needs and preferences and the design of a system. User-centered design is a process that aims to create usable systems that improve productivity, enhance user acceptance, reduce errors, and offer training and support. Human-centered design is based on the principle of actively involving users who have contextual knowledge of the tasks the system will be used for and the environment that the system will be used in. Human-centered design principles also include gaining an understanding of the tasks that the system will do, gaining early feedback from users through prototypes, and involving a multidisciplinary team (Maguire, 2001).

Many of the papers reviewed identified barriers and facilitators to use and adoption. There were some that also gathered requirements for and input on system development. These findings can be used in the user-centered design process. There could be additional exploratory research done to gain an understanding of the user in context and the tasks they aim to complete. Including the user at the beginning of the process ensures that their needs are a part of the design process. Participatory design approaches have been used in this framework to engage and empower older adults in designing technology such as smart homes (George Demiris et al., 2008; Friedman & Nathan, 2010). Using inclusive approaches can lead to unexpected discoveries of functions and features that are important to older adults.

Although studies in this review captured overall user experience, there is room for more exploration to better understand older adults' experience with and use of patient portals and ePHRs. Research could focus on usability by learning about participants' expectations and

navigation of systems. This information could then provide designers with necessary feedback to make iterative improvements to particular systems. To understand what older adults need from patient portals and ePHRs, designers should consider including older adults in the design process.

This review looked across the user experience, examining both patient portals and ePHRs. However, these technologies do offer different experiences. The primary difference is that, as patient portals are tethered to the patient's health record, patients do not need to manually enter their information, whereas ePHRs, which are not typically tethered to a patient's health record, require patients to manually enter information. This distinction has impacted the user experience and resulted in some of the feedback about desired functionality of ePHRs that is solved by patient portals, such as limiting the amount of text entry, providing access to lab results, and the ability to contact providers. However, there were still some desired features that could be further investigated, such as reminders for appointments and medication refills, lifestyle tips, help managing claims, and voice commands. The differences between patient portals and ePHRs can perhaps also be seen as an impact of technology developing over time.

Considering that people are increasingly incorporating technology into their daily lives, desired features that provide contextual advice are a reasonable expectation. However, further research with older adults is needed to understand how patient portals or ePHRs could be integrated into older adults' health management. In addition, researchers should consider relating their findings to the design of patient portals and ePHR systems. The recommendations could provide actionable changes and lead to opportunities to explore for potential features and functionality of the systems. For example, one desired feature mentioned in a paper was voice activation; patient portals could be paired with an intelligent personal assistant, such as the

Amazon Echo, to increase convenience and access to health information.

Another consideration is for researchers and designers to think about the long-term adoption of these systems. Friedman and Nathan proposed an approach called multi-lifespan information system design to challenge the short life cycle of a technology, which is usually 5 years. It asks researchers to think about the future of the technology, including its impact and how its use might change over time (Friedman & Nathan, 2010). The method may be fitting for the design of patient portals and ePHRs because they are systems available for a wide range of people and may be used over lifetimes and generations.

3.4.3 *Limitations*

The search terms for this systematic review were carefully chosen and aimed to draw a wide search. However, patient portals and ePHRs can be described differently, and some papers may have been missed. Our wide search also resulted in a diverse set of papers that presented challenges to drawing specific conclusions related to our research questions. Due to our focus on older adults, we eliminated papers that focused on provider perspectives as well as papers that focused on the health implications of patient portal implementation. We also excluded papers that were not in English, and so, we may have missed papers that were pertinent to our topic but in a different language. In addition, our key themes were determined based on a small number of papers. Even though our review included papers that analyzed patient portal and ePHR use among age groups other than older adults, we did not do a comparison between older adults and those other age groups. In addition, because of the large range of ages, 60 years and older, we did not distinguish the impact of age on the exposure to technology. Finally, our search criteria spanned over a 10-year period; it is important to recognize the constantly changing technology environment and the advances that have been made to patient portals and ePHRs over the 10-

year span of time. These advances likely impacted the use and experience of participants across the studies that were reviewed.

3.5 CHAPTER 3 SUMMARY

This review focused on understanding the barriers and facilitators to older adults' use and adoption of patient portals and ePHRs. This work addressed **RQ1** and found across the studies there were 2 main barriers: (1) concerns about privacy and security and (2) access and ability to use technology and the Internet. The 2 main facilitators were receiving technical assistance with a patient portal or ePHR and receiving advice to use patient portals from family and providers. In terms of older adults' experience using patient portals and ePHRs, some papers indicated that patient portals and ePHRs helped older adults to better manage their health information. Older adults liked having a single place that they could access and archive their information. In some cases, older adults felt their communication with providers had improved because of their use of patient portals. Older adults also suggested improving patient portals and ePHRs to help them manage their health beyond record storage, for example, by providing diagnosis and prognosis.

Overall, this review demonstrated that there are a range of studies and methods to understand patient portal and ePHR use and experience among older adults. However, more research is needed to better understand and address barriers to patient portal and ePHR use and adoption by older adults. As many health care systems offer their patients a portal to their health information, there are opportunities for it to be an integral part in keeping patients informed about their health information and encouraging them to take an active role in their health care. This opportunity is especially great for the older adult population as it is expected to grow rapidly. In addition, evaluation of patient portal and ePHR systems should be continually done

after they are launched to learn about the areas that are working and areas that could be improved. This is in line with the human centered design process and communicates to users the organization's commitment to deliver a positive user experience. This literature review provided the current research landscape about older adults' use and adoption of technologies such as, patient portals and ePHRs that can help them manage their personal health information. In the next chapter, I will discuss the complexities of how older adults manage their personal health information and how we developed design resources to translate the contextual factors that can influence design decisions in creating health technologies.

Chapter 4. Connected Personas: Translating the Complexity of Older Adult PHIM for Designers of Health Information Technologies

4.1 INTRODUCTION

Personal health information management (PHIM) is a process that includes creating, seeking, organizing, and sharing health information (A. L. Hartzler et al., 2018). PHIM for older adults often also includes activities that are supported by family and friends (Taylor, Hartzler, Osterhage, Demiris, & Turner, 2018). HIT, such as patient portals, ePHR and fitness trackers, have been designed to help people manage their health and health information. However, use and adoption of health technologies by older adults has been slow in comparison to the use of general technologies such as, email and the Internet (Anderson & Perrin, 2017; Levine et al., 2016). Human-centered design (HCD) and its methods have been embraced within the field of health informatics and used to develop technologies for patients (Dabbs et al., 2009; LeRouge, Ma, Sneha, & Tolle, 2013; Reeder, Zaslavsky, Wilamowska, Demiris, & Thompson, 2011; Turner, Reeder, & Ramey, 2013). However, there has been less work addressing the implementation of this approach, especially in regard to translating research study findings into artifacts for designers to use when designing HIT.

In this chapter, I will address **RQ2, How do designers and older adults perceive and/or use design resources (e.g., personas, design guidelines)?** I will describe how the HCD approach was used to develop personas, scenarios, and design guidelines for designers creating health information technologies (HIT) for older adults.

4.2 BACKGROUND

In health informatics, human centered design (HCD) has been advocated as an approach that can manage the complexity of health activities, such as the often invisible work of PHIM performed by older adults and their family members and friends (Ancker et al., 2015; Valdez, Holden, Novak, & Veinot, 2014). HCD methods have been used to develop and evaluate health technologies for managing diabetes (LeRouge et al., 2013), tracking health indicators (Dabbs et al., 2009), and managing personal health records (Czaja et al., 2015).

For our project we² chose to create personas, scenarios and design guidelines. Personas represent different people and their needs, and provide a sense of their behaviors, attitudes, needs, and goals in specific contexts (Beyer & Holtzblatt, 1998; A Cooper, Reimann, Cronin, & Noessel, 2014; Roson & Carroll, 2003). Personas are developed from user research, using methods such as interviews, observations, and surveys (A Cooper et al., 2014).

Personas aim to create a common language for designers, to encourage empathy for stakeholders, and to help designers understand stakeholder goals (A Cooper et al., 2014; Grudin, 2006).

Personas include elements such as the name of the individual they are describing, a photo of the individual, demographic information, personal goals, pain points (e.g. challenges), and a description of the individual's use and comfort with technology. Personas often include a scenario or narrative, that illustrates the context surrounding the individual and features their goals, challenges, and experiences with a technology (A Cooper et al., 2014).

Personas have been used and studied in a variety of contexts. In the field of health informatics, personas have been used to raise awareness of a particular population (Turner et al.,

² In Chapter 4 (this chapter), “we” refers to co-authors on this work, specifically, Anne M. Turner, Jean O. Taylor and Julie A. Kientz.

2013) and to translate study findings to inform the design process of health information systems (Turner et al., 2013). Studies seeking to understand how designers use personas in practice found that personas were often used in the initial stages of the design process as a communication tool within a team, to introduce new team members to their stakeholder groups and to help the team avoid making assumptions about their stakeholders (Nielsen & Storgaard Hansen, 2014; Vincent & Blandford, 2014). Personas have also been used to communicate with broader stakeholders, for example, others within the organization but outside of the project team, about the people using a system (Guðjónsdóttir & Lindquist, 2008; Miaskiewicz & Kozar, 2011; Vincent & Blandford, 2014).

Although the persona method is popular, it has not been without criticism. Some of the main critiques have been that it is difficult to trace persona details to specific data and validate personas using scientific methods (Chapman & Milham, 2006; Matthews, Judge, & Whittaker, 2012; Vincent & Blandford, 2014). In addition, some have argued that the persona method is limited in addressing the complexity of managing health and health information (Valdez et al., 2014). This study addresses these limitations with a modification of the persona method to accommodate the complexity of PHIM in the context of older adults. As described in this paper, we used findings from an extended study of older adults and their supportive networks to develop an expanded and connected set of personas, demonstrating the web of supportive relationships surrounding a central person's PHIM processes. This set of connected personas provides a fuller picture of the older adult's needs and experiences, providing information about the role that family, friends, and providers play in the older adult's PHIM. In addition to connected personas, we developed evidence-based design guidelines to support the design process for HIT for older adults. The process of guideline development and modification through

user and expert feedback is also described below.

4.3 METHODS

This work is a part of a larger project called SOARING (Studying Older Adults & Researching Information Needs and Goals) (SOARING, n.d.). It is a 5-year project at the University of Washington, funded by the Agency for Healthcare Research and Quality (AHRQ). SOARING seeks to deepen understanding of how older adults manage their health information and the role that family, friends, and providers play in that process. Its overall aim is to improve HIT for older adults to support their health and autonomy. To address these goals, the SOARING study design was based on the Balance Model, an ecological model which takes into consideration the role of social, organizational, technological influences in carrying out specific activities, in this case older adult PHIM (Carayon, 2009). As a part of SOARING, we conducted a qualitative study to investigate the health information management practices and needs of adults 60 years and older who lived in a variety of living situations (e.g., independent living, retirement communities, and assisted living). We conducted in-depth interviews with 88 older adults, 52 of their family and friends, and 27 health care providers (Turner, Osterhage, Loughran, et al., 2018; Turner, Osterhage, Taylor, Hartzler, & Demiris, 2018). Results from this research served as the foundation for the development of the personas, scenarios, and design guidelines.

I led the persona, scenario, and design guideline development effort with a small group of researchers from the SOARING team. We implemented a HCD approach to create these design resources. We refined the personas, scenarios and design guidelines through an iterative process with older adults and designers, as well as through feedback from subject matter experts. Subject matter experts included members of our SOARING team who have expertise in geriatrics, health informatics, nursing, medicine, biostatistics, and human-computer interaction. Figure 2 provides

an overview of our HCD approach.

4.3.1 HCD 1.1 Persona Process

We used SOARING study data from the interviews conducted with older adults, family and friends, and providers to draft each set (i.e., older adults, family and friends, providers) of personas. Once we drafted each set of personas (i.e., older adults, family and friends, providers) we sought feedback from our subject matter experts on the accuracy and completeness of the content and the design of the persona. After each feedback session, we incorporated the feedback in an iterative fashion into modifications of the personas. We held at least five feedback cycles for each set of personas - this included in-person meetings with the individual team members and a group of subject matter experts, as well as individual reviews where the personas were sent to the subject matter experts who provided in-document comments. As a result, we created six sets of connected personas.

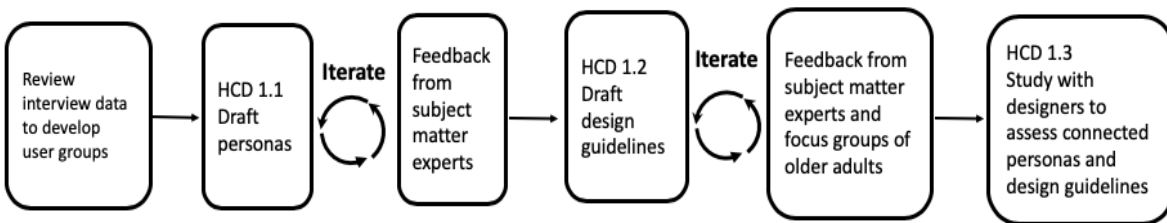


Figure 4. Overview of our human centered design approach

4.3.2 HCD 1.2 Design Guideline Process

The aim of the design guidelines was to provide a list of design considerations that would apply specifically to health information technology for older adults and complement the connected personas. To develop the guidelines we drew from the diverse perspectives of HCD designers, older adults, and subject matter experts. I first invited undergraduate and graduate students from the Human Centered Design and Engineering (HCDE) department at the

University of Washington to participate in an applied class of developing the design guidelines. I introduced the students to the SOARING project and its findings, as well as to the connected personas. Throughout the quarter, I asked students to brainstorm a list of preliminary design requirements using the personas and through sketching design ideas of health information technologies. Based on this work, students helped to prepare video scenarios of the design requirements to show to older adults in focus groups, see Figure 5.

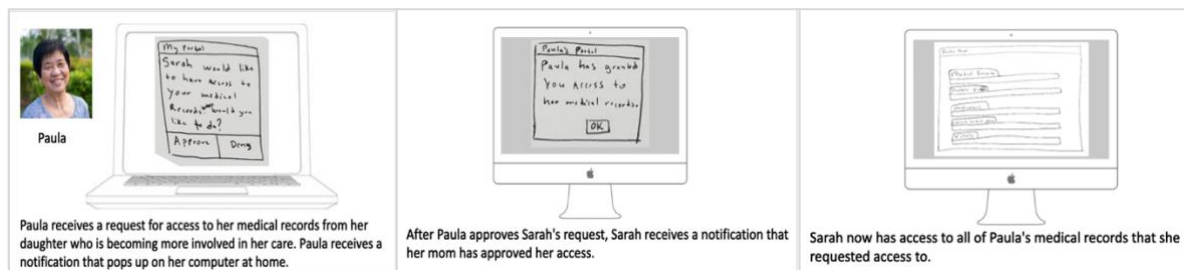


Figure 5. This set of slides illustrates the video scenario of two design requirements that allows older adults with the opportunity to choose who they share their health information with.

Next, I conducted three focus groups with older adults living in senior living communities and facilities to gain their feedback on the preliminary design requirements. Prior to the start of the session, participants completed a demographic questionnaire. Each session was facilitated by a SOARING researcher and observed by a student or a member of the SOARING team. Three students observed the first focus group, a SOARING researcher observed the second focus group, and one student observed the third focus group. All focus group sessions were recorded. Participants received a handout for each video scenario so they could follow along and take notes. Scenarios were used as discussion prompts to discuss and obtain feedback on preliminary design requirements. After each video, participants were asked whether the scenario resonated with their experience and their perspectives on concepts such as sharing and privacy. At study completion, the field notes were coded by myself and another researcher (DST, MX) using thematic analysis. We used the videos to support our analysis and to verify the themes. We

shared the design guidelines draft with the subject matter experts, and modified them based on their feedback. We had at least four feedback cycles.

4.3.3 *HCD 1.3 Study with designers*

I led a two-part study with designers to understand their perceptions of the connected personas in comparison to individual personas. We also wanted to understand how designers 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. The design challenge asked designers to design for this question: “How might we help older adults balance receiving support in managing their information related to their health and maintaining independence?”

To compare the designers’ experience between an individual persona and 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. The designers were then given all six sets of personas consisting of the primary older adult personas and their connected personas. The designers from the first session were invited to the second session. In the second session, designers worked in groups to prototype ideas for the same design challenge from the first session. In addition to the family of connected personas, the designers were provided with the design guidelines to inform their ideas.

All of the sessions were video- and audio-recorded. We also observed the groups and took notes. The groups reported their experiences throughout the design session through feedback forms with open-ended questions. The designers also produced sketches of their ideas and prototypes. Each designer completed an exit survey at the end of every session. After the sessions, I myself (DST) and three researchers (KK, AT, YW) conducted a thematic analysis by

reviewing the first session video recording. As a group, we reviewed the emerging themes and identified themes code in the rest of the video data. Each researcher reviewed a set of video recordings coded for the themes and transcribed those parts of the video. Then, three researchers used affinity diagramming to organize the themes. I (DST) triangulated the themes with the data from the group discussion feedback forms and individual exit surveys, while being open to additional themes that emerged.

4.4 RESULTS

The HCD methods we used guided us through an iterative process that was based on study data, informed by feedback from subject matter experts, evaluated by older adults and designers, and supported by academic literature and published information from organizations. This process provided the space for discussions about the complexity of older adults' PHIM and led to influential decisions about the personas and design guidelines. I discuss below some of the decisions and evaluations that occurred through using a HCD approach, including the emergence of connected personas, outcomes from focus groups that evaluated the design guidelines, and designers' experiences with both the personas and design guidelines.

4.4.1 *HCD 1.1 Drafting personas and emergence of connected personas*

I led the team through the personal development process. We started by following the typical process. Our goal was to develop a set of “stand-alone” personas that represented the different experiences of older adults and their family members, friends, and providers. We segmented the older adult personas based upon their living situation because we learned that it had a significant impact on the ways that older adults practiced PHIM (Matthews et al., 2012; Taylor et al., 2018). For example, older adults who live in an assisted living facility manage their

personal health information differently than older adults who live in a private residence. Older adults who live in an assisted living facility may rely on a variety of staff to gather and store their health information documents (e.g. after-visit summaries), while older adults who live in private residences may keep and file their documents on their own. Other parameters that distinguish the older adult personas from each other included health conditions, their organizational style, and the people in their lives that support their PHIM (Taylor et al., 2018; Turner, Osterhage, Taylor, et al., 2018).

For our first feedback session of the family and friends personas with subject matter experts, the family and friends personas were each drafted as individual personas. Since they were stand-alone personas, the format was similar to the older adult personas. However, as the subject matter experts reviewed these personas and reflected on their knowledge of older adults and related PHIM research, conversations emerged acknowledging that although the personas were representative of individuals, they did not illustrate the connective nature of the network of people who support the older adults in PHIM. We had gained a deep appreciation of this important aspect of older adult PHIM through embedding the SOARING interviews with family and friends into the ecological framework of The Balance Model (Carayon, 2009). This model led us to take an integrated approach to consider older adults' tasks, tools/technologies, social/organization systems, and the physical environment. Family, friends, and providers played a significant role in the ways that older adults organized, managed and shared their personal health information. Representing the older adults and friends and family in a traditional stand-alone fashion could not adequately capture the rich interconnected nature of these relationships, and the design needs that arose from these connections. As a result, we decided to break from the typical persona method of individual persona groups, and to instead create connected personas.

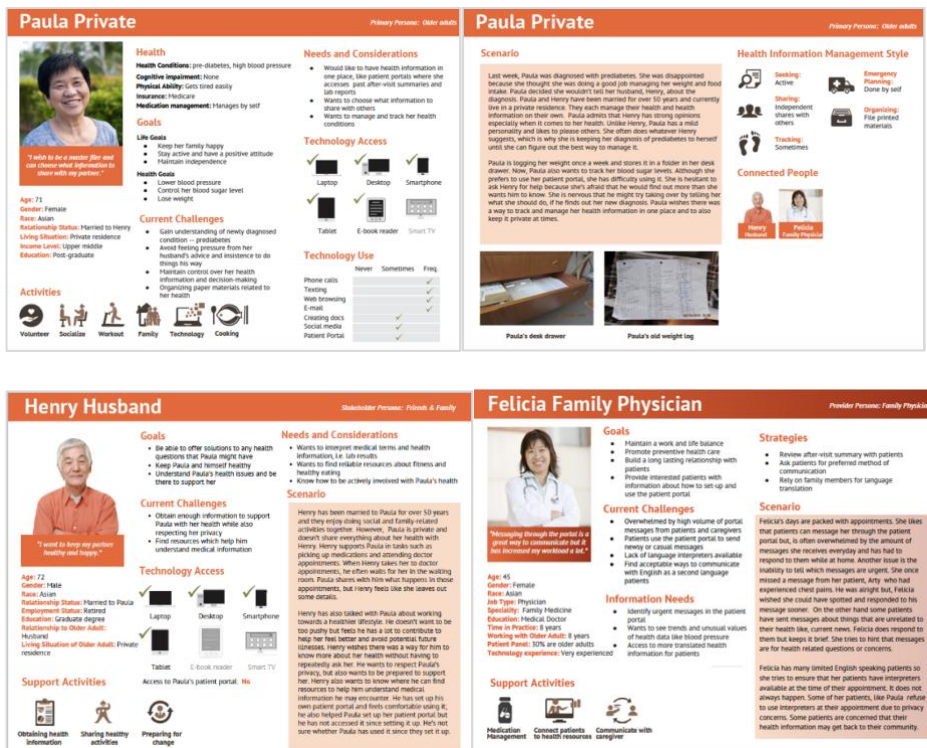


Figure 6. Older adult person, Paula Private and Connected personas: Henry Husband and Felicia Family Physician

In order to effectively describe the supportive role of connected personas, we changed the persona layout (Figure 6). The connected persona became one page, with the content focusing on the ways in which each stakeholder supported the PHIM of the older adult they were connected to. Each set of personas features an older adult in a different living situation (e.g., independent residence, retirement community, assisted living, etc.) and connected personas of family and friends and/or providers. Each persona within a set contains a scenario. The older adult scenario describes their current situation in terms of their health, their relationships with the people they are connected to, and with health information technologies, specifically patient portals. Similarly, the scenarios for connected personas (family and friends, and providers) illustrate a viewpoint on their relationship with the older adult and the ways they want to, or do, support the older adult. It also illustrates the goals and challenges they face related to their role in the older

adult’s PHIM. The final result of HCD 1.1 was six sets of personas, with each set featuring an older adult persona as the primary persona and connected personas of family and friends as well as providers who play a role in the older adult’s PHIM, see Figure 7.

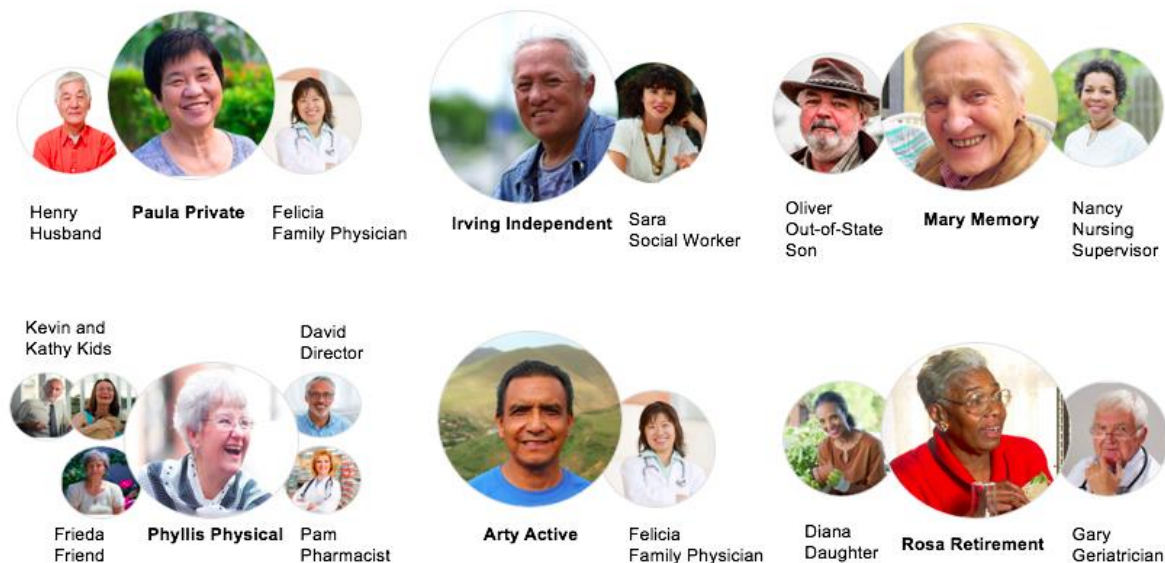


Figure 7. Family of connected personas

4.4.2 HCD 1.2 Development of Design Guidelines: Impact of older adult and subject matter feedback

The design guidelines were informed by the SOARING interviews, by the personas, and by feedback from older adults and subject matter experts. Below we present themes from the focus groups and feedback from subject matter experts that influenced and shaped the design guidelines. The guidelines encourage designers to consider PHIM-related needs (i.e. issues that might arise as an older adult is managing health information) and user experience needs (i.e. considerations for the use of the health information technology itself). For example, a PHIM-related guideline for family members of an older adult is, *Escalate support: Specifically consider tools that will allow older adults to plan for situations in which they may need extra help or full*

support from family and friends to manage their health and health information. An example of a user experience need is, *Design for diversity: Consider approaches like inclusive design to reach people across a wide range situations and with differing abilities.* All of the design guidelines were based upon the SOARING findings, academic literature and national organization websites.

To investigate whether our design guidelines resonated with older adults and explore additional design considerations, we conducted three focus groups with older adult participants. 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, balance between maintaining privacy and ease of use, and recognize the diversity among older adults in their use of, and attitudes toward, information technologies. These are described in more depth in the following paragraphs.

Some participants said that they expect that it should be easy to find information and complete tasks using health information technologies. One participant plainly stated, “**keep it simple**”. This theme also included the ability to understand information, and the suggestion that technologies should avoid using jargon and unfamiliar medical terms. During our sessions, we showed a video that demonstrated features such as, adjusting size of the text by using icons and buttons. Some participants noted that they were unfamiliar with some of the icons and with some of the terms.

“When I go to my patient portal, it is very simple. That’s what I want. I don’t have to hit all these buttons.” (Participant A, Focus group 2)

“The buttons should be labeled.” (Participant B, Focus group 2)

Another theme expressed was that technology should **support autonomy**. Several participants resonated with the scenario which described family members requesting access to the older adult’s health information. However, they also expressed that older adults should be able to choose who can have access to their health information. One participant acknowledged the challenge between maintaining autonomy and being safe.

“It’s difficult to maintain autonomy and control privacy and get the help you need. Some people are more willing to give that up than others.” (Participant, Focus group 1)

A third theme centered on the **balance between maintaining privacy and ease of use**. Ease of use arose as an issue in discussions about logging into a system. Participants expressed their frustrations with remembering passwords. Some participants offered ideas for password solutions, such as using a fingerprint, facial recognition, and voice assistant. However, the importance of privacy also came up in these discussions.

“I object to the idea of using the SSN (social security number), I’m not convinced that it’s safe.” (Participant, Focus group 3)

Although our primary discussions in the focus groups were about the guidelines for HIT, some participants voiced the need to **recognize the diversity among older adults in their use of, and attitudes toward, information technologies**. Four participants from two focus groups expressed a concern about technology taking away existing services or making those services difficult to use.

“My big concern is that I know a lot of people are like me. They don’t want to use a

computer. They don't want to use a smartphone. They just want to talk to someone. What do we do with those people who cannot get a hold of anybody? There has to be a way."

(Participant, Focus group 2)

In addition to guidelines generated from our own studies, where appropriate I incorporated existing guidelines and best practices for designing for this population and supporting the design of health information technologies. Resources used in the guideline development process include information from published reports, and organization websites including, the Pew Research Center, Bureau of Labor Statistics Occupational Outlook Handbook (Bureau of Labor Statistic U.S. Department of Labor, 2018), Center for Disease Control and Prevention (CDC) (Centers for Disease Control Prevention CDC, 2016), Alzheimer's Association (Alzheimer's Association, n.d.), Web Accessibility Initiative guidelines (Arch & Abou-Zahra, 2010) and plainlanguage.gov (Plain Language Action and Information Network, n.d.). I was thus able to address the diversity and range of technology experience among older adults and the importance of involving older adults in the design process. Also, I used academic literature for creation of the development of the design guidelines (Binda, Wang, & Carroll, 2018; Ellis & Cochran, 1999; Martin-Hammond, Vemireddy, & Rao, 2018; McHenry et al., 2015; Vines, Pritchard, et al., 2015). The final result of HCD 1.2 was a set of 37 design guidelines.

4.4.3 *HCD 1.3 Assessment: Designers' experiences with the personas and design guidelines*

The final stage was to provide both the connected personas and design guidelines to a group of designers. There were several themes that came from the two-session study I led with designers about their experiences with the connected personas and design guidelines. One of the themes was that the connected personas provided designers with a holistic perspective of the

older adult and of the problem space. Another was that designers refined their designs to include family, friends, and providers. Although the connected personas were positively received, there was also room for improvement. For example, designers were overwhelmed by the amount of information they had to digest and organize across the six sets of connected personas.

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 personas 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 that providing an overview summary of each set of personas with key information, or a video summary about each persona set, would be helpful. They also expressed that the design guidelines were useful and helped them to prioritize their design ideas.

4.5 DISCUSSION

This paper outlines the use of a HCD approach to translate and synthesize study findings into design materials in the context of designing HIT for older adult PHIM. I described our development and evaluation of connected personas and design guidelines for designers. Our approach involved close collaboration with SOARING researchers, feedback from subject matter experts, and insights from both older adults and designers. This work supports prior research in health informatics that has translated study data into personas (LeRouge et al., 2013; Turner et al., 2013). It also acknowledges the limitations of traditional personas to convey the complexity of health information (Valdez et al., 2014) by challenging the persona method to accommodate the complexity of PHIM for older adults. This work builds on prior work that expands the persona method to accurately describe user groups, their needs and behaviors (Dittmar & Hensch, 2015; Judge, Matthews, & Whittaker, 2012). Connected personas incorporate the

insights we have 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 (Carayon, 2009). Through utilizing this holistic framework, 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. Our personas needed to reflect this complexity because it was essential to the practice of PHIM for older adults. If we had developed traditional personas of individual older adults, we would lose valuable information that only rises out of the relationships between older adults and their social networks.

In using a HCD approach, we found it to be flexible and robust, allowing us to help designers navigate and appreciate the complexities of older adult PHIM. HCD methods have been advocated in health informatics as a way to design and evaluate health information systems that are informed by users, as well as their needs and behaviors (Behkami & Dorr, 2009; Searl, Borgi, & Chemali, 2010). Using a 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.

We found that designers appreciated the connected personas and found them to be useful to their design process. We also learned that the connected personas led designers to broaden their perspectives on the users of HIT beyond older adults, to include considerations for the older adults' family, friends and providers. This finding indicates that the connected personas were successful in communicating the complexity of older adults' PHIM. Overall, this study demonstrated that using connected personas has the potential to stretch the boundaries of the typical persona method to more accurately represent users and their context. This method may be

useful in other complex areas of healthcare in which a variety of roles influence activities, such as care management for children with disabilities and patients undergoing cancer treatment (A. Hartzler et al., 2011).

4.6 LIMITATIONS

Our personas and design guidelines are meant to provide information about older adult PHIM that should be considered in the design process of HIT. We did not focus on a particular HIT or explore other activities beyond PHIM. 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 (Blomquist & Arvola, 2002; Friess, 2012). Research into the use of these personas in actual practice is needed.

4.7 CHAPTER 4 SUMMARY

In this chapter, I described how using a HCD approach led to the development of connected personas and design guidelines for designers of HIT to better meet the needs of older adults. This approach allowed us to synthesize study findings about the complexity involved in the ways that older adults manage their health information. In particular, we were able to illustrate the importance of relationships to supporting older adults with their PHIM. Through feedback from designers, we learned that the connected personas were useful in communicating the complexity of PHIM for older adults, and led designers to consider the connections between older adults, their family, friends and providers related to PHIM in their design ideas. Overall, the connected personas and design guidelines helped designers dive into a greater understanding

about older adults and their PHIM. Having this knowledge will lead to HIT that meets the needs of older adults and as a result is used and adopted by older adults. This research also highlights the benefit of involving older adults in the design process. In the next chapter, I discuss a study that engages older adults more fully through co-design where they collaborate with student designers to create low-tech health and well-being technologies.

Chapter 5. Co-designing with older adults: examining and reflecting on collaboration with aging communities

Based on learnings about the value of communicating the complexity in PHIM of older adults to designers and researchers, I reflected on the usual design process and the need to have older adults' voices in that process. Participatory design (PD) approaches have been a way to ensure that technologies better meet the needs of older adults (Massimi et al., 2007; Uzor et al., 2012) and push against the assumptions about their abilities to contribute creative ideas (Davidson & Jensen, 2013a; Y. Rogers et al., 2014). Prior studies have included older adults in a range of design activities, including expressing their needs (Davidson & Jensen, 2013b; Harrington et al., 2018) and creating and evaluating prototypes (George Demiris et al., 2008; Ellis & Kurniawan, 2000; Hakobyan et al., 2013; Iacono & Marti, 2014; Massimi et al., 2007). Sharing the design process with people who may use technology is essential to the co-design approach, and researchers have provided frameworks (Kopeć et al., 2018; Lindsay, Jackson, Schofield, et al., 2012), considerations, and lessons learned (Davidson & Jensen, 2013a; Harrington et al., 2018; Iacono & Marti, 2014; Joshi & Bratteteig, 2016; Massimi et al., 2007) to facilitate successful collaborations with older adults. However, understanding interactions between older adults and designers remains an area of need to facilitate equal and equitable collaboration during design activities. The distinct differences between older adults and designers are often their ages and life experience. This gap can influence team dynamics and participation, so it is important to identify and understand aspects that contribute and distract from building a design partnership. While explorations in equal and equitable design partnerships have taken place with children e.g., (Druin, 2002; Yip et al., 2013, 2017), fewer studies are available to make sense of the dynamic collaborations between designers and older

adults.

This study aimed to address that gap by understanding the interactions between older adults and younger adult student designers in a series of co-design activities. We³ also wanted to understand student designers' experience in co-designing with older adults. In this chapter, I will address **RQ3 What interactions occur in co-design sessions with older adults and student designers to create health and well-being technologies** and **RQ4 How do co-design sessions impact student designers' perceptions of the aging population and of designing with older adults?**

I and a team of researchers adapted Yip et al.'s (Yip et al., 2017) framework to investigate the factors contributing to design partnerships in intergenerational collaboration between older adults and student designers. This framework emphasizes an equal and equitable collaboration between children and adults in designing new technologies for children. While it has only been adapted in the context of children and librarians (Yip, Lee, & Lee, 2019), we were inspired by how the approach levels power differentials between designers and participants in co-design sessions (Yip et al., 2017). In this chapter, we adapt this framework to understand better the collaboration between older adults and student designers.

Also, I offer insights about how co-designing with older adults impacted student designers' assumptions and heightened awareness of the value of co-design compared to other methods. Young adults often have preconceived notions of older adults associated with negative stereotypes (Kimuna, Knox, & Zusman, 2005; Y. S. Lee, 2009). Interestingly, other studies have demonstrated that engagement with older adults can positively affect and broaden college

³ In Chapter 5 (this chapter), "we" refers to co-authors on this work, specifically, Jay L. Cunningham, Wendy Roldan, Jason Yip and Julie A. Kientz.

students' perceptions of aging (Gutheil, Chernesky, & Sherratt, 2006; Kalisch, Coughlin, Ballard, & Lamson, 2013; Penick, Fallshore, & Spencer, 2014).

5.1 BACKGROUND

The work in this chapter has been informed by prior literature in co-design and participatory design approaches with older adults. Further, my understanding of collaboration in co-design teams was guided by Cooperative Inquiry (Druin, 2002; Yip et al., 2017) and literature that discuss participation by people who use tech in the design process. Additionally, I referenced prior work that explores the value of experiential learning and reflection for design students.

5.1.1 *Co-designing and Participatory Approaches with Older Adults*

The introduction of digital technologies into the lives of maturing communities, promises to improve the quality of life by supporting health, well-being, ability, and promoting aging in place. However, there seems to be a discrepancy between digital technologies that are developed and what older adults want and need (Light, Leong, & Roberston, 2015). Negative stereotypes associated with the older adult community often influence the invited participation of them in research and design of digital technology, thus expanding the digital divide (Light et al., 2015). Light et al. (Light et al., 2015) argues that the inclusion, rather than exclusion, of older adults in the design process and research is essential for technology to fulfill the promise of improving well-being.

We contribute to the growing body of literature that adopts participatory design approaches to support the integration of older adults into technology design processes, normalizing them as producers rather than just consumers of digital technologies (Waycott et al.,

2013). We employed PD approaches as a practice that focuses on engaging users in the design process and emphasizes a collaborative relationship between users and designers to create new technologies (Druin, 2002; Kensing & Blomberg, 1998; Yip et al., 2017). Co-design prompts the clear indication of collective collaboration and creation applied across the entire span of the design process. *“In a broader sense, co-design refers to the creativity of designers and people not trained in design working together in the design development process”* (p. 6) (E. B.-N. Sanders & Stappers, 2008). Users are subject matter experts of their life experiences and in the collaborative process are perceived as valuable partners (Beimborn, Kadi, Koberer, & Muhleck, 2016; Merkel & Kucharski, 2019).

5.1.2 *Benefits of Designing with Older Adults*

Participatory design approaches with aging communities is a practice that has proven to be of much value and a significant contribution (Frennert, Efring, & Ostlund, 2013; Merkel & Kucharski, 2019; Y. Rogers et al., 2014). This dynamic partnership changes the role of designers, developers, and/or researchers, who now have to view themselves as “facilitators” using appropriate methods to allow older adults to make their own decisions and to express their own perceptions (E. B.-N. Sanders & Stappers, 2008).

PD approaches, as modern techniques, have the potential to remove negative age-related stereotypes and connotations of ageism by targeting older users’ engagement and impressions of digital devices (Peine, Rollwagen, & Neven, 2014). A key advantage of interacting with older adults is learning from their instances of nostalgia and storytelling. Seniors who choose to participate in design projects can illustrate the value of lived experiences to the design process. Carroll and colleagues (Carroll et al., 2012) noted, *“they are the ones with the many years of memories, as well as with time and motivation for sharing these. By doing so, they can evoke*

commentary, community bonding, and reinforcement of community identity from other community members”. This study aimed to incorporate conversations about lived experiences through activities that encouraged team members to share events throughout their lifespan that impacted their current perceptions of health and well-being.

5.1.3 *Power Dynamics and Design Partnerships*

In traditional forms of design, individual homogeneous contributors typically hold the power of decision making. Even within the user-centered design process, the practitioner can prioritize decisions in the design practice. Within HCI, navigating power dynamics between designers is a well-known challenge, especially as it relates to social desirability bias, soliciting honest feedback, and acquiescence (Suchman, 2011). In Cooperative Inquiry (a PD method), Druin (2002) illustrated the four roles that a child could have in designing technologies: user, tester, informant, and design partner (Druin, 2002). Yip et al. (Yip et al., 2017) expanded upon Druin's (2002) description of a child's role in the design process by adding corresponding roles for designers, including observer, test facilitator, interpreter, and design partner. The roles are represented as two sets of concentric circles, one for the child's role and one for the adult's role. The circles also represented the child's level of interaction as user and adult as an observer as the smallest and most distant circles, with design partners as the largest and closest circles (Yip et al., 2017).

Unlike studies in co-designing with children, collaboratively engaging with older adults shifts the dynamics of power and expectations 1) as many senior citizens can be older than the designers; 2) designers' interactions employ a heightened sense of empathy, respect, and care with older adults; and 3) older adult needs and physical capabilities can affect their involvement, as lack of consideration of ways to support age-related changes can lead older adults reluctant to

participate in co-design activities (Sumner, Chong, Bundele, & Lim, 2020). Building toward a partnership between designers and older adults is essential to equal and equitable collaboration that is at the center of Cooperative Inquiry (1999). However, there has been little work examining the interactions between older adults and designers that contribute to understanding design relationships. This study aimed to fill this gap by investigating factors that lead to balanced or imbalanced interactions between older adults and student designers through a six-week co-design collaboration.

5.1.4 *Reflection in HCI Education*

Designers often create technologies for people different from themselves, so it is typical that students in HCI education engage in project-based learning, where they involve users like themselves in their process (Koppelman & Van Dijk, 2006). Project-based learning offers students the opportunity to experience real-world situations by engaging with stakeholders and users (Koppelman & Van Dijk, 2006). The experience of engaging with people who may use the technology being designed leads to understanding the value of including users in the process rather than relying on their experience and assumptions (Koppelman & Van Dijk, 2006).

We aimed to extend students' learning affordances by designing with people who were not like them in a real-world setting. Roldan et al. (2020) deepened our understanding of the value of involving users in HCI education through examining interactions in co-design activities between graduate students and children. They (Roldan, Gao, et al., 2020) advocated for reflection activities in HCI education to support meaning-making of graduate students' experiences and understanding how they build and navigate the complexities of interacting with users. Our study used reflection activities to understand undergraduate and graduate students' experiences in co-designing with older adults over time.

Reflection has been incorporated in experiential education programs such as, service-learning, which involves students taking part in a community-based project where all partners equally benefit (Furco, 1996; Lazar & Lidtke, 2002). Prior work has found service learning opportunities increased positive attitudes about aging and interest in working with older adults (Gardner & Alegre, 2019; Gutheil et al., 2006; Penick et al., 2014). Educators in HCI and computer science have also used service-learning to enable students to apply their knowledge to real problems and interact with users (Mankoff, 2006; Patricia, 2011; Sulaiman, Shahrol, & Samad, 2020). Despite challenges in recruiting community partners (Mankoff, 2006), the learning outcomes and community benefits of service learning are worthwhile. While our study was not a service-learning project, we had the components of community partnership and reflections as a key part of the course. This study contributes to prior work by sharing the students' experiences of participating in experiential learning.

5.2 METHODS

We examined team collaboration from two sites across six weekly co-design sessions, specifically focusing on student designer experiences from weekly audio reflections and artifacts from reflection activities. We conducted our study from January-March 2020. This study was completed prior to the state restrictions put in place because of the COVID-19 pandemic. The 12 total co-design sessions across two sites occurred once per week, over six weeks, within that time frame. This study received approval from the University of Washington's Institutional Review Board (IRB).

5.2.1 *Context and Participants*

Our study took place at two sites in a city in the US Pacific Northwest at a senior center

and a senior living community. I met with coordinators at each location to discuss this study and ensure that it would fit their older adults' community. I recruited people who self-identified as older adults, were interested in technology and willing to collaborate with students to brainstorm new technologies. A total of 16 older adults participated in study activity sessions, however two older adults dropped out after the first and second sessions, see Table 4. A majority (81%) of the older adults were retired. Many of the older adults (n=10) reported using technologies such as, computers, smartphones, or other devices to access the internet several times a day, some older adults (n=6) said they used technologies almost constantly. However, only half of older adults (n=8) reported being somewhat confident, while seven older adults reported that they were confident.

I recruited 11 student designers through a directed research group course offering that allows design students to gain research experience for course credit, see Table 5. In the prior quarter, three students participated in the study design. These students reviewed prior literature about PD and co-designing with older adults and engaged in discussions brainstorming the types of activities for the study sessions.

5.2.2 *Data Collection*

Co-design sessions with intergenerational teams: I led 12 co-design sessions (six sessions at each site) with seven smaller teams made up of older adults and student designers (2-3 older adults and 1-2 designers). The older adults and student designers stayed in this team throughout the six sessions. However, we grouped several teams together for some sessions due to team member absences. Each session was 90- minutes. We used two video cameras to record team interactions during the sessions, along with pictures of the activities and artifacts.

The sessions were aligned to the human-centered design process and had a general theme

around designing technologies for health and well-being. Each session was successively aimed at building team cohesion and ultimately co-creating a low-tech prototype of a new health and well-being technology. Some of the design activities were influenced by the Life Course approach, which stresses the need to consider life's context by examining individuals' life stages, transitions, agency, time, place, and relationships (Elder et al., 2003). One of our activities was tailored for teams to travel through each person's health and well-being histories (Table 3). We also encouraged team members to consider their histories and future needs as they narrowed in on their design area and target user.

At the start of the sessions, I presented an overview of the human-centered design steps (Dubberly, 2004) alongside the sessions to provide participants with a roadmap of how we would arrive at the low-tech prototype. I also showed the teams examples of low-tech prototypes. The steps were termed *Discover* (Sessions 1 and 2), *Define* (Sessions 3 and 4), *Ideate* (Session 5) and *Prototype* (Session 6). Before each session, I set-up the room, including hanging prior activity artifacts, placing name cards, and writing supplies on the table. Generally, each session started with people settling in and eating snacks and chatting with each other (~5 minutes). As a large group, I shared the agenda, described the activity and how it related to the study roadmap (~10 minutes). Then, everyone broke out into their teams to work on the activity (~45 minutes). After the activity, the teams shared their artifact or engaged in a larger group conversation to reflect on the activity (~15-20 minutes). I ended the session by letting everyone know what to expect next week (~5 minutes). There was variability in the session structure depending if teams needed more time to work on the activity from the prior session.

Table 4. Demographics of Older Adults (n=16). Asterisk* refers to older adults who reported they were retired

Age	Prior and Current Work Experience	Gender	Ethnicity	Highest Level of Education Completed
55 – 59	Business Owner	Woman	African American	4-year college degree
60 – 64	Design Consultant	Prefer not to answer	Prefer not to answer	Post graduate degree
65 – 74	International Development and Government Assistance*	Man	White	Post graduate degree
65 – 74	IT System Architect*	Man	White	Post graduate degree
65 – 74	Secondary Teacher*	Woman	White	Post graduate degree
65 – 74	Federal Government*	Woman	White	4-year college degree
65 – 74	Educator*	Woman	White	Post graduate degree
65 – 74	Graphic Artist and Business Owner*	Woman	White	2-year college degree /Technical Training
65 – 74	Librarian*	Woman	White	Post graduate degree
65 – 74	Registered Nurse and Volunteer	Woman	White	Post graduate degree
75 – 84	Director/ Technical*	Woman	White	4-year college degree
75 – 84	Secretary and Educator*	Woman	White	4-year college degree
75 – 84	Educator*	Woman	White	Post graduate degree
75 – 84	Educator*	Woman	White	Post graduate degree
85 years and over	Clinical Psychologist*	Woman	White	Post graduate degree
85 years and over	Educator*	Woman	White	2-year college degree /Technical Training

Table 5. Demographics of Student Designers (n=11)

Age Range	Student Status	Gender	Ethnicity
18 – 24	Undergraduate	Woman	White
18 – 24	Undergraduate	Woman	Asian
18 – 24	Undergraduate	Woman	Asian, White
18 – 24	Undergraduate	Woman	White
18 – 24	Undergraduate	Man	Asian
18 – 24	Undergraduate	Man	Asian, White
18 – 24	Graduate	Woman	White
25 – 34	Graduate	Woman	White
25 – 34	Graduate	Woman	Asian
25 – 34	Graduate	Man	Asian
45 – 54	Graduate	Woman	White

The activities within each session were adapted to the session goals and to accommodate our intergenerational teams, see Table 6. We looked to prior work (Harrington et al., 2018; Iacono & Marti, 2014; Kopeć et al., 2018; Lindsay, Jackson, Schofield, et al., 2012) for guidelines in designing with older adults and encouraging equal collaboration, such as, sharing personal experiences with technologies, engaging them in prototyping and persona building, providing concrete examples of design artifacts and bringing technologies to experience and evaluate. Overall considerations included implementing the study in a location that was convenient for older adults and partnering with site coordinators on session format (i.e., length of time, time of day, expressions of gratitude, and session activities) (Martin-Hammond et al., 2018; McHenry et al., 2015). Some researchers used familiar tools in co-design activities, such as, art supplies, sticky notes, paper and pens (Druin, 2002; Walsh, Foss, Yip, & Druin, 2013) and larger font sizes in handouts (Fisk, Rogers, Charness, Czaja, & Sharit, 2009).

Student designers' reflection activities: Student designers each participated in six co-design sessions at one site, one designer participated in sessions at two sites. Student designers also attended ten weekly meetings. After each co-design session, student designers audio-recorded a short reflection about their experience. For our weekly meetings, students participated in a range of reflection activities focused on a specific session or broader learning experiences. Each week students engaged with a different reflection activity. The students completed most of the 20-minute reflection activities prior to the weekly meetings.

Students shared their reflections in small groups during the session, and later in a larger group discussion. The learning goals of the reflection activities were two-fold: 1) To scaffold students in reflecting on their engagements with the older adults; and 2) To scaffold students in reflecting on their design approach to working with the older adults. I adapted many of the

activities, see Table 7, from Roldan et al. (2020) and received guidance about using them for our co-design study (W. Roldan, personal communication, January 16, 2020).

5.2.3 Data Analysis

Co-design sessions with intergenerational teams: The analysis of the co-design sessions was conducted by the lead researcher and nine students who participated in the sessions. In this study, we take an interpretivist stance believing that people who took part in the study can engage in sense-making of the data (Weber, 2004).

Table 6. Summary of Session Activities

Session #	Activity
1	Stickies (Walsh et al., 2013). We adapted Stickies for an exploratory activity. Teams captured individual perceptions of health and well-being and then sorted it to create a shared meaning of health and well-being.
2	Personal History (Blythe, Monk, & Park, 2002). Participants compared and contrasted their memories of changes to technology across their lifetime. We adapted this activity into a timeline of where team members shared health and well-being events across their lifetime and considered future goals.
3	Line Judging (Walsh et al., 2013). We adapted the line judging activity to accommodate physical limitations and spark discussions about technology rather than narrow in on an idea. Teams also had a questionnaire to guide their conversations.
4	“How Might We” (Dam & Siang, n.d.). A fill in the blank activity used in ideation to explore and brainstorm ideas. The goal of this session for teams to narrow down on a design area within health and well-being and create a persona based on artifacts they created in past sessions.
5	Ideation. The goal of this session was to brainstorm ideas for a new health and well-being technology. We presented the team with different ways to ideate such as sketching, jotting down ideas and storyboarding (Dam & Siang, 2020).
6	Bags of Stuff (Druin, 2002; Walsh et al., 2013). We made small adaptations to this activity. Teams used an assortment of craft supplies to translate their design ideas in a low-tech prototype.

Table 7. Student Designers Reflection Activities (Roldan, Lin, et al., 2020)

#	Activity	Description
0	Looking Ahead Activity	This activity was completed the week prior to the start of sessions. We aimed to understand students' expectations for their first session.
1	Micro-Reflection	This was a worksheet activity where students were asked to create a picture, diagram or representative that captures something they learned in their second session.
2	A Photo and Haiku	We asked students to take a photo that captured how they felt about their second session. They added a description of their photo and created a haiku of their session two experience.
3	Reflecting Back	We asked students to listen to their past audio reflections. Students separated into groups of 3 where each took turns taking on the role of either the facilitator, notetaker or responder. The facilitator asked the responder a question and the notetaker took corresponding notes.
4	Collective Meaning Making	In this activity, students responded to three prompts. Each prompt had a three-square grid where students wrote or used images to express their answers.
5	Making a Zine	Students wrote a 250-300-word description about things they think were the most important from their experiences in this study.
6	Supporting future designers	Students were asked to create an artifact (i.e., letter, poem, collection of images) to share with future designers who want to co-design with older adults.

We wrote memos and had peer debriefings to discuss the application of codes, discrepancies in codes and conducted member checks (Shenton, 2004). We deductively analyzed the session videos our teams' collaboration using Yip et al.'s framework that examines design partnerships in intergenerational teams, specifically between children and adults (Yip et al., 2017). The framework was developed through Cooperative Inquiry, an approach that has addressed power dynamics in intergenerational design, primarily between adults and children,

through building a partnership (Druin, 1999, 2002). The framework has four dimensions that describe design partnerships, 1) facilitation, 2) relationship building, 3) design-by-doing, and 4) elaboration (Yip et al., 2017). Each dimension of the framework is on a spectrum that describes interactions between older adults and designers from imbalanced to balanced.

The lead researcher started analysis with deductive coding to a subset of the co-design session videos. As a result, we had an initial codebook consisting of the four dimensions and 23 sub-codes such as leading, managing conversation flow, humor and grouping ideas. Next, the lead researcher and the nine student designers coded a small sample of the video data to validate the codes. We further added sub-codes for a total of 30 sub-codes, including snowballing, sharing life stories, and unbalanced interactions. Then, the researchers independently reviewed and coded all sessions. Throughout this process, we met weekly for peer debriefing. We drew codes across the sessions to develop initial themes (Creswell & Poth, 2018). The lead researcher refined the themes by triangulating the coded data with the analytical memos and determining whether interactions were balanced or unbalanced.

Student designers' reflection activities: The analysis of the student reflections was a separate effort from the co-design session. To analyze this qualitative data (transcripts and activity artifacts), one researcher conducted a thematic analysis (Creswell & Poth, 2018). The lead researcher open-coded transcripts from the student designers' weekly audio reflections to develop codes. The coding process was influenced by the principles of reflective design (Roldan, Gao, et al., 2020; Sengers, Boehner, David, & Kaye, 2005). The researcher refined the analysis by identifying patterns between codes and then developed themes. The analysis of the reflection activities and the co-design sessions occurred in tandem. We iterated on the themes when the researcher compared them to the artifacts from the reflection activities.

5.3 PART 1: INTERACTIONS PRESENT WHEN CO-DESIGNING WITH INTERGENERATIONAL TEAMS

I and fellow researchers described the interactions between older adults and students through adaptations to Yip et al.'s (Yip et al., 2017) framework. Balanced interactions are when both older adults and designers contribute equally to the discussion, generating ideas and creating their designs (Yip et al., 2017). Whereas unbalanced interactions are when older adults or student designers lead or dominate the collaboration (Yip et al., 2017). Given the fluidity of the team dynamics, we observed how teams could interact toward unbalanced and balanced ways within the same session. As such, we use contextual examples given in the findings as moments within a session. Here, we denote pseudonyms between the older adults and student designers by using superscript Student (Name^{SD}) for *student designers* and superscript OA (Name^{OA}) for *older adults*.

5.3.1 Facilitation

The facilitation dimension is defined as “*how much support and mediation takes place between adults and children.*” (Yip et al., 2017). It includes leading and managing the flow of the sessions. An unbalanced interaction is when only the adults facilitate the session, whereas a balanced interaction is when both the adult and child equally facilitate together (Yip et al., 2017). Yip et al. (Yip et al., 2017) point out that adults have specific responsibilities when collaborating with children, keeping them on task, managing their behavior, and motivating them to engage in design.

In our analysis, we found that Yip et al.'s (Yip et al., 2017) facilitation dimension was too broad for our interactions. We differentiated between *facilitating the activity* and *facilitating the*

discussion. We observed ownership of roles, student designers as experts in design and older adults as subject matter experts.

5.3.1.1 Facilitating the Activity

This dimension examines how the activity or task is carried out. A balanced interaction is when both the older adult team member and student designer equally negotiate their approach to an activity or task. An unbalanced approach is when either the student designer or older adult decide the direction of the activity or task.

Towards Balanced Facilitating the Activity: There were several instances when student designers shared this role leading toward a balanced interaction. For example, Session 5 focused on ideation. We encouraged teams to go with an ideation method that best fit their team's creative process. Team 1 had two student designers, Jessie^{SD} and Olivia^{SD} and two older adults, Nina^{OA} and Darlene^{OA}. After the general introduction of the ideation process, Olivia^{SD} asked Darlene^{OA} and Nina^{OA} about their thoughts. Darlene^{OA} commented that brainstorming far-out ideas may lead to useful ideas. Olivia^{SD} asked both older adult team members, "*Which method did you like in order to think of far-out ideas?*" Olivia^{SD} listed the options that were presented during the general introduction. Nina^{OA} suggested that they start with one piece of paper where one person writes an idea and passes it onto the next person, so that all of them could discuss the ideas.

Instead of suggesting an approach to the activity, Olivia^{SD} opened it for discussion with Nina^{OA} and Darlene^{OA}. This interaction is toward a balanced interaction because discussing how to approach the design activity was open to both the older adult team members and the student designers. This interaction is not fully balanced because the designer guided the conversation rather than an equal collaboration of ideas.

Another example happened in the Stickies (Walsh et al., 2013) activity when the older adults started grouping when sharing their perceptions. When Jake^{SD} shared his sticky note, Michelle^{OA} surveyed the table and suggested a grouping. Lily^{SD} indicated that grouping would happen later, she said, *“Later in the session we are going to put all the sticky notes on the wall.”* However, Lena^{OA} chimed in with a similar sticky and passed it to Michelle^{OA}. Jake^{SD} said, *“I think we are grouping afterwards, right?”*, Lily^{SD} confirmed. However, Lena^{OA} and Michelle^{OA} continued to group and so Lily^{SD} and Jake^{SD} went with it. They both handed Lily^{SD} a succession of similar stickies. Lily^{SD} accepted them and said, *“Oh wow!” “These are great!”* Michelle^{OA} said, *“We are doing our group thing over here!”* This example is towards balanced *facilitating the activity* because the older adults pushed for a different approach to the activity. The student designers tried to push back, but ultimately, they decided to go with the older adults' suggestion.

Towards Unbalanced Facilitating the Activity: Throughout the sessions we saw student designers take on the facilitator role by setting the direction of the activity. When everyone broke into their respective teams, the students often provided further explanation of the activity and suggested an approach. For example, during session 2 (timeline activity) Tammy^{SD} suggested that they could start with 1930 to 2010. She would write and share her events on the timeline first to give Joanne^{OA} and Colleen^{OA} time to think about their events. This interaction is towards an unbalanced interaction because the approach to the activity was set by one team member and not negotiated.

Older adult team members typically looked to the student designers as experts. For example, in session 4, teams were tasked to narrow down their design space and develop personas. A team with two student designers (one was missing that day) and two older adults sat at their table and worked on the “How Might We” statement, a design activity to help explore a

design space and target user (Dam & Siang, n.d.). Dorothy^{OA} was quiet. Lauren^{SD} asked, “*How do you feel about that [indicating a draft of the How Might We statement]?*” Dorothy^{OA} replied, “*Well, I’m just thinking I would approach this differently and so I’m just kind of*”. Marie^{OA} wanted to know more so Dorothy^{OA} continued, “*I mean it’s just probably because of my background in writing and so forth I would probably create the person and then think about, sort of what we’re doing. I mean, all of this is fine, I’m just saying.*” Then Marie^{OA} chimed in and said, “*Oh, let’s do the person, I’d like that.*” Lauren^{SD} started to say something but Dorothy^{OA} interrupted and said, that this approach is incremental, more logical and then said, “*I’m random and abstract.*” Lauren^{SD} mentioned that the order of the activities could vary and that they could continue to iterate on the “How Might We” statement and on the persona as they went along. This is toward an unbalanced interaction because although Dorothy^{OA} suggested an alternate approach there was no negotiation between the older adult team members and student designers.

5.3.1.2 Facilitating the Discussion

This dimension examines interactions that support or manage the flow of conversations, such as prompting, asking follow-up questions, summarizing, and refocusing team members on the task. Our sessions included both exploratory and generative design activities. The exploratory activities focused on discussions, such as gaining team consensus around their perspective of health and well-being. We examined interactions such as who started, managed, and maintained the conversations. A balanced interaction is when older adults and designers are actively engaged in discussions. An unbalanced exchange is when a student designer or an older adult manages the dialogue, and other team members are quiet.

Towards Balanced Facilitating the Discussion: In general, student designers and older adult team members were actively involved in conversations responding to and asking each other

questions. For example, during their discussion about health and well-being, Tammy^{SD} asked Joanne^{OA} and Colleen^{OA} about a sticky note that said “music”. Joanne^{OA} raised her hand and said, “*Music is mine, music is #1.*” She explained that she was physically impacted by music. Colleen^{OA} shared that music helped her when she had insomnia, she noted “*Music refreshes my spirit and soothes my soul.*” Tammy^{SD} also shared the influence music has had in her life and said that she used to do musical theater. This conversation demonstrates interactions towards balanced *facilitating the discussion* because the student designer and older adults were both contributing to the conversation.

Next, we observed older adult team members extending the conversation by asking probing questions. During session 3, the teams watched a video of a humanoid robot that imitated human facial expressions and gestures to have simple conversations. One team of two older adults and two students discussed the potential of this innovation. Cindy^{SD} asked what they thought about the robot. Lynn^{OA} thought it was creepy. Bob^{OA} said he did not understand how someone would use the robot. Lynn^{OA} said, “*I want the robot to assist, I don't want the robot to have control.*” Bob^{OA} suggested, “*Ah so say you have a robot, and you want it to assist, and you would say to it, remind me that I need to take this pill every four hours, and you would want the robot to remind you.*” Lynn^{OA} agreed. Bob^{OA} asked Lynn^{OA}, “*What if it could read you, audiobooks?*” Lynn^{OA} said, “*That would be nice.*” This is a snippet of an interaction that is toward a balanced interaction because while Cindy^{SD} started the discussion asking for feedback, Bob^{OA} took the lead in furthering the conversation by following up with Lynn^{OA}.

Towards Unbalanced Facilitating the Discussion: While many of the conversations were towards a balanced interaction there were some moments when the student designers and older adult interactions were towards unbalanced. Sandy^{OA} shared her sticky note, “*I just have this*

[sticky note], I was in a group, and someone said old has negative connotations, she said we have all short shelf life, right now, I have an expiration date! So that has stuck with me that now I'm at this short shelf life stage of my life." The rest of the team was quiet with no follow-up; instead, the student designer moved the conversation on by prompting another team member to share their sticky note. A student designer in their reflection explained that they were unsure of how to respond to that comment because it seemed like a sensitive topic. This interaction was towards unbalanced because there was no follow-up to what the older adult team member shared by the other team members.

Another example was when one team member expressed frustration about the direction of the conversation. During their conversation about health and well-being, Denise^{OA} asked Rachel^{SD} about the student designers' involvement in the study. While they talked, Carol^{OA} said, *"I'm going to ask that we focus and get our tasks done, you folks can talk after class but, I want to get this done."* Denise^{OA} and Rachel^{SD} both agreed, and they adjusted their conversation to grouping and organizing their sticky notes. This is toward an unbalanced interaction in facilitating the discussion because one team member was not engaged in the conversation and steered it in a different direction. However, the team member did steer the conversation back to the activity.

5.3.2 Relationship Building

This dimension focused on how team members engaged in social interactions and whether they were socially close or distant (Yip et al., 2017). A balanced interaction is when older adults and student designers *"establish closer relationships"*, whereas an unbalanced interaction is when the participants *"are socially distant from each other"* (Yip et al., 2017).

Towards Balanced Relationship Building: Relationship building was observed across the

sessions through interactions such as story sharing and humor. However, we saw the strongest impact on relationship building during the timeline activity, when team members shared events in their lives that influenced their perception of health and well-being. Older adults and student designers shared personal stories, including physical and mental health challenges, the loss of loved ones, professional achievements, current struggles, as well as lighthearted times and future goals. One example, Marie^{OA} shared that she lost her husband in the Vietnam War. Dorothy^{OA} asked, *“How long have you been married?”* Marie^{OA} replied, *“six years.”* The team nodded and listened. It was quiet for a moment, Marie^{OA} said, *“It sounds so depressing.”* The team responded, *“no”, “it’s okay”*. Dorothy^{OA} said, *“it is a huge thing.”* Marie^{OA}, apologetically repeated that it was depressing. Dorothy^{OA} said, *“whatever it was it turned into a lovely person.”* Lauren^{SD} and Jenny^{SD} agreed. Marie^{OA} said, *“thank you.”* This is an example towards balanced relationship building because of Marie^{OA}’s willingness to share a personally vulnerable event, and her teammates’ response of supportive words.

Relationship building was also illustrated through comments about the timeline activity: *“The members in our group, all of them, have gone through so many things and they were really open to share some of the events, the kind of things I couldn’t even imagine how to go through if it happened to me. For example, losing their spouse, losing their siblings, being diagnosed with cancer or other health problems. So, I was surprised by how open and willing they were to share.”*- Kelsie^{SD} At the end of the timeline session, Lynn^{OA} said that it was nice to see everyone’s stories and that it was fascinating. She told her teammates, *“Thank you for being here.”* Cindy^{SD} responded, thank you. Lynn^{OA}, *“We are all amazing in our survival.”*

Towards Unbalanced Relationship Building: Over time, the sessions enabled relationship building because the teams worked together to develop common ground on their perspective of

health and well-being, shared life experiences and designed together. However, there were some interactions that were towards unbalanced relationship building. One example was when teams worked to define their design area and create a persona. At one of the sites, two teams joined together because team members were missing that day. This newly formed team had two student designers and three older adults. The two student designers co-facilitated and guided the team through the activity. One older adult team member provided most of the content for the persona. The other two older adults provided some guidance and shared related stories. However, they were mostly quiet throughout the session. One older adult seemed disengaged during persona development. A few times, she checked her watch and fixed her sleeve. This interaction was towards unbalanced relationship building because several older adult team members seemed distant and disengaged from the team.

5.3.3 *Design-By-Doing*

This dimension describes interactions during design activities such as ideation, evaluating, and making prototypes and creating scenarios (Yip et al., 2017). Balanced interactions are when team members are engaged together in the activity, while unbalanced interactions are when team members are disengaged from the design activity or may be just observing (Yip et al., 2017).

Towards Balanced Design-By-Doing: Balanced interactions happen in most teams, where older adults and student designers actively engaged in building their prototype. For example, two student designers and two older adults worked together to create their prototype of a smart-toilet (Figure 8). In the week before their last session, Sarah^{OA}, refined the smart-toilet's sketch. During the session, she took the lead by providing her perspectives on the prototype's overall structure but was collaborative and flexible to her team members' ideas. For example, when Sarah^{OA} and

Rose^{SD} discussed cutting out the smart-toilet structure, Sarah^{OA} suggested a measurement, Rose^{SD} suggested cutting a larger piece. Throughout the session, the team members huddled together at their table, sometimes standing and sitting. They worked together by listening to each other's ideas, providing feedback, and negotiating the materials to use and different ways of constructing parts of their prototype.

Another example was a team that built a recipe application that helps older adults learn how to cook meals on a budget. The app customizes recipes according to the older adults' dietary needs and preferences. It also included a character called the buzzy bee who motivated users to be healthy. While they worked on their screens, Nina^{OA} said, *"I was just thinking it would be really swell to have, [in a sing song voice] I'm the working man, I'm the healthy man, remember an apple a day keeps the doctor away."* Jessie^{SD} said, *"You want to create a character."* Olivia^{SD} said, *"An avatar."* Nina^{OA} said, *"Yes, a character that we put in just before the recipes."* She explained her idea of a short 1-minute video of a bee that encourages healthy habits. Everyone nodded in agreement.

This example illustrated negotiation between older adults and students to translate their design idea into a physical prototype. This back-and-forth dynamic of constructing the prototype seems different from the exchange between adult and child in the Yip et al. (Yip et al., 2017) example, in which an adult and a child worked together to design technology. However, unlike the interaction we saw with the older adults and student designers, the adult mainly carried out the child's vision with little push back or suggestions (Yip et al., 2017).

5.3.4 *Elaboration*

This dimension examines interactions during the ideation process, where team members generate and mix ideas (Yip et al., 2017). A balanced interaction is when both older adults and student designers are contributing and building upon each other's ideas. An unbalanced interaction is when only the older adults or student designers generate and share ideas.

Towards Balanced Elaboration: Interactions toward balanced elaboration can happen in situations other than ideation, such as in discussions of life experiences. Throughout the study, team members built upon each other's experiences by sharing similar ones. For example, during the first session, teams engaged in a Stickies activity to develop a shared meaning of health and well-being. One team demonstrated interactions toward balanced elaboration when they were sorting the sticky notes of their health and well-being perceptions and grouping similar ones together. Lily^{SD} picked up one of her sticky notes and said, "*excitement*," Lena^{OA} said, "*Yes!*" and Michelle^{OA} added, "*Absolutely!*" Lena^{OA} and Michelle^{OA} handed Lily^{SD} similar sticky notes, including curiosity, lively, and active.

Life experiences were found to have played a role towards balanced elaboration. For example, a team with two student designers and two older adults focused on transitioning from independent living to an assisted living community for their ideation and prototyping sessions because Sandy^{OA} was in the planning stage of this transition, while Cheryl^{OA} already made the transition. In the ideation session, they came up with solutions for this life transition and decided to focus on downsizing. The team discussed how people organize things they are willing to let go, such as donating, selling, and giving away. Cheryl^{OA} suggested a color-coding idea for their design. Sandy^{OA} asked, "*How do you give it to the person?*" Steve^{SD} suggested posting it on social media. For items with the emotional attachment, Mark^{SD} said that they have digital storage

for pictures so people could have a digital memory. Cheryl^{OA} liked that idea. The team worked on detailing how to catalog items and listed ways they can let go of things. They created a mobile app called De-Clutter (Figure 9) that helps older adults transition from independent living to an assisted living facility by allowing them to donate, give away, sell, or keep items. This example is towards a balanced elaboration because both older adults and student designers contributed design ideas.

Towards Unbalanced Elaboration: Interactions that were towards unbalanced elaboration were less frequent than towards balanced elaboration. However, here are two examples of moments when the team's interaction was towards unbalanced. This first example happened in a team with three team members, two older adults and a student designer.

They developed a smartwatch low-tech prototype. In this session, one team member drove the design with little generation or mixing of ideas from others on the team. Before the session, Joanne^{OA} created a multi-page document with design requirements and used it to lead their prototype's design. Tammy^{SD} developed their low-tech prototype using a small notebook to sketch smartwatch screens and contributed to the design by asking questions such as, *"I'm thinking, how are we going to get from screen to screen on the watch? Do we want a big button, or do we want to swipe?"* Joanne^{OA} replied, *"I'll think about that. Why don't we go over the features and come back to that."* Colleen^{OA} contributed by sharing related life experiences but was mostly quiet. When Tammy^{SD} reflected on this session, she noted that she was proud of the prototype but felt their design was like smartwatches on the current market. She said if they had more time, they could have taken their design further. It is notable that Joanne^{OA} took the time and effort to create a document to guide their low-tech prototype. However, the document may have inhibited collaboration.

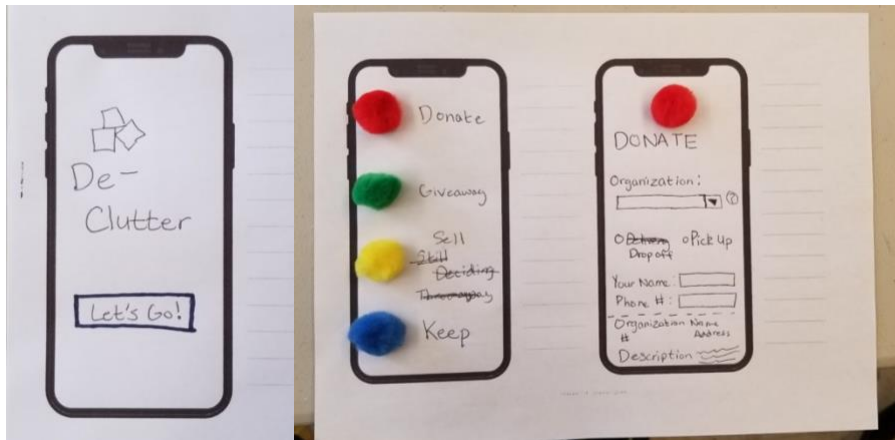


Figure 9. Screens from team's low-tech prototype of a mobile app called De-Clutter. First image is the home screen and the second image is of two selected screens showing options (Donate, Giveaway, Sell and Keep) to let go of personal items.

Another example occurred in a team with one student designer and two older adult team members during creation of their persona. Carol^{OA} pushed back on creating a persona and defining a design area. She questioned the need for specific characteristics such as, age and sex because the medication management technology they were thinking of could be applicable to a range of people. Rachel^{SD} suggested they start with defining their design areas through the “*how might we question*” activity. They discussed a target audience and goals. After they defined their area, Rachel^{SD} suggested creating their persona. Carol^{OA} said, “*Feel free, go ahead.*” Rachel^{SD} guided the conversation. She asked Carol^{OA} and Denise^{OA} questions about their persona characteristics. In the end, they created a persona. This is an example towards unbalanced elaboration because of the difficulty to engage and elaborate as a team on ideas for a design space and persona.

5.3.5 Older adults' views of co-design and involvement in the design process

At the end of the last session, we asked older adults questions about their overall

experience in the study. Older adults expressed surprise and enjoyment about their participation in the co-design sessions.

“This is much more fulfilling, much more and fun.” [How is it is more fulfilling?] Well, you’re actually planning for a new technology rather than sitting around and just evaluating old technology. I think really to be in the process of designing something or a possibility of designing is really much more integrating into the whole idea of being involved in technology and the overall process.” - Lena^{OA}

“I had thought that there was going to be more of sense of being test subjects that you were going to bring pieces of new technologies to us and ask us to evaluate that but this was way much more fun and I was surprised by what we came up with” - Nina^{OA}

Older adults’ advice to future designers who create technologies for an aging population was to include older adults in the design process.

“Talk to seniors, don't try to invent from your own observations or stereotype or whatever, ask people what do they want, that's the most effective way you'll bring about anything.” -Denise^{OA}

“What I think is interesting is that at your age, I didn’t know what’s ahead and each one of us has something a little bit different and yet their similar and you will never know what to develop unless you do talk to different ones of us that are going down these crazy roads.” -Joanne^{OA}

The older adults in this study also shared what worked in the study and areas for improvement. Nina^{OA} said that she enjoyed the timeline activity. Denise^{OA} liked that the teams had two student designers and two older adults. Also, working with the same people gave her a sense of being a team. The suggestions for improvement were to provide an overview of all the sessions to have a

clearer sense of the design process. Another suggestion was to extend the number of weeks to design and longer session times.

5.4 PART 2: UNDERSTANDING STUDENT DESIGNERS' PERCEPTIONS OF CO-DESIGNING WITH OLDER ADULTS THROUGH REFLECTION

Student designers engaged in reflection activities after each session and during weekly meetings. We found reflection activities helped student designers process their experiences in co-designing with older adults. This includes opening up their perspective on aging, identifying challenges, and recognizing the value of co-designing with older adults.

5.4.1 *Reflection Activities*

Our study used different reflection activities to explore both specific session experiences as well as broader learnings. We also wanted to keep the activities fun and engaging. Some students noted that reflection activities were a valuable tool for their learning experience. They liked discussing their reflections with their fellow students and appreciated the variety of reflection activities.

“[To future designers] Continuous reflection will help you identify assumptions/biases you may have had going in. Assumptions are ok but it is useful to understand them, so they don't lead the conversations you have with your co-design team.” -Cindy^{SD}

As the student designer noted, reflection is an important practice for designers to acknowledge the values and assumptions they bring into their designs and when engaging with people who may use their technology (Sengers et al., 2005). Reflection activities in our study were important because of the persistence of aging assumptions across society. As the student designers collaborated with older adults, it was important for the students to check those

assumptions and understand how it may affect their collaboration with their senior team members.

5.4.2 *Broadening Aging Perspectives*

Prior work has demonstrated that when young adults engage with older adults, it positively affects their perceptions of the aging population and reduces negative stereotypes (Gardner & Alegre, 2019; Gutheil et al., 2006; Penick et al., 2014). In our study, student designers acknowledged their assumptions, identified similarities with their older adult team members and realized that the differences in life experiences could make it difficult to connect with each other.

“Before attending my first session with the older adults, I had this assumption going into it that I would have to do a lot of explaining, talking slowly, facilitating more, etc. because that is my experience when talking with my older grandparents. However, working with these older adults was very different, because “older adults” is a huge age range where these people will have very different capabilities.” - Jake^{SD}

Co-designing with older adults challenged the student designers’ frame of aging and of older adults. The later phases in life can span a long period of time (Settersten, 2017). As people age, moments and events are experienced through different life circumstances, making the older adult population more diverse than alike (Vines, Pritchard, et al., 2015). When the student designers first engaged with the older adults, the students’ expectations and assumptions of the seniors quickly shifted.

5.4.3 *Balancing Roles*

Student designers identified balancing the role of facilitator and co-designer as a

challenge throughout the sessions.

“It was also hard for me to kind of figure out what my role is in the activity because you know I wanted to facilitate and make sure we chose a persona that everyone liked but I also wanted to make sure that it was matching with what our older adults wanted and needed as well.” -Cindy^{SD}

The student designers also wanted their older adult team members to take more ownership of the design process.

“Some things I wish I could have improved would be having my older adults present more of their work. Having them feel more like they can step into the shoes of the designer and that it wasn’t just my job. That they had more control over their project than I even did.” -Jenny^{SD}

5.4.4 Value of Co-design

The co-design sessions provided students with the opportunity to engage with people who may use technology that were not like them and apply methods and techniques students learned in class. Some of the student designers compared their co-design experience with other methods such as surveys, interviews, and observations.

“The first key learning from this co-design process is that sending out a survey is not enough to inform your research when working with older adults. I learned that from talking to the elders, they have so many stories and life events to share about a topic or an idea. Therefore, if we just take a written response at its face value, we may likely miss the point.” -Mark^{SD}

Surveys, interviews, and observations would not have gotten anywhere near what I was able to get and collect by working with my user group.” - Steve^{SD}

Student designers described the value of developing a design partnership with older adults:

“These weekly sessions have truly impressed upon me what it means to design in collaboration with others, especially those in a different demographic than you. In earlier sessions, I frequently heard comments like “you’re the designer” encouraging me to take the lead on writing down insights or presenting to the group. The whole point of co-design, though, is to break down the barriers between “designers” and “non-designers” - in our sessions, everyone’s a designer! And as we have moved into the design phase of personas and ideation, I’ve noticed my group taking more ownership of their ideas and becoming confident in their processes of design.” - Rachel^{SD}

At the end, student designers turned their experiences into lessons learned for future designers who plan to co-design with older adults, such as to recognize the differences among older adults, encourage team bonding through activities that explore life span, clarify co-design and facilitator roles, encourage older adults to take ownership of their design ideas and consider physical limitations such as, hearing issues. These learnings demonstrate the lasting impressions that co-designing with older adults left on the students.

5.5 DISCUSSION

This paper examined the interactions between older adults and student designers by adapting a framework (Yip et al., 2017) to understand interactions in intergenerational collaboration that lead to building a design partnership. We also learned the impact that co-design can have on a student designers’ perceptions of older adults and designing with them. This section is presented in two parts, the first discussing the use of this framework to identify interactions and build toward an equal collaboration between older adults and student designers.

The second part discusses the value of co-design and reflection to human computer interaction pedagogy.

5.5.1 *Part 1: Using the framework to understand interactions when co-designing with intergenerational teams*

This work adds to the growing literature of PD approaches to designing with older adults by examining the interactions in intergenerational collaboration and extending it by adapting a framework (Yip et al., 2017) to understand better design partnerships. The five dimensions, 1) facilitating the activity, 2) facilitating the discussion, 3) relationship building, 4) design-by-doing, and 5) elaboration made us aware of the differences in collaboration between teams and how the design activities can play a role in contributing to design partnerships. In this study, we explain the impact of balanced and unbalanced interactions in facilitating the activity and relationship building and provide considerations to promote balanced interactions in intergenerational co-design teams. Our team acknowledges that our understanding of collaboration in this study is influenced by the people who participated. The older adults bring with them experiences such as in their past or present professional lives as a graphic artist, IT systems architect, educator, or clinical psychologist. These and other experiences may have influenced how they interacted with other team members and collaborated in the design process.

5.5.1.1 Power Dynamics in Facilitating the Activity

Power dynamics at play were observed, weighing more heavily toward designers to facilitate the design activities. The unbalanced interactions demonstrated that there was little negotiation or collaboration on how to approach the design activities. It seemed natural that student designers took the lead in facilitating the activity because of their design knowledge. While co-design activities aim to support equal and equitable collaborations, researchers often

control the choice of activity and how it is conducted (Vines, Clarke, & Wright, 2013). I could have taken a more open approach, for example, placing emphasis on the flexibility of roles in the activities to support Dorothy^{OA}, who expressed that she would have created a persona differently but backed away from advocating for it.

5.5.1.2 Life Experiences Build Team Bonds

Sharing life experiences supported balanced interactions toward relationship building. It was especially prominent during our timeline activity when team members shared events across their lifespan that impacted their health and well-being perceptions. Personal histories revealed individual differences, thereby challenging the homogenization of older adults and strengthening team bonds (Foong, 2016; Franz et al., 2018; Vines, Pritchard, et al., 2015). This study supports prior work advocating for using the life course perspective in designing with older adults (Franz et al., 2018; Vines, Pritchard, et al., 2015). Our team extended this work by applying the life course perspective to design activities in intergenerational co-design teams. It should be seen as a way to learn how social forces shape our lives and lead us to be more different than the same and not as *“understanding the shadow of the past”* (p. 1) (Settersten, 2017).

The importance of design partnerships was demonstrated when the students recognized the age gap between them and their older adult team members. The students realized the life experiences they have not yet experienced, emphasizing that is not enough to rely on their previous experiences with older adults. Bennett and Rosner (2019) examined how designers may perform empathy techniques to understand users with disabilities, arguing that, in reality, they may be distancing themselves. For instance, designers wearing a blindfold to simulate the experiences of blind users. Bennett and Rosner (2019) explained that designers might focus on their experience wearing the blindfold rather than the experience of users with disabilities. They

too, recommended forming design partnerships to build empathy and understanding (Bennett & Rosner, 2019).

5.5.2 *Implications for building design partnerships in intergenerational co-design teams*

Involve older adults in study planning

I worked with the site coordinators and students to plan this study. Therefore, I got feedback on the design activities, the session's length of time, and the number of sessions. These meetings helped me to ensure that the study was a good fit for their clients and residents.

However, from the older adult participants we learned that they wanted longer and more sessions because it took time to get into the flow of the activities. Engaging older adults in the study planning can better help to define session parameters, support ownership in the design process and promote balanced interactions in facilitating the activity. This consideration also points to questions that Pradhan et al. (Pradhan, Jelen, Siek, Chan, & Lazar, 2020) raised about whether design training should be offered to older adult participants because prior experience with creative methods can help make workshops more successful.

Preparing for sensitive conversations

This study observed that when Sandy^{OA} shared a sticky note about the later phase of her life, her team members were quiet. The student designers moved the conversation forward without responding to that comment. This observation indicated a need to support teams in facilitating a discussion around the realities of aging and ensuring that people feel heard. It is also important for researchers to reflect upon their own assumptions about older adults because it could influence their design choices and perpetuate negative aging stereotypes (Garschall et al., 2016).

Maintaining team consistency

Keeping teams consistent throughout the study helped support interactions toward relationship building. An older adult mentioned that she appreciated working with one team throughout the study and liked the ratio of older adults and student designers. Merging teams together due to absences may have contributed to interactions toward unbalanced relationship building. Thoughtful consideration of the team, including the number of team members, the balance of younger and older adults on the team and maintaining the same team throughout the study can bolster bonding and relationship building. Relationship building can build trust allowing team members to take risks in voicing opinions and sharing ideas (Yip et al., 2019).

5.5.3 Part 2: Co-designing and Reflective Activities on the Learning Experience

Co-designing with older adults and engaging in reflective activities provided an impactful learning experience for the student designers. Our team suggests co-design as an experiential learning activity in HCI education to allow students to apply their learnings outside the classroom, engage with older adults as people who may use technology, and be open to challenging their stereotypes about aging (Roldan, Gao, et al., 2020). One program to consider is service-learning, where students participate in a community service project that enriches their community while engaging in instruction and reflection activities (Penick et al., 2014). Although this study was not formally a service-learning project, we had elements of it in our study, such as reflection activities. Student designers experienced a positive shift in their perceptions toward older adults and broadened their ideas of the aging process.

Reflection is recognized as an essential practice for designers in HCI to raise awareness of their values and assumptions in the design process (Sengers et al., 2005). Reflection activities are gaining attention as an educational tool in HCI to support students in assessing tensions and

complexities in designing with users who are different from them and re-understand their role in the design process (Roldan, Gao, et al., 2020). These principles are relevant to student designers, especially when they do not have the same frame of reference that older adults do in life-long topics such as health and well-being. Older adults as a community are uniquely differentiated by age from other societal groups and by diverse life experiences and physical conditions (Czaja & Lee, 2007). A life course approach elevates the urgency to study long-term, preferably lifelong changes in physical or cognitive abilities (Kuh, 2007).

Integrating reflection activities as part of the course provided regular opportunities for student designers to think deeply about their interactions with their older adult team members (Sengers et al., 2005). It also broadened the student designers' understanding by comparing their experiences with others in our weekly discussions. Some of the reflection activities had students step back to look across sessions and think about overall learnings about designing with older adults. Through these reflections, student designers identified challenging moments, such as not knowing how to respond to older adults when they bring up sensitive topics. This discussion provided the student designer the opportunity to return to that moment and examine the reason for the action they took (Roldan, Gao, et al., 2020). These reflections are critical to bringing issues to the forefront for educators. In our case, we were made aware of the need to prepare students for sensitive conversations. In our weekly meeting, we discussed this issue as a group and suggested different ways of handling it.

Engaging with users can be complex and it is difficult for students to prepare for every situation. Reflection can provide students with the opportunity to think critically about their engagement with people who may use technology and are different from them (Roldan, Gao, et al., 2020). The generation gap between older adults and students brings an added layer of

complexity, including the distance in life experiences, especially in time and place in an individual's personal histories and current life circumstances. Reflection activities can help students process their experiences in collaborating with older adults and allow educators to know how to better support students through those experiences.

5.6 LIMITATIONS AND FUTURE WORK

We conducted our study at two locations in a large city on the U.S. West Coast, which reduces the reach of our findings to other communities. We also recognize the diversity of the aging population. The experiences of the older adult participants in our study (i.e., expressed comfort and familiarity with technology, prior professional experiences in creative fields) likely influenced their engagement with the study (Pradhan et al., 2020). More work is necessary to gain a broader perspective of design partnerships with older adults in different communities, cultures, and levels of technology experience. Another limitation was while we provided structured reflection activities for the designers, we did not structure similar activities for the older adults in an effort to honor the time the older adults already offered us. Working with community site coordinators, we determined the length of the session was just enough time for the design activities. However, across the sessions, the integrational teams had opportunities to share their artifacts and respond to questions. We also had large group discussions after sessions about the technologies they tried out, and at the end of our study the older adult participants reflected on their participation. We believe future research could build in reflection activities into the co-design sessions with older adults and student designers. Sengers et al. (2005) suggested that when we support users in reflecting on their lives, it can invite them to challenge cultural and social norms that design might enforce.

5.7 CHAPTER 5 SUMMARY

Co-design has been a method researchers and designers have used to involve older adults in the design process. It has led designers to better understand the needs of older adults and has pushed back against stereotypes about older adults' ability to engage in design activities. A central element of co-design is the design partnership that fosters equal contributions from stakeholders in the design process. More work is necessary to understand the interactions that contribute to developing a balanced collaboration, and our research starts to build that understanding. We adapted a framework (Yip et al., 2017) to examine equal collaboration between older adults and student designers in co-design. We expanded the facilitation dimension into two sub-dimensions—*facilitating the activity* and *facilitating the discussion*—because we found that student designers often determined the direction of the design activity. However, older adults shared the facilitating role by asking follow-up questions and prompting team members. Also, our team found that using a life course perspective in design activities provides opportunities for older adults and student designers to share life experiences throughout their life span, which helped strengthened bonds between team members.

This study explored student designers' reflections of their co-designing experiences with older adults. We found this experience challenged student designers' previous notions of aging and about older adults. Student designers also reflected on their role in the design process and contemplated ways to balance that role. They became aware of the age distance between them and the older adults and admitted that it was hard to relate to someone when they have not yet experienced similar events. The student designers reflected on the co-design approach and ways it was different from other methods such as interviews and surveys. We believe that there is value in students engaging in experiential learning to apply their knowledge to a real-world

context and collaborate with users who are different from them. Co-designing with older adults was a great way for student designers to engage in experiential learning. The reflection activities were essential to the student designers' sensemaking of their values, assumptions and ways it shows up in their collaboration with older adults and their designs.

Through this research we learned that the life course perspective had an impact on strengthening the bond between older adults and student designers. In the next chapter, we explore the life course perspective as a way to understand the design choices that teams made throughout the process to create their low-tech prototype of a health and well-being technology.

Chapter 6. Life Course Perspective Influence on Design: A Case Study of Intergenerational Co-design

In the last chapter, I described the types of interactions that occurred among co-design intergenerational teams. This chapter will address **RQ5, How does the life course perspective influence design ideas of intergenerational co-design teams?** I will present design ideas, artifacts and prototypes from three teams to show influences from life course principles and concepts. The designs are from the six-week intergenerational co-design study described in Chapter 5. I will discuss three themes, *turning points*, *linked lives* and *independence*. My work provides implications for co-designing with intergenerational teams.

6.1 LIFE COURSE PERSPECTIVE

The life course perspective incorporates contextual factors throughout an individual's lifetime to understand their current behavior and perceptions (Elder et al., 2003; Wethington, 2005). The factors reflect the choices made and the effects of timing, place, and social connections on a person's life situation (Elder et al., 2003; Wethington, 2005). The life course perspective are represented in five principles, namely the principle of life-span development, the principle of agency, the principle of time and place, the principle of timing and the principle of linked lives (Elder et al., 2003). More detail about the life course perspective is found in Chapter 2.

While the life course perspective has been encouraged (Vines, Pritchard, et al., 2015), it has not been widely used in HCI because the current approaches that explore user needs tended to focus on current experiences. The benefits of the life course perspective are that it pushes against tendencies to relate characteristics, behavior, attitudes, and abilities of older adults to

their age (Vines, Pritchard, et al., 2015). Incorporating personal histories in the design process can lead to a deeper understanding of needs and new design opportunities (Vines, Pritchard, et al., 2015). Brown and De Schutter (2016) used a life course perspective and found that gaming preferences among middle-aged and older adults were developed in their youth and carried on through adulthood. Also, it highlighted that gamers wanted to continue and expand their gaming experiences through life transitions such as, having a family (Brown & De Schutter, 2016). My case study aimed to show the impact of personal histories and key life moments on health and well-being design ideas for older adults.

6.2 METHOD

I derived the case study from the co-design study introduced in Chapter 5. I conducted a total of 12 sessions, one session per week over six weeks. This study was conducted at two sites in a city in the US Pacific Northwest. One site was a senior center, and another was a senior living community.

6.2.1 *Participants*

There were a total of 16 older adults and 11 student designers that participated in the co-design sessions. The older adults ranged in age. Half were between 54 - 74 years old. They also varied in prior and current work experiences, including Business Owner, Nursing, Educator, IT System Architect Graphic Designer, and Clinical Psychologists. The majority (81%) of the older adult identified as women, and 88% reported their ethnicity as White. The student designers ranged in age, with 64% of them between 18 - 24 years old and about half were undergraduate students. Most student designers (73%) identified as women, and over half (55%) reported their ethnicity as Asian.

6.2.2 *Study Teams*

This case study focused on three teams. Each team had two older adults and two student designers. Two of the teams were from a senior center, and one team was from a senior living community. These teams were selected because their prototypes and design decisions best illustrated the influence of the life-course perspective. Throughout this study, I will refer to them as Team A, Team B, and Team C.

6.2.3 *Co-design Sessions*

There were six co-design sessions that aimed to guide the teams to create a low-tech prototype of a health and well-being technology for older adults. A low-tech prototype is made with art and craft supplies such as markers, paper, scissors, felt, glue, and foam boards to allow equal opportunity to design and easily iterate ideas (Walsh et al., 2013). The sessions were structured by stages, *Discover* (Session 1 and 2), *Define* (Session 3 and 4), *Ideation* (Session 5), and *Prototype* (Session 6). See Chapter 5 for details about the session goals and a description of the activities. Below is a summary of the activities by the session. See Table 8. For more detail about the session, see Chapter 5.

6.2.4 *Data Analysis*

I conducted a thematic analysis (Creswell & Poth, 2018; Nowell, Norris, White, & Moules, 2017) of the session videos and artifacts, including the teams' posters of their shared understanding of health and well-being, their timelines, personas, and prototypes. I started my analysis by reviewing all the session videos across the three teams. I took notes on the stories and life events shared, as well as interactions and behaviors. I used deductive coding by applying the life course principles to the session notes across all teams. Throughout the data analysis process, I wrote

memos. After the initial coding, I reviewed the principles that emerged as being significant, but found that more nuance was needed to capture significant life events and stories. So, I incorporated key concepts that were a part of the life course approach to better identify these experiences. The codes I added were, turning points, transitions and trajectories. Then, I went back through the data to revise the codes. I triangulated the data with the artifacts from the session and my memos to develop emerging themes. After a peer review of the themes, I refined them by revisiting the codes and comparing them to team artifacts and my analytic memos.

6.2.5 *Team Descriptions*

In this section, I introduce Teams A, B and C and highlight artifacts from some of their sessions. I decided to focus on sessions 1, 2, 4 and 6 because teams created artifacts that demonstrated design decisions that related to their final low-tech prototype. We used pseudonyms to denote whether they are an older adult or student designer by using superscript OA (Name^{OA}) for older adult team members and SD (Name^{SD}) for student designer team members.

6.2.5.1 Team A

Team A consisted of two older adult women, Audrey^{OA} and Kelly^{OA} and two student designers, Misty^{SD} and John^{SD}, see Figure 10. Through Team A, I gained an understanding of the importance of attitude and choice in reacting to health and age-related changes. These impacts influenced their design area and how they would support older adults who are at critical decision points in taking action toward a health issue.

Table 8. Summary of Activities

Stage	Session Goal	Activity
Discover	Session 1: Teams aimed to come to a shared understanding of health and well-being	Adapted Stickies activity (Walsh et al., 2013) Each team member used sticky notes to write their perceptions of health and well-being. They shared their perceptions and organized their sticky notes into categories. The prompts were, What does health and well-being mean to you? What things represent health and well-being? What activities contribute to health and well-being?
Discover	Session 2: Teams aimed to gain an understanding of each other's health and well-being perceptions through sharing personal histories.	We ⁴ adapted an activity called Personal History (Blythe et al., 2002). Teams were asked to write down five or more events across a printed timeline.
Define	Session 3: Goal was for teams to discuss and try out technologies to begin thinking about design requirements.	The teams engaged in an adapted activity called Line judging (Walsh et al., 2013). We used painter's tape to create a line on each team's table as a rating scale. Each team member used one sticky note per technology and rated them by placing the sticky note on the line.
Define	Session 4: The teams aimed to scope an area of design and define their user.	Teams engaged in a "How Might We" (HMW) activity, a fill-in-the-blank exercise that aims to help teams narrow in on a design area and audience (Dam & Siang, n.d.) and build personas (A Cooper et al., 2014)
Ideation	Session 5: The teams brainstormed design ideas and then narrowed their ideas that they might want to prototype.	No structured activities were given, rather we provided activity ideas such as, sketching, storyboarding, quarters and brainwriting.
Prototype	Session 6: Teams transferred their design idea into a low-tech prototype using craft and art supplies.	Teams engaged in an adapted activity called Bags of Stuff (Druin, 2002; Walsh et al., 2013). Teams were given craft and art supplies to use to translate their design idea into a prototype.

⁴ In Chapter 6 (this chapter), "we" refers to co-authors on this work, specifically, Jay L. Cunningham, Wendy Roldan, Jason Yip and Julie A. Kientz.

In the **first session**, Team A worked on their shared understanding of health and well-being, see Table 8. The prompts included, “What does health and well-being mean to you?” “What things represent health and well-being?” and “What activities contribute to health and well-being?”. After each team member wrote their perceptions of health and well-being on sticky notes they shared what they wrote with each other. As they did, they organized the stickies into groups.



Figure 10. Photo of Team A

The team created a hierarchy of their health and well-being perceptions, see Figure 11. At the base, were two categories, *physicality* (stickies included: stamina, mobility, physical health, strong, dance, growth, active and eating healthy) and *resources* (stickies included: medicine, doctors, financially, good health care, security, and work as a choice). The middle layer categories were, *connection* (stickies included: family, friends, community, and pets), *lively* (stickies included: excitement, interests, hobbies, curious and adventurous), *clarity*, *resilience*, *receptive (open-minded)* (stickies included: read books, flexible, give up some stuff and be able to accept new ideas) and *ease* (stickies included: feeling good, calm, balance and relaxation). At the top of the hierarchy, were *joy* (stickies included: happy, joyful, fun, satisfying, peace of

mind, and laughter) and *independence* (stickies included: stability, freedom, independence).

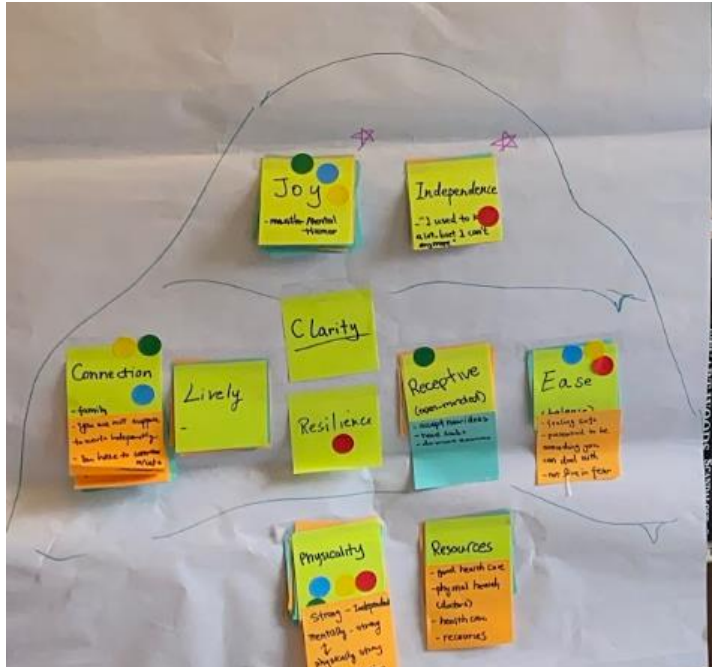


Figure 11. Team A's shared understanding of health and well-being poster

Audrey^{OA} pointed out that *joy* and *independence* were supported by the categories lower on the hierarchy, see Figure 11. She said, “I think looking at the whole thing as a series of steps so if you want to start you’re going to do things that help physicality, resources is one I cannot imagine a technology that would improve resources, but I don’t know. **But you have start there at that base.** You can cherry-pick technologies that would help with clarity or ease or something, **but the ultimate goal is to be independent and joyful in your life.**” This quote demonstrates how Team A understood their shared perceptions of health and well-being.

In the **second session**, Team A shared events in their lives that impacted their perceptions of health and well-being by listing them on a timeline, see Figure 12. All of the team members shared transitions such as their births and retirements. They also shared turning points, for example, surgeries, near-death experiences due to alcoholism, and moving to another country.

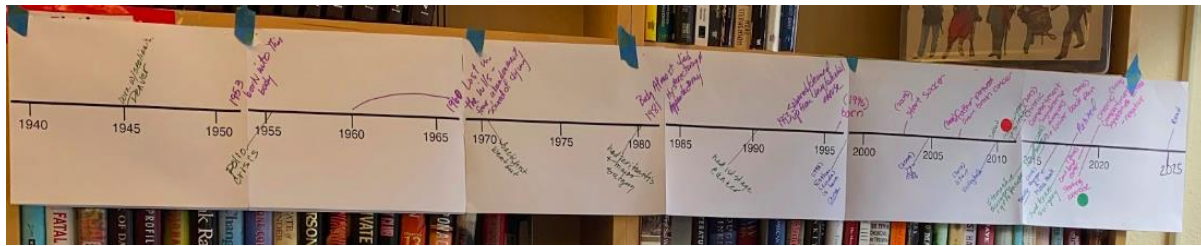


Figure 12. Team A's timeline of health and well-being events

During **session 4**, the teams were provided with short introductions to narrow down their design area and create a persona. I suggested that they review their past artifacts and vote on categories or ideas that were important to them. Then, the teams discussed things they voted on, for example a life event that was important to them. Teams also worked on a fill-in-the-blank activity called “How Might We” to describe their design area and general audience. From there, teams created a persona. Team A narrowed down their design space with this “How Might We” (HMW) statement: *“How might we connect adults with issues to others with similar issues to foster sharing to learn, accept, make choices, take action, and move forward?”* Their persona’s name was Sheila. She was a 67-year-old woman who experienced pain in her hip. She was worried about taking care of her dog if her mobility reduces. Some of the sticky notes on the personas included *“learning about how to deal about physical limitation,” “education care,”* and *“what’s possible”*, see Figure 13. Team A’s HMW question and persona reflected their interest to support older adults in discovering information to help make decisions. This interest was illustrated in the beginning sessions when the team discussed the approaches that older adults take toward health challenges and the consequences of those choices. For example, the older adult team members noted that when people resign to their health issues it could lead to a faster decline.

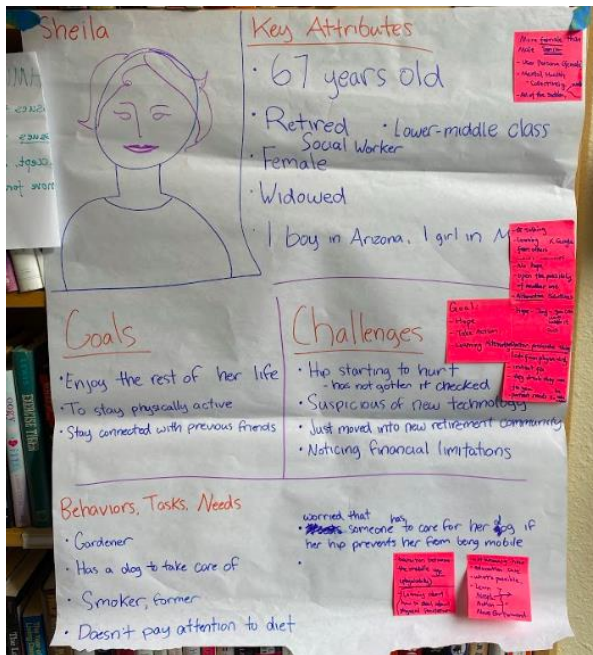


Figure 13. Team A's persona, Sheila

In **session 6**, teams turned their ideas into low-tech prototypes. Team A created three prototypes, see Figure 14. One was a 4-player board game called Discover. This game aimed to offer a casual environment to talk about issues that people may not normally seek to discuss. Another prototype was a mobile application that helps people connect to others who are facing or have gone through similar health experiences. The mobile application has a chat and a resource bank for information about health issues. Team A's third prototype was a virtual reality (VR) headset that was comfortable. The week prior to the session, one of the older adult team members volunteered to crochet a cap to represent the VR headset. The aim of the VR design was for people to gain a sense of familiarity with situations they might be curious or nervous about by trying out scenarios such as, a yoga class or going through the steps for hip replacement surgery. Across the sessions, we see that Team A's goal was to provide older adults with a choice by offering them opportunities to gain information about a health issue so they can choose how to take action that can improve their current situation.

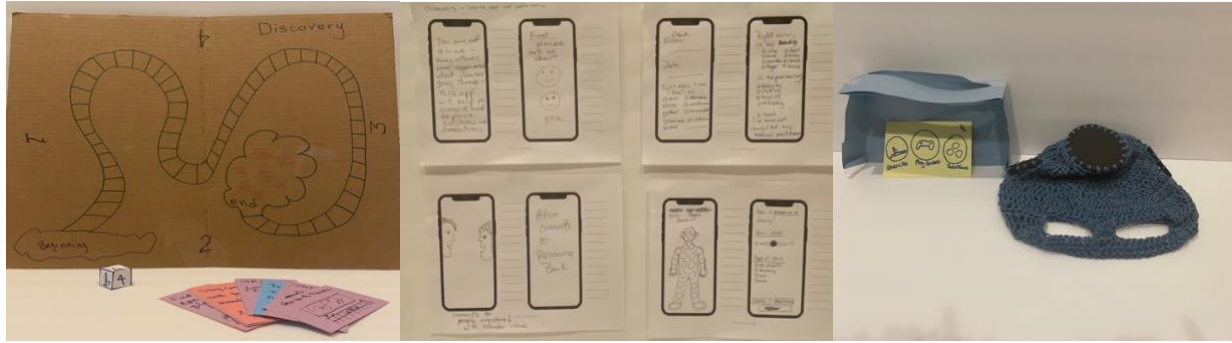


Figure 14. Team A's prototypes: (a) Discover Board Game, (b) Mobile application that connects people with similar issues, (c) VR headset that people can try out scenarios such as, a yoga class or go through the steps for hip replacement surgery.

6.2.5.2 Team B

Team B consisted of two older adults, a man and a woman, Wade^{OA} and June^{OA} and two women student designers, Amelia^{SD} and Luna^{SD}, see Figure 15. Team B showed how turning points can shift perceptions of health and well-being and influence lifelong behaviors. It also shows how turning points can be inspiration for design opportunities.



Figure 15. Photo of Team B

In the **first session**, Team B described their shared understanding of health and well-being poster as four different categories, *physical activity* (stickies included: walking, be active, yoga, sunlight, nature, mobility), *physical health* (stickies included: staying hydrated, skincare, free from illness, Chinese medicine, good night sleep), *fun and games* (stickies included: social

support, listening to music, living independently, hobbies, mental games and activities) and *mindfulness and spirituality* (stickies included: feel positive, engaging in activities sound fun and not stressful, balance, be in the moment, holistic well-being), see Figure 16. The team said they noticed that their categories overlapped and it was difficult to separate, for example, yoga could go in either physical activity, mindfulness or spirituality, so they put it in between the two categories. Amelia^{SD} noted two subcategories relating to doing activities alone and doing activities with other people. *“Another thing in the fun part is that we feel there are two kinds, one of the things is that we want independence, like doing something on our own, like listening to music but some include social support so maybe have some activities or games with other people, that is some of the sub-categories.”*

In **session 2**, the team engaged in a timeline activity, see Figure 17. Like Team A, Team B shared events in their lives that impacted their perception of health and well-being. They shared turning points in life. For example, June^{OA} discussed that she was diagnosed with cancer in the 1980s. She said, *“That changed my life because I had to deal with what am I doing in my life? Why did this happen? I started reading underground stuff.”* June^{OA} explained that she had to go to health food stores to get information because conventional medicine did not address her concerns. Luna^{SD} mentioned that a significant moment for her is when she lost her grandmother and could not be there. Amelia^{SD} mentioned that her diet was influenced by her boyfriend because he mainly ate fish and vegetables. She also shared her grandmother’s experience of surviving pancreatic cancer. Amelia^{SD} said through her grandmother she learned the importance of advocating for your own well-being. These turning points show the commonalities in life experiences between a student designer who was a younger adult and their older adult team member. Also, these experiences appeared to be a contributing reason their design direction went

toward dietary needs.



Figure 16. Team B's shared understand of health and well-being poster

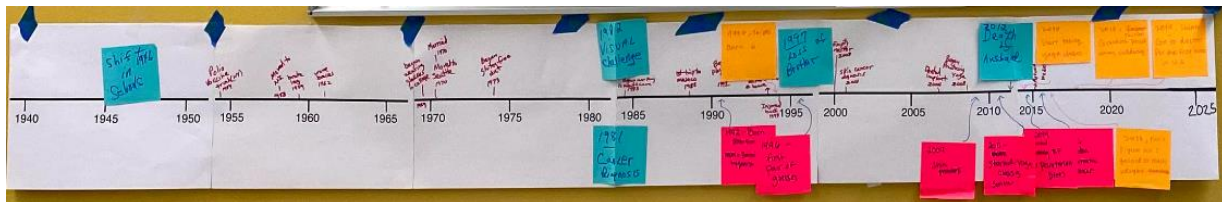


Figure 17. Team B's timeline of health and well-being events

In session 4, Team B narrowed their design space with the HMW question, “How might we assist based on needs and wants to achieve dietary goals?” They decided to design for older adults with dietary issues who have difficulty preparing food due to low vision. The team arrived at this statement by reviewing their prior artifacts (their shared health and well-being poster and timeline). They voted on topics with dot stickers that they felt were important. There were two topics that received majority of the dots, social support and eating well. During their discussion,

June^{OA} said that she voted for dietary assistance because some apps require the user to do a lot of input. After that discussion, Wade^{OA} added his vote there too. The student designers shared their experiences with tracking the amount of water they have drunk.



Figure 18. Team B's persona, Magoo

Team B created a persona named Magoo, see Figure 18. Magoo is an older adult who is 73 years old, retired and lives at home alone. Magoo is living with low vision, is health conscious and has food allergies including dairy, shellfish and gluten. They listed needs and goals including setting nutritional goals, an affordable meal plan, learning what to eat, and weight loss or gain. The two pain points listed were difficulty preparing foods and difficulty reading ingredients. An older adult team member noted that doctors often suggest keeping a food diary to track the food they eat however, noted that it is hard to do. Another older adult team member noted that their

design could help address this pain point.

In **session 6**, Team B created a low-tech prototype that reflected topics they discussed in session 4 such as, dietary assistance, low vision and social support, see Figure 19. They created an app that could work on a smartphone or tablet.

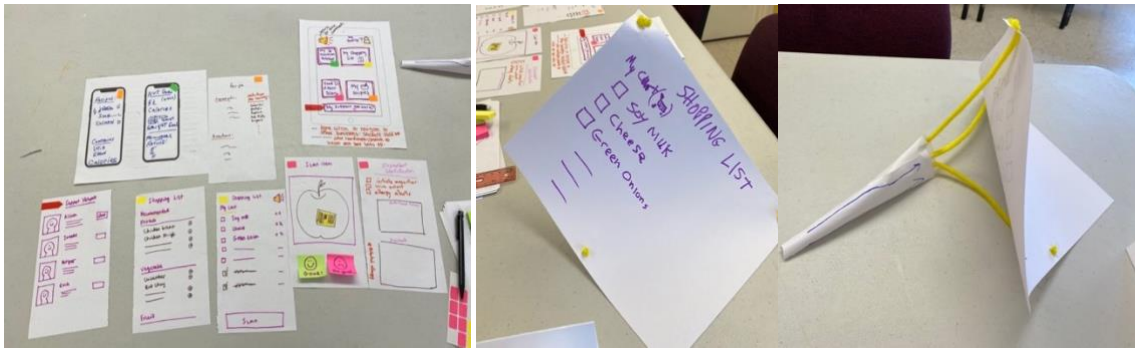


Figure 19. Team B's prototype: (a) Dietary application, (b) Front view of pen, (c) Side view of pen

Team B's dietary app would support people living with dietary allergies by helping them shop for the right food and offer recipes. Users could reach out to others who use the app for support. The dietary app had features such as, a shopping list with the ability to scan items and then to their list. It also had tracking capabilities and an audio component to support people with low vision. Team B created a pen as a companion to their app, it could upload and project it to magnify their shopping list.

6.2.5.3 Team C

Team C consisted of three older adults, two women, Anna^{OA} and Nora^{OA}, and one man, Norm^{OA}. There were two men student designers, James^{SD} and Thomas^{SD}. Participation among the older adults varied in the first four sessions. In the first session, Anna^{OA} and Norm^{OA} participated in the sessions.



Figure 20. Photo of Team C

Anna^{OA} missed the second session, Norm^{OA} attended and it was Nora's^{OA} first session in the study. Norm^{OA} stopped attending after the second session. So from session 3 on, the older adult participants were Anna^{OA} and Nora^{OA}, see Figure 20. Team C showed how life transitions play an important part of health and well-being, in particular preparing for a move from independent living to assisted living or a retirement community. Also, they demonstrated life transition as a design opportunity to support older adults through this change in life.

In **session 1**, Team C's shared health and well-being poster included categories, *physical* (stickies included: exercising, balance, walking, yoga, Tai Chi, Kung Fu, Moving active, physical strength), *social* (stickies included: going with friends, social activities, taking care of others, feeling of work-volunteer activities) and *personal capacity* (stickies included: having energy, health, body, mind, soul, mental health, reading, being able to do what you love).

Norma^{OA} said that she related personal capacity to sorting things. She noted that currently she is interested in downsizing her things. Other categories were, *diet/eating* (stickies included: eating, eating health diet), *emotional impact* (stickies included: feeling peaceful, happiness, relaxed, calm, comfortable) and *etc* (stickies included: sleep, feeling confident, sleeping well, financial

issues, old negative connotation “short shelf life”), see Figure 21.

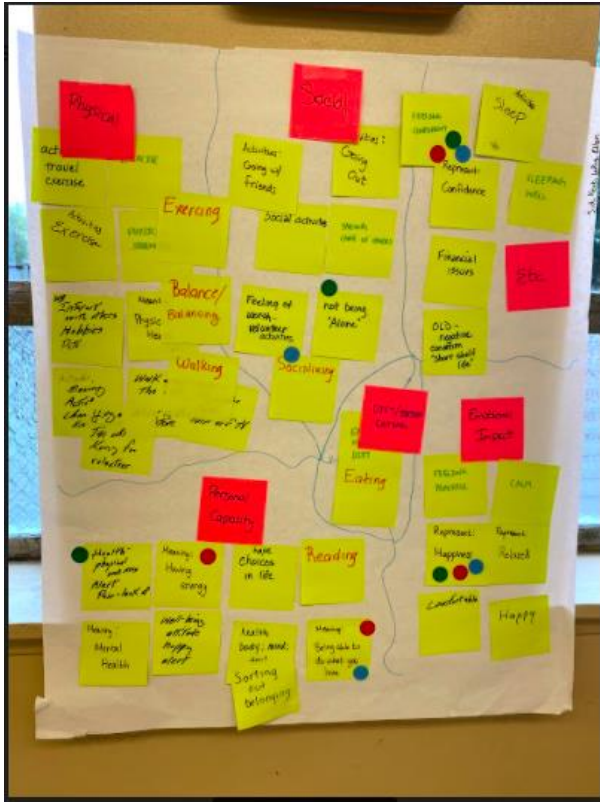


Figure 21. Team C's shared understanding of health and well-being

In **session 2**, Team C worked together on a timeline to share events that influenced their health and well-being perceptions, see Figure 22. There are two timelines. Anna^{OA}, who missed the sessions, completed the timeline on her own in between sessions. The team members shared events as they wrote them on the timeline. Similar to Team A and Team B, they shared celebratory times for example, graduations, births of children, marriage and running a marathon. They also shared the volunteer work they do with Habitat for Humanity, as well as health issues they faced and the loss of family members.



Figure 22. Team C's timeline of health and well-being events

In **session 4**, Team C, Anna^{OA}, James^{SD} and Thomas^{SD} started the session by reviewing artifacts from prior sessions to vote on health and well-being topics and events that they might want to focus on as a design area. Nora^{OA} was missing from this session. They discussed the areas that they voted on, such as energy, confidence and social life. Anna^{OA} mentioned that she was touring assisted living and independent living communities. She explained that she wanted to choose where she lives in the future. This conversation was influential in narrowing the scope of their design area and persona. Team C collaborated on a HMW question which was, “*How might we help plan major life transitions for retired seniors?*”

Team C’s persona was named Richard the Retired, see Figure 23. He lived independently, was retired, liked to travel and has grandchildren. Some of his goals were to plan for a move into an assisted living/independent living community, spend time with family and maintain energy. Richard the Retired’s challenges included knowing when to prepare for the move, downsizing and the fear of not finding the right community. His needs were what to plan, who to ask, traveling, creating memories and finding senior benefits.

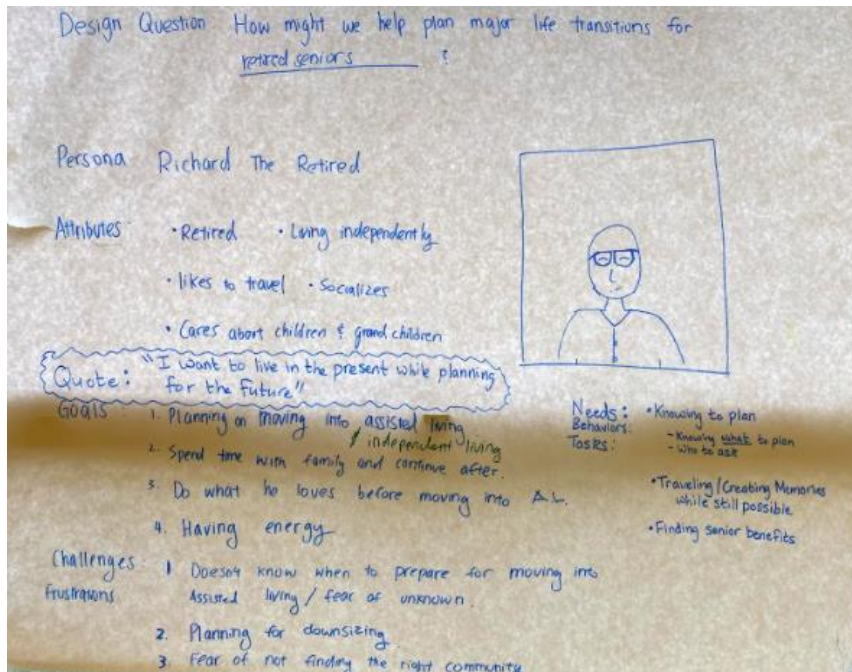


Figure 23. Team C's persona, Richard the Retired

In **session 6**, Team C created a low-tech prototype of a mobile application called De-Clutter, see Figure 24. The aim of the De-Clutter app is to help older adults downsize their home. Through De-Clutter older adults decide which belongings to let go of and which ones to keep. It aimed to reduce anxiety among older adults who felt uncertain about when and how to transition from independent living. For each item, the older adult can choose to donate, giveaway, sell or keep. For donating and giving away an item, the app helps the older adult to reach out to family, friends or the community. If they decided to keep the item there was a reminder option to revisit that decision at later time. The De-Clutter app also has the option to be voice-enabled.

Across the six sessions, Team C illustrated that transitioning from independent living to a senior living community is a significant event and provides an opportunity for design. They demonstrated the complexity of the transitions in planning and preparing for a move which includes touring potential communities, considering space availability and reducing the number of things in preparation for the move.

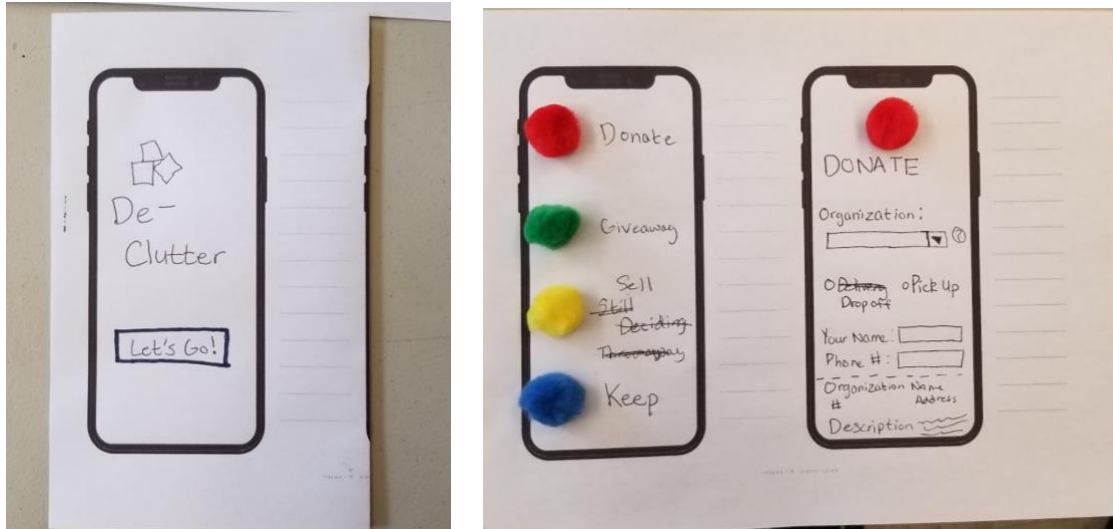


Figure 24. Team C's prototype De-Clutter, (a) App home page, (b) Selection menu and Donate feature

6.3 FINDINGS

There were three life course concepts and principles that were illustrated in the teams' designs. The themes were *turning points*, *linked lives* and *autonomy*.

6.3.1 Turning points

A key concept in the life course perspective was turning points, which “*involves a substantial change in the direction of one's life, whether subjective or objective.* (p. 8)” (Elder et al., 2003). Two prototypes related to turning points in their older adult team members' lives. Team B's prototype, the dietary assistance app, supports older adults with low vision and food allergies to shop and cook. This prototype was influenced by the topic of dietary needs that was discussed throughout their sessions. In session 1, dietary assistance was a sticky under the physical health category on their poster of shared understanding of health and well-being. In

session 2, June^{OA} shared her experience about eating out as someone who has allergies. She said, *“Can you do it this way, but I can’t have that, you have this can you substitute the potatoes for the polenta or whatever it is, so you drive people crazy.”* Wade^{OA} said, *“They also want your business.”* June^{OA} replied, *“Exactly, they want you to come back and meanwhile six people at the table are waiting for you to decide.”*

June^{OA} also shared that she had a detached retina but was able to regain her vision. The following year, she battled cancer and went to great lengths to learn about alternative medicine and ways to change her diet. Later, Amelia^{SD} shared that she also experienced visual challenges. Amelia^{SD} said she has been wearing glasses since she was four years old because of astigmatism in both eyes. She also shared a change in her diet. These experiences shared by June^{OA} and Amelia^{SD} directly influenced their persona and prototype.

Team C’s low-tech prototype was called De-Clutter and also highlights the concept of turning points. Their idea aimed to help older adults plan for a future move into a senior living community by helping them downsize their homes. The topic of downsizing started in session 1, where a sticky note on their team’s shared understanding of health and well-being poster said, *“sorting out belongings.”* Anna^{OA} and Nora^{OA} related to this sticky note because of experiences. In 2011, Nora^{OA} moved into a retirement community. Currently, Anna^{OA} is starting to plan to move into a senior living community. Anna^{OA} recounted a story about her friend who suddenly suffered a stroke and could no longer live independently. Her friend moved into a senior living community that had an opening, but it was not a good fit. Considering her friend’s experience, Anna^{OA} wanted to choose where she lives in the future, and so she had started to tour senior living communities.

This theme continued into their persona development. Their persona’s name was Richard

the Retired. His quote was, “*I want to live in the present while planning for the future.*” Team C decided to focus on downsizing during their brainstorming session. Nora^{OA} suggested downsizing as a design focus, and Anna^{OA} asked Nora^{OA} if she found it difficult to downsize. Anna^{OA} added, “*I’ve been downsizing for five years.*” Planning for a significant life change such as, moving from independent living to a senior living community was a need that seemed to surface throughout Team C’s sessions and ultimately became the design focus for their prototype. The life course perspective helped teams to surface health and well-being needs, and expand upon it through sharing personal histories that illustrate reasons why the need is important to them.

6.3.2 *Linked Lives*

Linked lives is a life course principle and is defined as “*dependence of the development of one person on the presence, influence, or development of another*” (p.116) (Wethington, 2005). All teams expressed that social connection was a factor in their shared understanding of health and well-being. Team A had a category called *connection* that included loved ones, friends, pets and community. During the timeline activity, Audrey^{OA} shared that when her family went camping she wandered off and got lost. She noted that a dog came and showed her the way back. Audrey^{OA} said, “*It gave me the sense of being unconnected to other people and how horrible that is.*” Team A had three prototypes, two of which had a social component. Discovery was a board game that engaged others to seek ideas for health challenges that people may encounter. Team A’s mobile app also engaged others by matching its users with others who may have had similar health experiences.

Team B had stickies under the category *fun and games* called social support, social activities and social combating isolation. Throughout their sessions, Team B pointed to social

connections such as the challenges of eating out with friends and family when living with dietary allergies. Their dietary assistance app prototype included a feature to connect with others with similar food allergies and even meet-up for a meal together. Another feature that had a social component was being able to see the foods other people who have similar allergies have purchased.

Team C had a category on their shared health and well-being poster called *social* with stickies referring to activities such as, going out with friends, taking care of others, and work-volunteer activities. Linked lives played a role in Team C's perception of the importance of planning for the transition from independent living to a senior living community. Anna^{OA} shared a story about her friend who had a health event which forced him to move from independent living to an assisted living facility. Anna^{OA} said since this move was urgent her friend had to move to a place that had an available space, leaving him with little choice of where to live. This experience played a role in her decision to be proactive in touring senior living communities and getting on waitlists. Team C's prototype was a mobile app called De-Clutter. It had features that connected older adults to family, friends, and the community to help them downsize the belongings in their home. Team C cited downsizing as a part of transitioning from independent living to community living.

Teams discussed social connection as a factor in their health and well-being, and demonstrated its importance by incorporating it into their prototypes. Social connections are recognized as having a positive impact on the quality of life of aging adults (Nassir, Leong, & Roberston, 2015). The life course perspective helped to bring out stories around social connections providing clues to reasons for the teams design direction or choices in features included in their prototype.

6.3.3 Independence

Being independent means “*not influenced or controlled by others in matters of opinion, conduct, etc.*” (Dictionary.com, n.d.). Independence relates to the life course principle of agency, where people's choices impact their life path (Elder et al., 2003). All three teams expressed independence as an essential factor in their understanding of health and well-being. Team A created a mountain to illustrate their shared understanding of health and well-being. At the top of that mountain were two stickies, one labeled joy, and the other labeled independence. Team C had a category on their shared understanding poster called *personal capacity*, and two of the stickies were “being able to do what you love” and “have choices in life.” Both teams conveyed independence as having choices in the way they want to live.

Teams A and B expressed agency in their attitude about living life and encountering life challenges. On their shared understanding poster, Team B had a category called mindfulness and spirituality, where they had stickies with the following phrases, “*feel positive,*” “*be in the moment,*” and “*be proactive.*” Audrey^{OA} on Team A said when people focus too much on their physical illness they can decline quicker. Kelly^{OA} agreed. One of Audrey^{OA}'s stickies was “humor” and she explained, “*if you take yourself too freakin' seriously you're just going to crab out.*” Both teams expressed independence as a choice in the way they respond to life's challenges.

Supporting the ability to make choices are demonstrated in the prototypes that the teams created. Team A's virtual reality prototype aimed to help older adults try out different experiences such as, an exercise class, or help older adults understand medical procedures they might be contemplating, such as, hip surgery. The latter example reflected Team A's design goal to support decision making and moving people forward to take action.

Team B's dietary assistance app aimed to support people with low vision and dietary allergies by helping

information and connection to others to support decision making.

6.4 DISCUSSION

This case study illustrated **how** the life course perspective influenced design ideas through sharing personal stories about health and well-being. Teams engaged in activities that explored their past and future, for example in session 2, teams took part in a timeline activity to share events that impacted their perception of health and well-being. In session 4, teams revisited their shared health and well-being poster (session 1) and their timeline (session 2) to narrow in on a design area and persona. Team members voted on areas that were important to them. These activities aimed to facilitate conversation about one another's views and to identify design opportunities.

There were three themes illustrated across the prototypes, *turning points*, *linked lives* and *independence*. Two teams' prototypes were inspired by *turning points* or momentous health and well-being life events shared by team members. *Linked lives* and *independence* were incorporated as features or goals in all the prototypes, illustrating the importance of these aspects of life to the teams.

Linked lives and *independence* themes support prior work in aging, such as models that identify and describe factors that contribute to the quality of life as individuals age (Nassir et al., 2015). Also, many technology innovations have been designed to support and improve social connection and independence such as social robots (PARO Robots, 2014), social communication technologies, for example, StoryVisit, that allows grandparents to connect with their grandchildren by virtually reading a story together (Raffle et al., 2011), and smart home

technologies (G. Demiris & Hensel, 2008) aimed to help older adults continue to live independently in their homes.

6.4.1 *Life course perspective contributions*

Our case study adds to prior work that utilizes the life course perspective to gain a deeper understanding of older adult needs and identify new design opportunities (Brown & De Schutter, 2016; Foong, 2016). We extended this work by illustrating how the life course perspective can be incorporated into co-design activities and influence design ideas. The timeline activity offered a way for team members to share their point of view of health and well-being through personal stories. The teams documented their events on a paper timeline providing a visual of their collective histories. The artifact was then incorporated in a future session (session 4) to identify moments that were of interest to them and an area for design opportunity.

One benefit of using the life course perspective was that it brought awareness of individual differences. This awareness is particularly relevant to designing with older adults because they have often been characterized as a homogenous group (Vines, Pritchard, et al., 2015). While this chapter has focused on the life course perspective in relation to older adults, the student designers also shared life events that influenced their health and well-being perceptions. Some of their experiences related to their older adult team members and also contributed to prototype designs. For example, Misty^{SD} shared “*autonomy*” as a health and well-being perception because her grandmother, who was in a wheelchair, had to rely heavily on a caretaker for a lot of activities such as going to the grocery store. Team A’s prototype aimed to support independence by providing opportunities for knowledge sharing about an issue that an older adult might be experiencing so they could make informed decisions. The life course perspective has been helpful for co-designing with intergenerational teams to broaden

understanding of health and well-being as a topic that is a part of life but is experienced in different ways because of time, place, social relationships, and other contextual factors that one may encounter throughout their lifetime.

Through these case studies, I also observed the complexity of health and well-being because teams expressed that many of the factors contributing to their perceptions and shared understanding were interconnected. Team A showed that the connections between the factors were tightly related because they built upon each other to reach joy and independence. Team B talked about the difficulty of categorizing and organizing their stickies because they overlapped and all seemed important.

Recognizing the complexity in health and well-being relates to my prior work with translating health information needs into design resources. I led a team in modifying the persona approach to create connected personas to show the importance of social relationships in supporting older adults in managing their personal health information (Sakaguchi-Tang, Turner, Taylor, & Kientz, 2019). The life course perspective allowed teams to gain a greater understanding of each other's perspectives. The teams then collaborated and negotiated to determine a design area. Most teams decided to scope their ideas to focus on one area.

Given the complexity of health and well-being there is an opportunity for co-design teams to explore ways their prototype could impact other factors of health and well-being. Activities such as, the future design workshop that focus on imagining a desired future (Vidal, 2006) could be a good exploration activity. Friedman and Hendry (2012) created envisioning cards based on their value sensitive design framework. It aimed to spark conversations among designers about their design or technology's long-term implications. These types of activities are related to the life course perspective in that they encourage designers to consider context and

implications of their technologies into the future.

Considerations for using the life course perspective in co-designing with an intergenerational team include building a deeper understanding of needs through sharing personal histories, highlighting the diversity of experiences and potential design opportunities based on the stories shared. However, discussing personal histories has the potential of bringing up sensitive conversations, which we discussed as a consideration for future studies in Chapter 5.

6.5 LIMITATIONS

The life course approach is used to understand changes in individual attitudes and the impact contextual factors can have throughout a person's lifetime (Hardy et al., 2015). A longitudinal study is typically the best method to observe changes over time, however, time and cost are high for this type of research (Franz et al., 2018). Our study was limited in both time and cost, but we wanted teams to have a broader understanding of each other's perceptions of health and well-being, so we used the life course perspective as an activity to explore their personal histories.

Since this case study was pulled from the same study in Chapter 5, it has the same limitations. The case study allowed us to focus on teams to understand how the life course perspective influenced their design ideas and prototypes. However, focusing on a subset of our teams limits the generalizability of our findings.

6.6 CHAPTER 6 SUMMARY

In this chapter, I presented a case study of three intergenerational co-design teams to illustrate the influence of the life course perspective on their design ideas and prototypes. Three themes related to the life course perspective and key concepts throughout the teams' design were

turning points, linked lives, and independence. The findings aligned with prior work that demonstrated the importance of social relationships and independence to the aging population. This work adds to existing literature by incorporating the life course perspective as a design activity that lead team members to gain a broader understanding of each other's perceptions of health and well-being and realize similarities and differences in their experiences across their lifetimes. Using the life course perspective created an opportunity to discuss life events and transitions that influenced the teams' design ideas and prototypes. Ultimately, this work illustrated the value of using the life course perspective with intergenerational teams engaging in co-design. Like learnings from developing design resources for health information designers (Chapter 4), this study showed the impact of loved ones on older adults' health and well-being, and in a prior chapter how loved ones can impact older adults' choice to use health technologies (Chapter 3). Designers should consider the role that these networks of relationships play when designing health technologies for older adults.

Chapter 7. Discussion

Across the studies in this dissertation, I have examined and explored ways to involve older adults in designing health technologies. This work is grounded in understanding the barriers and facilitators to using and adopting health information technologies, specifically electronic personal health records (ePHRs) and patient portals. Through this evaluation, we⁵ found opportunities for human centered design and participatory design approaches to understand ways these technologies can integrate better into the lives of older adults and identify features and functions not initially expected. Stemming from this work, I led the human centered design process to create personas and design guidelines for health information technology designers to raise awareness of the role that relationships and living situations have on ways that older adults manage their personal health information.

The interconnectedness of relationships, health, and aging demonstrate that involving older adults in the design process is essential. However, the added layer of societal perception of aging could influence how we design with older adults. To gain an understanding of how to challenge those perceptions and level collaboration, I led a co-design study. Through this study, we identified interactions between older adults and student designers that described their collaboration. We also used the life course perspective in our co-design activities to help team members broaden conversations about their health and well-being perceptions. Team members shared their personal histories allowing each other to gain greater context of one another's health and well-being perceptions. This activity increased team bonds and also showed how significant

⁵ “We” refers to the authors on the relevant paper as described earlier in this document.

life events can influence older adult needs and be a source of design ideas.

The studies in this dissertation were conducted before the restrictions imposed by the COVID-19 pandemic. However, these times have led me to consider how I could translate the methods I used to a remote setting. Several studies have demonstrated using video conferencing tools and online discussions to do research remotely during the pandemic (Chen et al., 2020; Nurain, Caldeira, & Connelly, 2021). The methods in this dissertation, specifically the focus groups with older adults, the design workshops with the student designers (Chapter 4), and the co-design sessions (Chapter 5), could leverage video conferencing technology such as, Zoom. However, an important consideration is how being remote would affect rapport between researchers and participants, especially in co-design sessions where the older adults and student designers aimed to form a team bond. A lack of connection could affect engagement in the sessions and design activities.

Additionally, many activities required participants to use physical items such as, sticky notes and poster paper. These activities could be done remotely using digital tools for example, Google Jamboard or interactive whiteboard. Prototyping in the design workshop (Chapter 4) and the co-design study (Chapter 5) could be scoped to digital solutions, such as online prototyping tools (e.g., proto.io or slide show technologies). However, using these tools to design may not be familiar to all participants and would challenge equal collaboration and impact creating a design partnership. As a result, researchers should consider low-tech alternative ways to prototyping activities such as, divvying up the design and using paper and pen to make prototypes.

Conducting the studies in this dissertation remotely would impact recruitment. If I were to use online tools, participants would need access to the Internet and feel comfortable using online tools. These criteria would skew participation to those who have access and have more technical

experience.

Through the work in this dissertation, I sought to reinforce awareness that older adults are more different than they are the same, and so are their needs and preferences. I demonstrated this through the personas and design guidelines we developed for health information technology designers (Chapter 4). From our co-design study, we adapted Yip et al (2017)'s framework to understand balanced and unbalanced interactions between older adults and student designers in creating low-tech health and well-being technologies (Chapter 5). We also delivered implications for co-designing with older adults and shared the benefits of using the life course perspective in the design process (Chapter 5 and 6).

The research in this dissertation with older adults focused on health topics that influenced the activities conducted, especially in the co-design study. I chose activities that aimed to create a common ground within intergenerational teams because health and well-being are life-long topics that people can interpret differently. Additionally, compared to other topics such as, entertainment, where the focus may be on the individual, health and well-being are complex, spanning time and place, and involve other people such as, family and friends. To capture those experiences, the teams engaged in a timeline activity where they shared health and well-being events across their lifetime. They talked about health issues they experienced and other events. For example, moving to an assisted living facility and losing loved ones. This chapter will discuss the themes that ran through my studies, specifically the complexity in health and well-being, challenging aging perspectives, and considerations for co-designing with older adults.

7.1 DISCOVERING COMPLEXITY

One theme observed throughout my studies is that involving older adults in the design process surfaces the complexities of their needs. Through the systematic literature review, we

learned that there were varying factors that contribute to the use and adoption of patient portals and ePHRs, including demographic factors, preferences, experience with technology and relationships with others (Chapter 3). I experienced this when creating personas and design guidelines for health information technology designers (Chapter 5). These design resources aimed to communicate how older adults manage their personal health information (PHIM). Through the human centered design process we learned that older adults' relationships and living situations played a key role. We knew we needed to demonstrate this added complexity in the design resources. So, I led expanding the persona format and created *connected personas* to show the differences in older adults' life situations and the network of people that support and influence their PHIM. It was important to show this complexity because it reflected the reality of PHIM for older adults. Also, it challenged the typically held assumptions about older adults and the tendency to apply those assumptions broadly across the aging population (Vines, Pritchard, et al., 2015). This work contributes to the need to embrace this complexity by expanding the boundaries of the design process (Blandford, 2019).

In the co-design study I led, we also saw how life experiences influenced the perceptions of health and well-being among older adults and student designers. During an activity where teams worked together to establish a shared understanding of health and well-being, they pointed out how the categories they created were connected to each other (Chapter 6). They noted how some categories were dependent on others, such as how access to resources can affect the ability to stay healthy and active. This activity highlighted how health and well-being factors are intertwined with their life experiences.

Building upon their shared understanding, the teams engaged in a timeline activity to learn about life events that affected their views of health and well-being. Through these

activities, we gained a contextual understanding of the teams' perception of health and well-being and the many factors that support older adults' health and well-being goals. This study shows the complexities designers face in identifying and prioritizing the needs of older adults, in particular for health and well-being technologies. However, designing with older adults provides an opportunity to gain a real understanding of their needs (Davidson & Jensen, 2013b) and ways their needs are influenced by their life course (Brown, 2012). In addition, designers should consider implications of their designs and how it will support older adults in the future.

7.2 CHALLENGING AGING PERCEPTIONS

The studies in this dissertation have drawn attention to the differences between older adults and the need to challenge the typical way we refer to the aging population as a homogenous group. It also advocates for broadening the design scope to the strengths of aging or *positive design* (Carroll et al., 2012). For a long time, design efforts have focused on the losses of aging or *deficit driven design* (Carroll et al., 2012; Vines, Pritchard, et al., 2015). While it is necessary to have a focus on these needs, we miss opportunities to support older adults at different stages of their lives.

I showed the differences between older adults and their context through the six sets of connected personas and design guidelines we developed as design resources for health information technology designers (Chapter 4). The sets showed different living situations such as living independently, living in a retirement community and living in an assisted living facility. They also featured the various relationships that impact how older adults manage their PHIM. Having six sets of connected personas showed a variety of life circumstances that influence the needs and goals that health technologies should support. Student designers who participated in

design workshops to evaluate the personas and design guidelines expressed that the connected personas provided them with a holistic picture of the older adults' situation and a better understanding of the design space (Chapter 4).

My co-design study challenged the aging assumptions held by younger adult student designers. Prior research has demonstrated that when younger adults spend time with older adults it can help to reduce their aging stereotypes (Hernandez & Gonzalez, 2008). After their co-design session, student designers reflected on their experiences and recognized that their expectations of working with older adults were challenged. They acknowledged that they shared commonalities with their older adult counterparts about their perceptions of health and well-being. However, the student designers also found it difficult to relate sometimes because of the differences in years lived and experienced. I argue that co-designing with older adults can be an approach that not only brings designers closer to the real needs of older adults but also provides an opportunity for designers to recognize their assumptions about aging and reflect on how it can influence their design choices.

We also captured insights from older adults about their experiences in the co-design study. They saw the value of the method and expressed how it differed from what they expected of the study. They noted that it was fun and they enjoyed being creative. A couple of older adults said they were surprised that they could translate their design ideas into a prototype in one session. Some said they thought they would be asked to evaluate technologies and that they would feel like "test subjects" (Chapter 5). This sentiment aligned with the typical role that older adults play in the design process, which is primarily providing feedback on designs and participating in idea generation (Merkel & Kucharski, 2019). Engaging older adults in co-design as design partners throughout the process communicates to them the value of their involvement

and offers a different experience than they are accustomed to with design.

7.3 CONSIDERATIONS FOR CO-DESIGNING WITH OLDER ADULTS

In this section, I reflect upon designing with older adults and present considerations for future engagements. Leading the development of design guidelines for health information technology designers and practitioners provided me with the foundation for planning my co-design study with older adults and student designers. The guidelines were based upon findings from the SOARING project, a review of literature and best practices. Considerations such as partnering with senior communities, schedule flexibility, accommodating older adults' needs, and showing participant appreciation were factors included in my planning for the co-design study.

In the co-design study, I aimed to understand the interactions that contribute to equal collaboration in intergenerational teams. As part of preparing for the study, I also considered the experience of participating in the study. It translated into how I worked with site partners, planned sessions, and the reasons I incorporated students' reflection activities. I believe that attention to these details communicated to participants the value of their participation. The below considerations were highlighted in chapter 5 and chapter 6.

- 1. Partner with the site coordinators.** Connecting with site coordinators during study planning was essential to ensure that the study aligned with their residents' and clients' interests. I met with site coordinators a few times before starting the study to share the study goals, activities, and to plan recruitment. Partnering with site coordinators supports prior work that found establishing relationships with service providers was key to recruiting older adults because they were often viewed as gatekeepers and can support study activities such as, setting up the facility and helping to get the word out about the

study (McHenry et al., 2015). While this partnership can provide connections to older adults, it can also pose challenges, for example, the time required to find sites and develop relationships with site partners. Additionally, site partners may have little knowledge about co-design and so it may not be clear what they are signing up for (Mankoff, 2006). It is recommended that the outcomes be communicated to sites to prepare them for the study (Mankoff, 2006).

- 2. Involve older adults and student designers study planning.** Feedback from older adults about the co-design study was that they wanted longer and more sessions. I collaborated with site coordinators on the number and length of sessions. For future studies, it seems beneficial to include older adults in conversations about the study structure and activities (Huldtgren, Detweiler, Alers, Fitriani, & Guldmond, 2013; Righi, Sayago, Rosales, Ferreira, & Blat, 2018). Involving older adults in these discussions could help better align the sessions to their expectations. Participation in the planning process could also help to facilitate equal collaboration during co-design. In our study, we found that student designers typically took the lead in guiding the activity's direction (Chapter 5). If older adults were more involved in study planning, it could encourage them to take ownership of the process and increase likelihood to take the lead in activities which would help to level collaboration.
- 3. Consider team size and maintaining consistency.** During the co-design study, some team members were missing a couple of sessions, and we decided to merge groups just for that one session. We found that it interrupted team dynamics and led some to withdrawal from the activity. At the end of the study, some older adults noted they appreciated the team's size and ratio, typically four team members, (two older adults, and

two student designers). One older adult noted that she liked working in one team throughout the study. So decisions about the team size and consistency are important to think about for participant experience and team dynamics, both of which can influence collaboration.

- 4. Incorporate life course perspective into co-design activities.** By including activities influenced by the life course perspective, we gained a deeper understanding behind team members' perceptions of health and well-being. This finding supports past research that has used a life course perspective to get a deeper understanding of needs for game design (Brown, 2012). Also, sharing life experiences helped members to develop a bond with each other.
- 5. Prepare student designers for potential of sensitive conversations.** Both older adults and student designers demonstrated a willingness to share life experiences and stories. Although this was valuable to understanding each other and developing a connection with each other, it can also lead to sensitive topics being discussed. We observed an instance where an older adult team member shared a perception of health and well-being related to the later phase in her life. The student designers moved the conversation forward rather than responding to it. In their reflection, the student designers noted that they didn't know how to respond to that comment. This interaction proved the need to prepare students for potentially sensitive conversations that may arise during discussions, especially around health and well-being.
- 6. Design reflection activities for older adults and student designers.** The student designers participated in the co-design sessions and also in weekly reflection activities. In chapter 5, we pointed out that these activities provided an opportunity for the student

designers to think deeply about their experiences in the co-design sessions and share those experiences with fellow student designers. Reflection activities are recognized practice among designers and raise awareness of their values and assumptions in the design process (Sengers et al., 2005). The older adult participants in our study did not have the same reflection activities because of time constraints. Reflection activities involving older adults should be included in future co-design studies with older adults because they are co-designers in the process and may also hold their assumptions about older adults and aging (Gendron, Welleford, Inker, & White, 2016).

7.4 CONTRIBUTIONS

The first contribution of this work is a survey of the use and adoption of patient portals and ePHRs, by synthesizing literature across a decade and identifying the barriers and facilitators. To date, even though there has been research about the use of patient portals and ePHRs, there has been less work on the use of these technologies by older adults. I also examined the user experience of these technologies and how older adults were involved in the process. I identified the opportunities for approaches that integrate older adults, such as, the human centered design and participatory design approaches.

The second contribution of this work is translating empirical findings about how older adults manage their personal health information into personas and design guidelines. We expanded the typical format of personas into *connected personas* to show the interconnected relationships of family, friends, and health care providers with older adults about their personal health information management. Also, I contributed new knowledge about the benefit of using the life course perspective for co-design activities. The life course perspective provided a space for team members to share personal histories leading to deeper understanding of each other. We

found that the team members' stories were represented in life course principles and were a source of inspiration for design ideas.

The third contribution is methodological. Through the co-design study I led, we adapted a framework used to identify interactions that contribute to creating design partnerships with adult designers and children (Yip et al., 2017) to older adults and student designers. With this framework, we examined dimensions including relationship building, elaboration, and design-by-doing, and expanded the facilitation into two sub-dimensions: facilitating the activity and facilitating the discussion. Both of these dimensions capture that weight of collaboration can be affected by who sets the activities' direction and whether both older adults and student designers participated in discussions.

7.5 FUTURE WORK

The aim of co-designing with older adults in this dissertation was to understand the factors that facilitate equal collaboration and foster design partnership. However, there is room to grow and deepen the value of co-design to deliver health and well-being technologies that meet older adults' needs and support their goals. Future work can draw designers and older adults closer together in the design process and better support equal collaboration. Also, more exploration is needed to better understand how to translate academic research into user experience practice.

7.5.1 *Design perspectives*

Using the life course perspective in co-design activities demonstrated an increased bond between intergenerational team members and a greater understanding of older adults' health and well-being needs. However, other approaches that explore individuals' past or future may also

lead to a greater understanding of older adult needs and opportunities for design ideas. One approach is called historical analysis, which involves using a variety of sources, such as newspaper reports, diaries, patents, and oral histories, to consider how past events influence the preferences and behaviors of users, for example, the consideration of how housework can perpetuate gendered roles into designing smart homes (Wyche, Sengers, & Grinter, 2006). Researchers can incorporate historical analysis into design activities. For example, Wyche et al. (2006) used photo elicitation to facilitate conversations about memories around a particular topic, much like the timeline activity we used in our co-design study. Like the life course perspective, this approach aims to understand the impact of past events on current perceptions and behaviors. However, the life course perspective also incorporates other aspects of life, including agency, human development, and relationships (Elder & Johnson, 2003). These aspects helped us better understand the decisions teams made in developing their prototypes.

Another perspective that could be useful in co-designing with older adults is *Envisioning Cards* (Friedman & Hendry, 2012). These cards are derived from the value sensitive design approach that considers human values in the design process (Friedman, Kahn Jr., & Borning, 2008). The cards aim to spark recognition of issues in design and are based on four key concepts, stakeholder, time, value, and pervasiveness. The **stakeholder** refers to people who may come in contact with the technology, **time** referring to the long-term implications of the technology, **value** refers to what is essential to the individual. **Pervasiveness** refers to the adoption of the technology (Friedman & Hendry, 2012). While the Envisioning Cards focus on the impact of the technology on the individual, they help explore future implications of the technologies, which is an opportunity for the life course approach.

7.5.2 *Community Based Co-design*

Exploring community-based co-design could be a next step. It shifts focus from older adults to the community in which they are situated. For recruitment, this means age would not be the criteria for participation in the study. Doing so can mitigate issues researchers have encountered when attributing biological age to the term "older adult" which conflicted with the self-identity of the participant (Brandt, Binder, Malmborg, & Sokoler, 2010; Huldtgren et al., 2013). I tried to take that approach in my co-design study by working with sites where older adults were the primary clients and residents. This recruitment approach worked well because the people who participated self-identified as older adults, they were interested in technology, willing to collaborate in groups and turn ideas into something tangible.

The community-based co-design approach also encourages researchers to embed themselves in the community to drive ideas that are relevant to their values, goals, interests, and practices (Huldtgren et al., 2013; Righi et al., 2017). It moves away from centering the design process around technology-oriented solutions and instead toward solutions that are community-oriented (Harrington, Erete, & Piper, 2019; Righi et al., 2017). Organizing around what's important to the community means working with them to define study goals. This approach would increase transparency of study outcomes, which is an important piece for communicating how participants' feedback would be used (Huldtgren et al., 2013). In the co-design study, the topic was defined as health and well-being. It was a broad topic and relevant to the participants; however, if the community drove the topic, it may have furthered their investment in idea creation, negotiation, and equal collaboration.

7.5.3 *Translating Findings to Practice*

The studies in this dissertation focused on examining ways to improve designing health

technologies through co-designing with older adults. Teams created low-tech prototypes of health technologies to solve real issues, for example, helping older adults downsize their homes to move to a senior living community. However, it was a hypothetical product. If we were developing an actual product, we would need to consider other parts of the design process, the user and their needs, for example, the business and technologies arms of the design process (Alan Cooper, Reimann, Cronin, & Noessel, 2014). Some considerations would be the cost and time it takes to build the technology and take it to market. These factors play a role in design decisions and could lead to negotiating features and functions. For example, one team created a prototype of a VR headset that would be comfortable and less bulky. The VR technology would allow older adults to experience a medical procedure virtually to help them decide whether they should go through with the procedure in real life. Cost and time would be factors in designing this product to determine the feasibility of creating a comfortable headset and developing the technology. These evaluations would influence the design decisions and probably change the team's original prototype. While co-designing with older adults is ideal, mainly because it can lead to products that better align with the needs of older adults, it is only one facet of the design process. Future work should consider how researchers can communicate knowledge about co-designing with older adults from research to design practice.

Translating research to practice is a known challenge in HCI because academic content is difficult to access and complex to understand (Colusso, Bennett, Hsieh, & Munson, 2017; Velt, Benford, & Reeves, 2020). Prior work has recommended that academic researchers and practitioners work together to translate knowledge into actionable resources, such as, design tools or visual examples of theories that could inform understanding, brainstorming, building, and advocacy (Colusso et al., 2017; Velt et al., 2020). They also suggested that researchers share

knowledge in design communities, for example, UXPA and SIGHCHI (Colusso et al., 2017).

Communicating the value of designing with older adults through actionable guidelines or design tools can raise awareness and make co-designing with older adults applicable to the design process.

Chapter 8. Conclusion

The work in this dissertation has focused on understanding the needs of older adults and advocating for their inclusion in the design process. The aging population has often been left out of the design process. Through the work in this dissertation, I led a survey of literature to gain a foundational understanding of the barriers and facilitators of adopting ePHRs and patient portals by older adults. We identified an opportunity for older adults to have a more involved role in the design process.

I led the human centered design process to translate study findings of how older adults manage their personal health information into design resources, specifically personas and design guidelines for health information technology designers. Through these resources, we wanted to communicate to designers the complexity of personal health information management for older adults and to consider this when designing health information technologies for them. We showed this complexity by expanding the persona format to include relationships, such as, family, friends, and health care providers who play a role in how older adults manage their health information. The resources were iterated through feedback from older adults and designers.

Embracing the complexity through design resources demonstrated the need to involve older adults throughout the design process. I led a co-design study with intergenerational teams to understand the interactions that can lead to design partnerships. Co-designing with older adults

also led student designers to challenge their assumptions of aging. Our design activities were guided by the life course perspective, which provided a broader context for team members to share common ground behind their health and well-being perceptions. It also guided us to understand how personal histories influence design ideas and decisions. We gained a better understanding of the interactions that facilitate equal and equitable collaboration by adapting and extending a framework of dimensions typically used to understand adult-child design partnerships (Yip et al., 2017). We provided considerations for future co-designing work with older adults, including involving them in study planning, preparing participants for sensitive conversations, and implementing reflection activities for both student designers and older adults.

REFERENCES

- Alzheimer's Association. (n.d.). What is Alzheimer's?
- Ancker, J. S., Hafeez, B., & Kaushal, R. (2016, August 1). Socioeconomic disparities in adoption of personal health records over time. *American Journal of Managed Care*. Ascend Media. Retrieved from <http://www.cdc.gov/>
- Ancker, J. S., Witteman, H. O., Hafeez, B., Provencher, T., Van De Graaf, M., & Wei, E. (2015). The invisible work of personal health information management among people with multiple chronic conditions: Qualitative interview study among patients and providers. *Journal of Medical Internet Research*, 17(6), e137. <https://doi.org/10.2196/jmir.4381>
- Anderson, M., & Perrin, A. (2017). Tech adoption climbs among older adults. *Pew Research Center*, (May), 1–22. Retrieved from <http://www.pewinternet.org/2017/05/17/technology-use-among-seniors/>
- Arch, A., & Abou-Zahra, S. (2010). Developing Websites for Older People: How Web Content Accessibility Guidelines (WCAG) 2.0 Applies. Retrieved March 9, 2019, from <https://www.w3.org/WAI/older-users/developing/>
- Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbin, K. A., & Straus, S. E. (2011, July). Personal health records: A scoping review. *Journal of the American Medical Informatics Association*. J Am Med Inform Assoc. <https://doi.org/10.1136/amiajnl-2011-000105>
- Baker, S., Waycott, J., Carrasco, R., Hoang, T., & Vetere, F. (2019). Exploring the design of social VR experiences with older adults. In *DIS 2019 - Proceedings of the 2019 ACM Designing Interactive Systems Conference* (pp. 303–315). <https://doi.org/10.1145/3322276.3322361>
- Barron, J., Bedra, M., Wood, J., & Finkelstein, J. (2014). Exploring three perspectives on feasibility of a patient portal for older adults. In *Studies in Health Technology and Informatics* (Vol. 202, pp. 181–184). IOS Press. <https://doi.org/10.3233/978-1-61499-423-7-181>
- Behkami, N. a, & Dorr, D. a. (2009). User centered design in complex healthcare workflows: the case of care coordination and care management redesign. *Annual Symposium Proceedings / AMIA Symposium*. *AMIA Symposium, 2009*, 39–43.
- Beimborn, M., Kadi, S., Koberer, N., & Muhleck, M. (2016). Focusing on the Human:

- Interdisciplinary Reflections on Ageing and Technology. In E. Dominguez-Rue & L. Nierling (Eds.), *Ageing and Technology* (pp. 311–334). <https://doi.org/10.14361/9783839429570-015>
- Bennett, C. L., & Rosner, D. K. (2019). The promise of empathy: Design, disability, and knowing the “other.” *Conference on Human Factors in Computing Systems - Proceedings*, 1–13. <https://doi.org/10.1145/3290605.3300528>
- Beyer, H., & Holtzblatt, K. (1998). *Contextual design: defining customer-centered systems*. Morgan Kaufmann Publishers.
- Binda, J., Wang, X., & Carroll, J. M. (2018). Recruiting Older Adults in the Wild : Reflections on Challenges and Lessons Learned from Research Experience. *PervasiveHealth*, 2–5. <https://doi.org/10.1145/3240925.3240947>
- Blandford, A. (2019). HCI for health and wellbeing: Challenges and opportunities. *International Journal of Human Computer Studies*, 131, 41–51. <https://doi.org/10.1016/j.ijhcs.2019.06.007>
- Blomquist, Å., & Arvola, M. (2002). Personas in action: ethnography in an interaction design team. *Proceedings of the Second Nordic Conference on Human-Computer Interaction - NordiCHI '02*, 197. <https://doi.org/10.1145/572020.572044>
- Blythe, M., Monk, A., & Park, J. (2002). Technology biographies: field study techniques for home use product development. In *CHI'02 Extended Abstracts on Human Factors in Computing Systems* (pp. 658–659). <https://doi.org/10.1145/506486.506532>
- Brandt, E., Binder, T., Malmberg, L., & Sokoler, T. (2010). Communities of everyday practice and situated elderliness as an approach to co-design for senior interaction, 400. <https://doi.org/10.1145/1952222.1952314>
- Brereton, M. (2013). Habituated objects. *Interactions*, 20(4), 20. <https://doi.org/10.1145/2486227.2486233>
- Brown, J. A. (2012). Let’s play: Understanding the role and meaning of digital games in the lives of older adults. *Proceedings of the International Conference on the Foundations of Digital Games - FDG '12*, 273. <https://doi.org/10.1145/2282338.2282396>
- Brown, J. A., & De Schutter, B. (2016). Game Design for Older Adults: Lessons from a Life Course Perspective. *International Journal of Gaming and Computer-Mediated Simulations*, 8(1),

1–12. <https://doi.org/10.4018/IJGCMS.2016010101>

Bureau of Labor Statistic U.S. Department of Labor. (2018). Occupational Outlook Handbook, Social Workers. Retrieved March 8, 2019, from <https://www.bls.gov/ooh/community-and-social-service/social-workers.htm>

Caine, K. E., Fisk, A. D., & Rogers, W. A. (2006). Benefits and privacy concerns of a home equipped with a visual sensing system: A perspective from older adults. In *Proceedings of the Human Factors and Ergonomics Society* (pp. 180–184).

<https://doi.org/10.1177/154193120605000203>

Caine, K. E., Zimmerman, C. Y., Schall-Zimmerman, Z., Hazlewood, W. R., Sulgrove, A. C., Camp, L. J., ... Shankar, K. (2010). DigiSwitch: Design and evaluation of a device for older adults to preserve privacy while monitoring health at home. In *IHI'10 - Proceedings of the 1st ACM International Health Informatics Symposium* (pp. 153–162).

<https://doi.org/10.1145/1882992.1883016>

Carayon, P. (2009). The balance theory and the work system model. Twenty years later. *International Journal of Human-Computer Interaction*, 25(5), 313–327.

<https://doi.org/10.1080/10447310902864928>

Carroll, J. M., Convertino, G., Farooq, U., & Rosson, M. B. (2012). The firekeepers: Aging considered as a resource. *Universal Access in the Information Society*, 11(1), 7–15.

<https://doi.org/10.1007/s10209-011-0229-9>

Centers for Disease Control Prevention CDC. (2016). What is health literacy?

Chapman, C. N., & Milham, R. P. (2006). The Personas' New Clothes: Methodological and Practical Arguments against a Popular Method. *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, 50(5), 634–636.

<https://doi.org/10.1177/154193120605000503>

Chen, A. T., Ge, S., Cho, S., Teng, A. K., Chu, F., Demiris, G., & Zaslavsky, O. (2020). Reactions to COVID-19, information and technology use, and social connectedness among older adults with pre-frailty and frailty Annie. *Geriatric Nursing*, (January), 1–8.

Coleman, G. W., Gibson, L., Hanson, V. L., Bobrowicz, A., & McKay, A. (2010). Engaging the Disengaged: How do we Design Technology for Digitally Excluded Older Adults? *Proceedings*

of the 8th ACM Conference on Designing Interactive Systems, 175–178.

<https://doi.org/10.1145/1858171.1858202>

Colusso, L., Bennett, C. L., Hsieh, G., & Munson, S. A. (2017). Translational resources: Reducing the gap between academic research and HCI practice. In *DIS 2017 - Proceedings of the 2017 ACM Conference on Designing Interactive Systems* (pp. 957–968).

<https://doi.org/10.1145/3064663.3064667>

Consolvo, S., Roessler, P., Shelton, B. E., LaMarca, A., Schilit, B., & Bly, S. (2004). Technology for Care Networks of Elders. *Pervasive Computing*, 22–29.

<https://doi.org/10.4017/gt.2008.07.04.008.00>

Cooper, A., Reimann, R., Cronin, D., & Noessel, C. (2014). *About face: the essentials of interaction design*. John Wiley & Sons.

Cooper, Alan, Reimann, R., Cronin, D., & Noessel, C. (2014). *About Face: The Essentials of Interaction Design*. Wiley (4th ed.). John Wiley & Sons. <https://doi.org/10.1007/s13398-014-0173-7.2>

Covidence. (2017). Covidence.

Cozza, M., De Angeli, A., & Tonolli, L. (2017). Ubiquitous technologies for older people. *Personal and Ubiquitous Computing*, 21(3), 607–619. <https://doi.org/10.1007/s00779-017-1003-7>

Creswell, J. W., & Poth, C. N. (2018). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (4th ed.). Thousand Oaks, CA: SAGE Publications.

Culter, S. J. (2005). Ageism and Technology. *Generations*, 29(3), 67–72.

Czaja, S. J., & Lee, C. C. (2007). The impact of aging on access to technology. *Universal Access in the Information Society*, 5(4), 341–349. <https://doi.org/10.1007/s10209-006-0060-x>

Czaja, S. J., Zarcadoolas, C., Vaughn, W. L., Lee, C. C., Rockoff, M. L., & Levy, J. (2015). The usability of electronic personal health record systems for an underserved adult population. *Human Factors*, 57(3), 491–506. <https://doi.org/10.1177/0018720814549238>

Dabbs, A. D. V., Myers, B. A., McCurry, K. R., Dunbar-Jacob, J., Hawkins, R. P., Begey, A., & Dew, M. A. (2009). User-Centered Design and Interactive Health Technologies for Patients.

Comput Inform Nurs, 27(3), 1–16. <https://doi.org/10.1097/NCN.0b013e31819f7c7c>. User-Centered

Dam, R. F., & Siang, T. Y. (n.d.). Define and Frame Your Design Challenge by Creating Your Point Of View and Ask “How Might We.” Retrieved from <https://www.interaction-design.org/literature/article/define-and-frame-your-design-challenge-by-creating-your-point-of-view-and-ask-how-might-we#:~:text=“We use the How Might,perfect frame for innovative thinking.”>

Dam, R. F., & Siang, T. Y. (2020). Introduction to the Essential Ideation Techniques which are the Heart of Design Thinking. Retrieved March 4, 2021, from <https://www.interaction-design.org/literature/article/introduction-to-the-essential-ideation-techniques-which-are-the-heart-of-design-thinking>

Damodaran, L. (1996). User involvement in the systems design process-a practical guide for users. *Behaviour & Information Technology*, 15(6), 363–377. <https://doi.org/10.1080/014492996120049>

Davidson, J. L., & Jensen, C. (2013a). Participatory Design with Older Adults : An Analysis of Creativity in the Design of Mobile Healthcare Applications. *C&C '13: Proceedings of the 9th ACM Conference on Creativity & Cognition*, 114–123. <https://doi.org/https://doi.org/10.1145/2466627.2466652>

Davidson, J. L., & Jensen, C. (2013b). What health topics older adults want to track:A Participatory Design Study. In *ASSETS '13: Proceedings of the 15th International ACM SIGACCESS Conference on Computers and Accessibility* (pp. 1–8). New York, New York, USA: ACM Press. <https://doi.org/https://doi.org/10.1145/2513383.2513451>

Davis, J. (2017a). Molina healthcare breached, exposed patient data for over a month.

Davis, J. (2017b). Phishing attack on UC Davis health breaches data on 15,000 patients.

De Keizer, N. F., Talmon, J., Ammenwerth, E., Brender, J., Nykanen, P., & Rigby, M. (2010). Mini stare-HI: Guidelines for reporting health informatics evaluations in conference papers. *Studies in Health Technology and Informatics*, 160(PART 1), 1206–1210. <https://doi.org/10.3233/978-1-60750-588-4-1206>

Demiris, G., & Hensel, B. K. (2008). Technologies for an aging society: a systematic review of

“smart home” applications. *Yearbook of Medical Informatics*, 33–40. <https://doi.org/10.1055/s-0038-1638580>

Demiris, George, Oliver, D. P., Dickey, G., Skubic, M., & Rantz, M. (2008). Findings from a participatory evaluation of a smart home application for older adults. *Technology and Health Care*, 16(2), 111–118. <https://doi.org/10.3233/THC-2008-16205>

Dictionary.com. (n.d.). Independent.

Dittmar, A., & Hensch, M. (2015). Two-Level Personas for Nested Design Spaces. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15*, 3265–3274. <https://doi.org/10.1145/2702123.2702168>

Druin, A. (1999). Cooperative inquiry: developing new technologies for children with children. *Conference on Human Factors in Computing Systems*, 592–599. <https://doi.org/10.1145/302979.303166>

Druin, A. (2002). The role of children in the design of new technology. *Behaviour and Information Technology*, 21(1), 1–25. <https://doi.org/10.1080/01449290110108659>

Dubberly, H. (2004). *How do you design?* Retrieved from <http://www.dubberly.com/articles/how-do-you-design.html>

Durick, J., Robertson, T., Brereton, M., Vetere, F., & Nansen, B. (2013). Dispelling ageing myths in technology design. In *OzCHI '13: Proceedings of the 25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration* (pp. 467–476). New York, New York, USA: ACM Press. <https://doi.org/10.1145/2541016.2541040>

Elder, G. H., & Johnson, M. K. (2003). The Life Course and Aging: Challenges, Lessons, and New Directions. In R. A. Settersten (Ed.), *Invitation to the Life Course: Toward New Understanding of Later Life* (pp. 49–81). New York: Baywood Publishing Company.

Elder, G. H., Johnson, M. K., & Crosnoe, R. (2003). The Emergence and Development of Life Course Theory. In *Handbook of the Life Course* (pp. 3–19). https://doi.org/10.1007/978-0-306-48247-2_1

Ellis, R. D., & Cochran, D. L. (1999). Practices to encourage participation of older adults in research and development. *CHI '99 Extended Abstracts on Human Factors in Computing*

Systems - CHI '99, (May), 39. <https://doi.org/10.1145/632716.632744>

Ellis, R. D., & Kurniawan, S. H. (2000). Increasing the Usability of Online Information for Older Users: A Case Study in Participatory Design. *International Journal of Human-Computer Interaction*, 12(2), 263–276. https://doi.org/10.1207/S15327590IJHC1202_6

Epic. (2016). Patient engagement.

Ferri, G., Bardzell, J., & Bardzell, S. (2017). Rethinking Age in HCI Through Anti-Ageist Playful Interactions. *Interacting with Computers*, 29(6), 779–793. <https://doi.org/10.1093/iwc/iwx012>

Fisk, A. D., Rogers, W. A., Charness, N., Czaja, S. J., & Sharit, J. (2009). *Designing for Older Adults: Principles and Creative Human Factors Approaches* (2nd ed.). Boca Raton, FL. <https://doi.org/10.1201/b22189>

Foong, Pi. S. (2016). The Value of the Life Course Perspective in the Design of Mobile Technologies for Older Adults. In *Mobile Communication and the Family* (pp. 165–181). <https://doi.org/10.1007/978-94-017-7441-3>

Ford, E. W., Hesse, B. W., & Huerta, T. R. (2016). Personal Health Record Use in the United States: Forecasting Future Adoption Levels. *Journal of Medical Internet Research*, 18(3), e73. <https://doi.org/10.2196/jmir.4973>

Franz, R., Findlater, L., & Wobbrock, J. O. (2018). Lost in Transition: The Importance of Conceptualizing Aging as a Process in Accessibility Research. In *CHI '18 Workshop on Designing Interactions for the Ageing Populations* (pp. 53–58).

Frennert, S., Efrting, H., & Ostlund, B. (2013). Older People's Involvement in the Development of a Social Assistive Robot. In G. Hermann, M. J. Pearson, A. Lenz, P. Bremner, A. Spiers, & U. Leonards (Eds.), *Social Robotics. ICSR 2013. Lecture Notes in Computer Science* (Vol. 8239). Springer, Cham.

Friedman, B., & Hendry, D. G. (2012). The Envisioning Cards: A toolkit for catalyzing humanistic and technical imaginations. In *Conference on Human Factors in Computing Systems - Proceedings* (pp. 1145–1148). <https://doi.org/10.1145/2207676.2208562>

Friedman, B., Kahn Jr., P. H., & Borning, A. (2008). *Value Sensitive Design and Information*

- Systems*. (K. E. Himma & H. T. Tavani, Eds.), *The Handbook of Information and Computer Ethics*. Hoboken, New Jersey: John Wiley and Sons Inc. <https://doi.org/10.1145/242485.242493>
- Friedman, B., & Nathan, L. P. (2010). Multi-lifespan information system design. In *Proceedings of the 28th international conference on Human factors in computing systems - CHI '10* (Vol. 4, p. 2243). New York, New York, USA: ACM Press. <https://doi.org/10.1145/1753326.1753665>
- Friemel, T. N. (2016). The digital divide has grown old: Determinants of a digital divide among seniors. *New Media and Society*, 18(2). <https://doi.org/10.1177/1461444814538648>
- Friess, E. (2012). Personas and Decision Making in the Design Process : An Ethnographic Case Study. *Conference on Human Factors in Computing Systems*, 1209–1218. <https://doi.org/10.1145/2207676.2208572>
- Furco, A. (1996). Service-Learning: A Balanced Approach to Experiential Education. In B. Taylor (Ed.), *Expanding Boundaries: Serving and Learning* (pp. 2–6). Washington, DC: Corporation for National Service.
- Gardner, P., & Alegre, R. (2019). “Just like us”: Increasing awareness, prompting action and combating ageism through a critical intergenerational service learning project. *Educational Gerontology*, 45(2), 146–158. <https://doi.org/10.1080/03601277.2019.1584976>
- Garschall, M., Hamm, T., Hornung, D., Muller, C., Neureiter, K., Schorch, M., & van Velsen, L. (2016). Challenges and experiences in designing for an ageing society. Reflecting on concepts of (age)ing and communication practices. In *Proceedings of the COOP 2016-Symposium on challenges and experiences in designing for an ageing society* (Vol. 13). Retrieved from https://www.iisi.de/wp-content/uploads/2018/07/irsi_vol13-iss3_2016.pdf
- Gendron, T. L., Welleford, E. A., Inker, J., & White, J. T. (2016). The language of ageism: Why we need to use words carefully. *Gerontologist*, 56(6), 997–1006. <https://doi.org/10.1093/geront/gnv066>
- Giacomin, J. (2016). What Is Human Centred Design ?, 6925(July). <https://doi.org/10.2752/175630614X14056185480186>
- Goldzweig, C. L., Orshansky, G., Paige, N. M., Towfigh, A. A., Haggstrom, D. A., Miake-Lye, I., ... Shekelle, P. G. (2013, November 19). Electronic patient portals: Evidence on health outcomes, satisfaction, efficiency, and attitudes. *Annals of Internal Medicine*.

<https://doi.org/10.7326/0003-4819-159-10-201311190-00006>

Gordon, N. P., & Hornbrook, M. C. (2016). Differences in access to and preferences for using patient portals and other ehealth technologies based on race, ethnicity, and age: A database and survey study of seniors in a large health plan. *Journal of Medical Internet Research, 18*(3).

<https://doi.org/10.2196/jmir.5105>

Graetz, I., Gordon, N., Fung, V., Hamity, C., & Reed, M. E. (2016). The Digital Divide and Patient Portals: Internet Access Explained Differences in Patient Portal Use for Secure Messaging by Age, Race, and Income. *Medical Care, 54*(8), 772–779.

<https://doi.org/10.1097/MLR.0000000000000560>

Grudin, J. (2006). Why personas work: The psychological evidence. In J. S. Pruitt & T. Adlin (Eds.), *The Persona Lifecycle: Keeping People in Mind Throughout Product Design* (pp. 642–663). San Francisco, CA: Elsevier Science & Technology.

<https://doi.org/10.1145/1031607.1031707>.

Guðjónsdóttir, R., & Lindquist, S. (2008). Personas and scenarios: Design tool or a communication device? *Proceedings of the 8th International Conference on the Design of Cooperative Systems*, 165–176.

Gutheil, I. A., Chernesky, R. H., & Sherratt, M. L. (2006). Influencing student attitudes toward older adults: Results of a service-learning collaboration. *Educational Gerontology, 32*(9), 771–784. <https://doi.org/10.1080/03601270600835470>

Hakobyan, L., Lumsden, J., O’Sullivan, D., & Bartlett, H. (2013). Designing a mobile diet diary application with and for older adults with AMD: A case study. In *HCI 2013 - 27th International British Computer Society Human Computer Interaction Conference: The Internet of Things* (pp. 1–10). <https://doi.org/10.14236/ewic/hci2013.9>

Hardy, R., Lawlor, D., & Kuh, D. (2015). A life course approach to cardiovascular disease prevention. *Future Cardiol, 11*, 101–113.

Harrington, C. N., Erete, S., & Piper, A. M. (2019). Deconstructing community-based collaborative design: Towards more equitable participatory design engagements. *Proceedings of the ACM on Human-Computer Interaction, 3*(CSCW). <https://doi.org/10.1145/3359318>

Harrington, C. N., Wilcox, L., Connelly, K., Rogers, W., & Sanford, J. (2018). Designing health

and fitness apps with older adults: Examining the value of experience-based co-design. In *ACM International Conference Proceeding Series* (pp. 15–24).

<https://doi.org/10.1145/3240925.3240929>

Harte, R., Quinlan, L. R., Glynn, L., Rodríguez-Molinero, A., Baker, P. M. A., Scharf, T., & Ólaighin, G. (2017). Human-centered design study: Enhancing the usability of a mobile phone app in an integrated falls risk detection system for use by older adult users. *JMIR MHealth and UHealth*, 5(5). <https://doi.org/10.2196/mhealth.7046>

Hartzler, A. L., Osterhage, K., Demiris, G., Phelan, E. A., Thielke, S. M., & Turner, A. M. (2018). Understanding views on everyday use of personal health information: Insights from community dwelling older adults. *Informatics for Health and Social Care*, 43(3), 320–333. <https://doi.org/10.1080/17538157.2017.1297815>

Hartzler, A., Skeels, M. M., Mukai, M., Powell, C., Klasnja, P., & Pratt, W. (2011). Sharing is caring, but not error free: Transparency of granular controls for sharing personal health information in social networks. *Proceedings of the AMIA Annual Fall Symposium, 2011*, 559. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3243199/>

Haverhals, L. M., Lee, C. A., Siek, K. A., Darr, C. A., Linnebur, S. A., Ruscin, J. M., & Ross, S. E. (2011). Older adults with multi-morbidity: Medication management processes and design implications for personal health applications. *Journal of Medical Internet Research*, 13(2), e44. <https://doi.org/10.2196/jmir.1813>

Heinz, M., Margrett, J. A., Franke, W., Wong, J., & Chang, C. K. (2013). Perceptions of Technology Among Older Adults. *Journal of Gerontological Nursing*, 39(1).

Hernandez, C. R., & Gonzalez, M. Z. (2008). Effects of intergenerational interaction on aging. *Educational Gerontology*, 34(4), 292–305. <https://doi.org/10.1080/03601270701883908>

Hourcade, J. P., Chrischilles, E. A., Gryzlak, B. M., Hanson, B. M., Dunbar, D. E., Eichmann, D. A., & Lorentzen, R. R. (2011). Design lessons for older adult personal health records software from older adults. In *Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics)* (Vol. 6766 LNCS, pp. 176–185). https://doi.org/10.1007/978-3-642-21663-3_19

Huldtgren, A., Detweiler, C., Alers, H., Fitrianie, S., & Guldemond, N. A. (2013). Towards

- Community-Based Co-creation. In A. Holzinger, M. Ziefle, M. Hitz, & M. Debevc (Eds.), *Human Factors in Computing and Informatics First International Conference, SouthCHI 2013, Maribor, Slovenia, July 1-3, 2013, Proceedings* (pp. 585–592). Berlin Heidelberg: Springer-Verlag Berlin Heidelberg.
- Hung, L. Y., Lyons, J. G., & Wu, C. H. (2020). Health information technology use among older adults in the United States, 2009–2018. *Current Medical Research and Opinion*, *36*(5), 789–797. <https://doi.org/10.1080/03007995.2020.1734782>
- Iacono, I., & Marti, P. (2014). Engaging older people with participatory design. In *Proceedings of the 8th Nordic Conference on Human-Computer Interaction: Fun, Fast, Foundational* (pp. 859–864). New York, NY, USA: ACM. <https://doi.org/10.1145/2639189.2670180>
- Irani, J. S., Middleton, J. L., Marfatia, R., Omana, E. T., & D’Amico, F. (2009, September). The use of electronic health records in the exam room and patient satisfaction: A systematic review. *Journal of the American Board of Family Medicine*. *J Am Board Fam Med*. <https://doi.org/10.3122/jabfm.2009.05.080259>
- Iversen, T. N., Larsen, L., & Solem, P. E. (2009). A conceptual analysis of ageism. *Nordic Psychology*, *61*(3), 4–22. <https://doi.org/10.1027/1901-2276.61.3.4>
- Jimison, H., Gorman, P., Woods, S., Nygren, P., Walker, M., Norris, S., & Hersh, W. (2008). Barriers and drivers of health information technology use for the elderly, chronically ill, and underserved. *Evidence Report/Technology Assessment*, (175), 1–1422.
- Joshi, S. G., & Bratteteig, T. (2016). Designing for prolonged mastery. On involving old people in participatory design. *Scandinavian Journal of Information Systems*, *28*(1), 3–36.
- Joyce, K., Williamson, J., & Mamo, L. (2007). Technology, Science, and Ageism: An Examination of Three Patterns of Discrimination. *Indian Journal of Gerontology*, *21*(2), 110–127.
- Judge, T., Matthews, T., & Whittaker, S. (2012). Comparing collaboration and individual personas for the design and evaluation of collaboration software. *Proceedings of the 2012 ACM Annual Conference on Human Factors in Computing Systems - CHI '12*, (January 2012), 1997. <https://doi.org/10.1145/2207676.2208344>
- Kalisch, H. R., Coughlin, D. R., Ballard, S. M., & Lamson, A. (2013). Old Age Is a Part of

Living: Student Reflections on Intergenerational Service-Learning. *Gerontology and Geriatrics Education*, 34(1), 99–113. <https://doi.org/10.1080/02701960.2012.753440>

Kampmeijer, R., Pavlova, M., Tambor, M., Golinowska, S., & Groot, W. (2016). The use of e-health and m-health tools in health promotion and primary prevention among older adults: A systematic literature review. *BMC Health Services Research*, 16(Suppl 5).

<https://doi.org/10.1186/s12913-016-1522-3>

Kavandi, H., & Jaana, M. (2020). Factors that affect health information technology adoption by seniors: A systematic review. *Health and Social Care in the Community*, 28(6), 1827–1842.

<https://doi.org/10.1111/hsc.13011>

Kensing, F., & Blomberg, J. (1998). Participatory Design : Issues and Concerns. In *Computer Supported Cooperative Work* (Vol. 7, pp. 167–185). <https://doi.org/10.1023/A:1008689307411>

Kerai, P., Wood, P., & Martin, M. (2014). A pilot study on the views of elderly regional Australians of personally controlled electronic health records. *International Journal of Medical Informatics*, 83(3), 201–209. <https://doi.org/10.1016/j.ijmedinf.2013.12.001>

Kim, E. H., Stolyar, A., Lober, W. B., Herbaugh, A. L., Shinstrom, S. E., Zierler, B. K., ... Kim, Y. (2009). Challenges to using an electronic personal health record by a low-income elderly population. *Journal of Medical Internet Research*, 11(4). <https://doi.org/10.2196/jmir.1256>

Kim, S., Gajos, K. Z., Muller, M., & Grosz, B. J. (2016). Acceptance of mobile technology by older adults: A preliminary study. *Proceedings of the 18th International Conference on Human-Computer Interaction with Mobile Devices and Services, MobileHCI 2016*, 147–157.

<https://doi.org/10.1145/2935334.2935380>

Kimuna, S. R., Knox, D., & Zusman, M. (2005). College students' perceptions about older people and aging. *Educational Gerontology*, 31(7), 563–572.

<https://doi.org/10.1080/03601270590962514>

Kneale, L., & Demiris, G. (2017). Lack of diversity in personal health record evaluations with older adult participants: a systematic review of literature. *J Innov Health Inform*, 23(4), 789–798.

Knowles, B., & Hanson, V. L. (2018). The wisdom of older technology (non)users.

Communications of the ACM, 61(3), 72–77. <https://doi.org/10.1145/3179995>

- Kopec, W., Nielek, R., & Wierzbicki, A. (2018). Guidelines towards better participation of older adults in software development processes using a new SPIRAL method and participatory approach. In *CHASE '18: Proceedings of the 11th International Workshop on Cooperative and Human Aspects of Software Engineering* (pp. 49–56). New York, New York, USA: ACM Press. <https://doi.org/10.1145/3195836.3195840>
- Koppelman, H., & Van Dijk, B. (2006). Creating a realistic context for team projects in HCI. In *Working Group Reports on ITiCSE on Innovation and Technology in Computer Science Education 2006* (pp. 58–62). <https://doi.org/10.1145/1140124.1140142>
- Kuh, D. (2007). A Life Course Approach to Healthy Aging, Frailty, and Capability. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 62(7), 717–721. <https://doi.org/10.1093/gerona/62.7.717>
- Kuhn, S., & Muller, M. (1993). Participatory design. In *Communications of the ACM* (Vol. 36, pp. 24–28). <https://doi.org/10.1145/153571.255960>
- Kumar, A., Maskara, S., & Chiang, I. J. (2014). Building a prototype using Human-Centered Design to engage older adults in healthcare decision-making. *Work*, 49(4), 653–661. <https://doi.org/10.3233/WOR-131695>
- Lam, K., Lu, A. D., Shi, Y., & Covinsky, K. E. (2020). Assessing Telemedicine Unrediness Among Older Adults in the United States During the COVID-19 Pandemic. *JAMA Internal Medicine*, 180(10), 1389–1391.
- Lam, R., Lin, V. S., Senelick, W. S., Tran, H. P., Moore, A. A., & Koretz, B. (2013). Older adult consumers' attitudes and preferences on electronic patient-physician messaging. *The American Journal of Managed Care*, 19(10), eSP7–eSP11.
- Large, A., Nessel, V., Beheshti, J., & Bowler, L. (2006). “Bonded design”: A novel approach to intergenerational information technology design. *Library and Information Science Research*, 28(1), 64–82. <https://doi.org/10.1016/j.lisr.2005.11.014>
- Latulipe, C., Gatto, A., Nguyen, H. T., Miller, D. P., Quandt, S. A., Bertoni, A. G., ... Arcury, T. A. (2015). Design Considerations for Patient Portal Adoption by Low-Income, Older Adults. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15* (pp. 3859–3868). New York, New York, USA: ACM Press.

<https://doi.org/10.1145/2702123.2702392>

Lazar, J., & Lidtke, D. (2002). Service-Learning Partnerships in the Information Systems Curriculum. In *Managing IT/Community Partnerships in the 21st Century* (pp. 1–16). <https://doi.org/10.4018/978-1-93070-833-4>

Le, T., Thompson, H., & Demiris, G. (2013). An examination of electronic health information privacy in older adults. In *Studies in Health Technology and Informatics* (Vol. 192, pp. 709–713). IOS Press. <https://doi.org/10.3233/978-1-61499-289-9-709>

Lee, C. C., Czaja, S. J., Moxley, J. H., Sharit, J., Boot, W. R., Charness, N., ... Rogers, W. A. (2019). Attitudes Toward Computers Across Adulthood From 1994 to 2013. *The Gerontologist*, 59(1), 22–33. [https://doi.org/10.1016/0038-1098\(79\)91043-3](https://doi.org/10.1016/0038-1098(79)91043-3)

Lee, C., & Coughlin, J. F. (2015). PERSPECTIVE: Older Adults' Adoption of Technology: An Integrated Approach to Identifying Determinants and Barriers. *Journal of Product Innovation Management*, 32(5), 747–759. <https://doi.org/10.1111/jpim.12176>

Lee, D. R., Lo, J. C., Ramalingam, N., & Gordon, N. P. (2020). Understanding the Uptake of Digital Technologies for Health-Related Purposes in Frail Older Adults. *Journal of the American Geriatrics Society*, jgs.16841. <https://doi.org/10.1111/jgs.16841>

Lee, Y. S. (2009). Measures of student attitudes on aging. *Educational Gerontology*, 35(2), 121–134. <https://doi.org/10.1080/03601270802523577>

LeRouge, C., Ma, J., Sneha, S., & Tolle, K. (2013). User profiles and personas in the design and development of consumer health technologies. *International Journal of Medical Informatics*, 82(11). <https://doi.org/10.1016/j.ijmedinf.2011.03.006>

Levine, D. M., Lipsitz, S. R., & Linder, J. A. (2016). Trends in Seniors' Use of Digital Health Technology in the United States, 2011-2014. *JAMA*, 316(5), 538. <https://doi.org/10.1001/jama.2016.9124>

Light, A., Leong, T. W., & Roberston, T. (2015). Ageing Well with CSCW. In *ECSCW 2015: Proceedings of the 14th European Conference on Computer Supported Cooperative Work* (pp. 19–23). <https://doi.org/10.1007/978-3-319-20499-4>

Light, A., Pedell, S., Roberston, T., Waycott, J., Bell, J., Durick, J., & Leong, T. W. (2016).

- What's special about aging. *Interactions*, 23(2), 66–69. <https://doi.org/10.1145/2886011>
- Lindley, S., Harper, R., & Sellen, A. (2008). Designing for elders: exploring the complexity of relationships in later life. *Proceedings of the 22nd Annual Conference of the British HCI Group (HCI 2008)*, Volume 1, 77-86. <https://doi.org/10.1080/13607860902774485>
- Lindsay, S., Jackson, D., Ladha, C., Ladha, K., Brittain, K., & Olivier, P. (2012). Empathy, participatory design and people with dementia, 521. <https://doi.org/10.1145/2207676.2207749>
- Lindsay, S., Jackson, D., Schofield, G., & Olivier, P. (2012). Engaging older people using participatory design. In *Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems - CHI '12* (p. 1199). <https://doi.org/10.1145/2207676.2208570>
- Lober, W. B., Zierler, B., Herbaugh, A., Shinstrom, S. E., Stolyar, A., Kim, E. H., & Kim, Y. (2006). Barriers to the use of a personal health record by an elderly population. *AMIA Annual Symposium Proceedings*, 514–518. <https://doi.org/86608> [pii]
- Loe, M. (2010). Doing it my way: old women, technology and wellbeing. In *Technogenarians: Studying Health and Illness Through an Ageing, Science, and Technology Lens* (Vol. 101, pp. 142–156). <https://doi.org/10.3732/ajb.1400340>
- Logue, M. D., & Effken, J. A. (2012). An exploratory study of the personal health records adoption model in the older adult with chronic illness. *Informatics in Primary Care*, 20(3), 151–169. <https://doi.org/10.14236/jhi.v20i3.21>
- Maguire, M. (2001). Methods to support human-centred design. *International Journal of Human Computer Studies*, 55(4), 587–634. <https://doi.org/10.1177/0972150916656693>
- Mankoff, J. (2006). Practical service learning issues in HCI. In *CHI '06 extended abstracts on Human factors in computing systems - CHI EA '06* (p. 201). New York, New York, USA: ACM Press. <https://doi.org/10.1145/1125451.1125494>
- Martin-Hammond, A., Vemireddy, S., & Rao, K. (2018). Engaging Older Adults in the Participatory Design of Intelligent Health Search Tools. In *Proceedings of the 12th EAI International Conference on Pervasive Computing Technologies for Healthcare* (pp. 280–284). New York, NY, USA: ACM. <https://doi.org/10.1145/3240925.3240972>
- Massimi, M., Baecker, R. M., & Wu, M. (2007). Using participatory activities with seniors to

critique, build, and evaluate mobile phones. In *Proceedings of the 9th international ACM SIGACCESS conference on Computers and accessibility - Assets '07* (Vol. 6185, p. 155). New York, New York, USA: ACM Press. <https://doi.org/10.1145/1296843.1296871>

Matthews, T., Judge, T. K., & Whittaker, S. (2012). How do designers and user experience professionals actually perceive and use personas? In *Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 1219–1228). Austin, Texas.

McHenry, J. C., Insel, K. C., Einstein, G. O., Vidrine, A. N., Koerner, K. M., & Morrow, D. G. (2015). Recruitment of older adults: Success may be in the details. *Gerontologist*, *55*(5), 845–853. <https://doi.org/10.1093/geront/gns079>

Mennicken, S., Hwang, A., Yang, R., Hoey, J., Mihailidis, A., & Huang, E. M. (2015). Smart for Life: Designing Smart Home Technologies that Evolve with Users. In *CHI'15 Extended Abstracts* (pp. 2377–2380). Seoul, Republic of Korea. <https://doi.org/10.1145/2702613.2702631>

Merkel, S., & Kucharski, A. (2019). Participatory Design in Gerontechnology: A Systematic Literature Review. *Gerontologist*, *59*(1), E16–E25. <https://doi.org/10.1093/geront/gny034>

Miaskiewicz, T., & Kozar, K. A. (2011). Personas and user-centered design: How can personas benefit product design processes? *Design Studies*, *32*(5), 417–430. <https://doi.org/10.1016/j.destud.2011.03.003>

Mitzner, T. L., Boron, J. B., Fausset, C. B., Adams, A. E., Charness, N., Czaja, S. J., ... Sharit, J. (2010). Older adults talk technology: Technology usage and attitudes. *Computers in Human Behavior*, *26*(6), 1710–1721. <https://doi.org/10.1016/j.chb.2010.06.020>

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., Altman, D., Antes, G., ... Tugwell, P. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Annals of Internal Medicine*. American College of Physicians. <https://doi.org/10.7326/0003-4819-151-4-200908180-00135>

Montelius, E., Åstrand, B., Hovstadius, B., & Petersson, G. (2008). Individuals appreciate having their medication record on the web: A survey of attitudes to a national pharmacy register. *Journal of Medical Internet Research*, *10*(4), e35. <https://doi.org/10.2196/jmir.1022>

Muñoz, J. E., Gonçalves, A., Rúbio Gouveia, É., Cameirão, M. S., & BermúdezBadia, S. (2019). Lessons Learned from Gamifying Functional Fitness Training through Human-Centered Design

Methods in Older Adults. *Games for Health Journal*, 8(6), 387–406.

<https://doi.org/10.1089/g4h.2018.0028>

Nassir, S., Leong, T. W., & Roberston, T. (2015). Positive ageing: elements and factors for design. *OzCHI*, 264–268. <https://doi.org/10.1145/2838739.2838796>

National Science and Technology Council. (2019). *Emerging Technologies to Support an Aging Population*. Retrieved from <http://www.whitehouse.gov/ostp>.

Neves, B., & Amaro, F. (2012). Too old for technology? How the elderly of Lisbon use and perceive ICT. *The Journal of Community Informatics*, 8(1), 1–22.

<https://doi.org/10.1016/j.athoracsur.2014.12.068>

Nielsen, L., & Storgaard Hansen, K. (2014). Personas is applicable: a study on the use of personas in Denmark. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1665–1674). <https://doi.org/10.1145/2556288.2557080>

Norman, D. (2019). I wrote the book on user-friendly design. What I see today horrifies me. Retrieved from https://www.fastcompany.com/90338379/i-wrote-the-book-on-user-friendly-design-what-i-see-today-horrifies-me?utm_source=pocket-newtab

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*, 16(1).

<https://doi.org/10.1177/1609406917733847>

Nurain, N., Caldeira, C., & Connelly, K. (2021). Older Adults' Experiences of Autonomy during COVID-19 Pandemic. In *Conference on Human Factors in Computing Systems - Proceedings*.

<https://doi.org/10.1145/3411763.3451674>

Ostlund, B. (2005). Design Paradigms and Misunderstood Technology: The Case of Older Users. In B. Jaeger (Ed.), *Young technologies in old hands - An international view on senior citizen's utilization of ICT* (pp. 25–39). Copenhagen: DJØF Publishing.

Oudshoorn, N., Neven, L., & Stienstra, M. (2016). How diversity gets lost: Age and gender in design practices of information and communication technologies. *Journal of Women and Aging*, 28(2), 170–185. <https://doi.org/10.1080/08952841.2015.1013834>

PARO Robots. (2014). PARO Therapeutic Robot.

- Patricia, L. (2011). Service learning. In *Proceedings of the 16th Western Canadian Conference on Computing Education - WCCCE '11* (pp. 12–16). New York, New York, USA: ACM Press. <https://doi.org/10.1145/1989622.1989626>
- Peine, A., Rollwagen, I., & Neven, L. (2014). The rise of the “innosumer”—Rethinking older technology users. *Technological Forecasting and Social Change*, 82(1), 199–214. <https://doi.org/10.1016/j.techfore.2013.06.013>
- Penick, J. M., Fallshore, M., & Spencer, A. M. (2014). Using Intergenerational Service Learning to Promote Positive Perceptions about Older Adults and Community Service in College Students. *Journal of Intergenerational Relationships*, 12(1), 25–39. <https://doi.org/10.1080/15350770.2014.870456>
- Petsani, D., Mantziari, D., Zilidou, V., Konstantinidis, E. I., Billis, A., Timoleon, M., ... Bamidis, P. D. (2019). Co-design the future CAPTAIN system with older adults. In *Proceedings of the 12th ACM International Conference on PErvasive Technologies Related to Assistive Environments - PETRA '19* (pp. 639–644). New York, New York, USA: ACM Press. <https://doi.org/10.1145/3316782.3322765>
- Plain Language Action and Information Network. (n.d.). What is plain language?
- Pradhan, A., Jelen, B., Siek, K. A., Chan, J., & Lazar, A. (2020). Understanding Older Adults' Participation in Design Workshops. In *Conference on Human Factors in Computing Systems - Proceedings*. <https://doi.org/10.1145/3313831.3376299>
- Price, M. M., Pak, R., Müller, H., & Stronge, A. (2013). Older adults' perceptions of usefulness of personal health records. *Universal Access in the Information Society*, 12(2), 191–204. <https://doi.org/10.1007/s10209-012-0275-y>
- Quan-Haase, A., Williams, C., Kicevski, M., Elueze, I., & Wellman, B. (2018). Dividing the Grey Divide: Deconstructing Myths About Older Adults' Online Activities, Skills, and Attitudes. *American Behavioral Scientist*, 62(9), 1207–1228. <https://doi.org/10.1177/0002764218777572>
- Raffle, H., Go, J., Spasojevic, M., Revelle, G., Mori, K., Ballagas, R., ... Freed, N. (2011). Hello, is grandma there? let's read! StoryVisit. *Proceedings of the 2011 Annual Conference on Human Factors in Computing Systems - CHI '11*, 1195. <https://doi.org/10.1145/1978942.1979121>

- Reeder, B., Zaslavsky, O., Wilamowska, K. M., Demiris, G., & Thompson, H. J. (2011). Modeling the oldest old: personas to design technology-based solutions for older adults. *AMIA Annual Symposium Proceedings, 2011*, 1166–1175. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/22195177>/<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3243168/><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3243168&tool=pmcentrez&rendertype=abstract>
- Righi, V., Sayago, S., & Blat, J. (2017). When we talk about older people in HCI, who are we talking about? Towards a ‘turn to community’ in the design of technologies for a growing ageing population. *International Journal of Human Computer Studies*, *108*, 15–31. <https://doi.org/10.1016/j.ijhcs.2017.06.005>
- Righi, V., Sayago, S., Rosales, A., Ferreira, S. M., & Blat, J. (2018). Co-designing with a community of older learners for over 10 years by moving user-driven participation from the margin to the centre. *CoDesign*, *14*(1), 32–44. <https://doi.org/10.1080/15710882.2018.1424206>
- Rogers, W. A., & Mitzner, T. L. (2017). Envisioning the future for older adults: Autonomy, health, well-being, and social connectedness with technology support. *Futures*, *87*, 133–139. <https://doi.org/10.1016/j.futures.2016.07.002>
- Rogers, Y., & Marsden, G. (2013). Does he take sugar? *Interactions*, *20*(4), 48. <https://doi.org/10.1145/2486227.2486238>
- Rogers, Y., Paay, J., & Brereton, M. (2014). Never Too Old: Engaging Retired People Inventing the Future with MaKey MaKey. In *CHI 2014 , One of a CHIInd, Toronto, ON, Canada* (pp. 3913–3922). <https://doi.org/10.1145/2556288.2557184>
- Roldan, W., Gao, X., Hishikawa, A. M., Ku, T., Li, Z., Zhang, E., ... Yip, J. (2020). Opportunities and Challenges in Involving Users in Project-Based HCI Education. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems* (pp. 1–15). New York, NY, USA: ACM. <https://doi.org/10.1145/3313831.3376530>
- Roldan, W., Lin, S., Xu, Y., Sequeira, A., & Turns, J. (2020). Visual Note-taking: Opportunities to Support Student Agency in Active Learning. In *2020 ASEE Virtual Annual Conference Content Access* (p. Virtual Online). <https://doi.org/10.18260/1-2--35489>
- Roson, M. B., & Carroll, J. M. (2003). Scenario-based design. In *The human-computer*

- interaction handbook : fundamentals, evolving technologies and emerging applications* (pp. 1033–1050). Lawrence Erlbaum Associates Inc.
- Rowan, J., & Mynatt, E. D. (2005). Digital Family Portrait Field Trial: Support for Aging in Place. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 521–530. <https://doi.org/10.1145/1054972.1055044>
- Sack, O., Pak, R., & Ziefle, M. (2011). Older adults' perception of costs and benefits of web-based and mobile PHR technologies: A focus group approach. In *Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics)* (Vol. 7058 LNCS, pp. 707–710). https://doi.org/10.1007/978-3-642-25364-5_52
- Sakaguchi-Tang, D. K., Bosold, A. L., Choi, Y. K., & Turner, A. M. (2017). Patient Portal Use and Experience Among Older Adults: Systematic Review. *JMIR Medical Informatics*, 5(4), e38. <https://doi.org/10.2196/medinform.8092>
- Sakaguchi-Tang, D. K., Turner, A. M., Taylor, J. O., & Kientz, J. A. (2019). Connected Personas: Translating the Complexity of Older Adult Personal Health Information Management for Designers of Health Information Technologies. In *AMIA Annual Symposium Proceedings* (pp. 1177–1186).
- Sanders, E. B.-N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *CoDesign*, 4(1), 5–18. <https://doi.org/10.1080/15710880701875068>
- Sanders, E. B. N., Brandt, E., & Binder, T. (2010). A framework for organizing the tools and techniques of Participatory Design. *ACM International Conference Proceeding Series*, 195–198. <https://doi.org/10.1145/1900441.1900476>
- Schuler, D., & Namioka, A. (Eds.). (1993). *Participatory design principles and practices*. Hillsdale, New Jersey.
- Searl, M. M., Borgi, L., & Chemali, Z. (2010). It is time to talk about people: A human-centered healthcare system. *Health Research Policy and Systems*, 8, 1–7. <https://doi.org/10.1186/1478-4505-8-35>
- Sengers, P., Boehner, K., David, S., & Kaye, J. “Jofish.” (2005). Reflective design. In *Proceedings of the 4th decennial conference on Critical computing between sense and sensibility - CC '05* (p. 49). New York, New York, USA: ACM Press.

<https://doi.org/10.1145/1094562.1094569>

Settersten, R. A. (2017). Some Things I Have Learned About Aging by Studying the Life Course. *Innovation in Aging*, 1(2). <https://doi.org/10.1093/geroni/igx014>

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22(2), 63–75. <https://doi.org/10.3233/EFI-2004-22201>

Siek, K. A., Khan, D. U., Ross, S. E., Haverhals, L. M., Meyers, J., & Cali, S. R. (2011). Designing a personal health application for older adults to manage medications: A comprehensive case study. In *Journal of Medical Systems* (Vol. 35, pp. 1099–1121). <https://doi.org/10.1007/s10916-011-9719-9>

SOARING. (n.d.). What's the SOARING project about? Retrieved July 10, 2019, from <http://www.soaringstudy.org/>

Spinuzzi, C. (2005). The Methodology of Participatory Design. *Technical Communication*, 48(3), 309–323.

Stowe, J. D., & Cooney, T. M. (2015). Examining Rowe and Kahn's concept of successful aging: Importance of taking a life course perspective. *Gerontologist*, 55(1), 43–50. <https://doi.org/10.1093/geront/gnu055>

Subasi, Ö., Malmborg, L., Fitzpatrick, G., & Östlund, B. (2014). Reframing design culture and aging. *Interactions*, 21(2), 70–73. <https://doi.org/10.1145/2574561>

Suchman, L. (2011). Anthropological relocations and the limits of design. *Annual Review of Anthropology*, 40(2011), 1–18. <https://doi.org/10.1146/annurev.anthro.041608.105640>

Sulaiman, S., Shahrol, S. J. M., & Samad, A. R. A. (2020). Service Learning in Application Development Course. In *ICSCA, 2020* (pp. 158–162). <https://doi.org/10.1145/3384544.3384601>

Sumner, J., Chong, L. S., Bundele, A., & Lim, Y. W. (2020). Co-Designing Technology for Aging in Place: A Systematic Review. *The Gerontologist*, 1–15. <https://doi.org/10.1093/geront/gnaa064>

Taha, J., Sharit, J., & Czaja, S. J. (2014). The Impact of Numeracy Ability and Technology Skills on Older Adults' Performance of Health Management Tasks Using a Patient Portal. *Journal of Applied Gerontology*, 33(4), 416–436 21p. <https://doi.org/10.1177/0733464812447283>

- Talmon, J., Ammenwerth, E., Brender, J., de Keizer, N., Nykänen, P., & Rigby, M. (2009). STARE-HI -statement on reporting of evaluation studies in health informatics. *Yearbook of Medical Informatics*, 8, 23–31. <https://doi.org/10.1016/j.ijmedinf.2008.09.002>
- Taylor, J. O., Hartzler, A. L., Osterhage, K. P., Demiris, G., & Turner, A. M. (2018). Monitoring for change: The role of family and friends in helping older adults manage personal health information. *Journal of the American Medical Informatics Association*, 25(8), 989–999. <https://doi.org/10.1093/jamia/ocy037>
- Tjora, A., Tran, T., & Faxvaag, A. (2005). Privacy vs usability: a qualitative exploration of patients' experiences with secure Internet communication with their general practitioner. *Journal of Medical Internet Research*, 7(2), e15. <https://doi.org/10.2196/jmir.7.2.e15>
- Turner, A. M., Osterhage, K., Hartzler, A., Joe, J., Lin, L., Kanagat, N., & Demiris, G. (2015). Use of Patient Portals for Personal Health Information Management: The Older Adult Perspective. *AMIA ... Annual Symposium Proceedings / AMIA Symposium. AMIA Symposium, 2015*, 1234–1241.
- Turner, A. M., Osterhage, K., Loughran, J., Painter, I., Demiris, G., Hartzler, A. L., & Phelan, E. A. (2018). Emergency information management needs and practices of older adults: A descriptive study. *International Journal of Medical Informatics*, 111(February 2017), 149–158. <https://doi.org/10.1016/j.ijmedinf.2017.12.001>
- Turner, A. M., Osterhage, K. P., Taylor, J. O., Hartzler, A. L., & Demiris, G. (2018). A Closer Look at Health Information Seeking by Older Adults and Involved Family and Friends : Design Considerations for Health Information Technologies. In *AMIA Annu Symp Proc*.
- Turner, A. M., Reeder, B., & Ramey, J. (2013). Scenarios, personas and user stories: User-centered evidence-based design representations of communicable disease investigations. *Journal of Biomedical Informatics*, 46(4), 575–584. <https://doi.org/10.1016/j.jbi.2013.04.006>
- US Department of Veterans Affairs. (n.d.). MyHealtheVet.
- Uzor, S., Baillie, L., & Skelton, D. (2012). Empowering Seniors to Design Enjoyable Falls Rehabilitation Tools Stephen. In *Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems - CHI '12* (p. 1179). New York, New York, USA: ACM Press. <https://doi.org/10.1145/2207676.2208568>

- Valdez, R. S., Holden, R. J., Novak, L. L., & Veinot, T. C. (2014). Transforming consumer health informatics through a patient work framework: Connecting patients to context. *Journal of the American Medical Informatics Association*, 22(1), 2–10. <https://doi.org/10.1136/amiajnl-2014-002826>
- Velt, R., Benford, S., & Reeves, S. (2020). Translations and boundaries in the gap between HCI theory and design practice. *ACM Transactions on Computer-Human Interaction*, 27(4). <https://doi.org/10.1145/3386247>
- Vidal, R. V. V. (2006). The future workshop: Democratic problem solving. *Economic Analysis Working Papers*, 5(4), 21.
- Vincent, C. J., & Blandford, A. (2014). The challenges of delivering validated personas for medical equipment design. *Applied Ergonomics*, 45(4), 1097–1105. <https://doi.org/10.1016/j.apergo.2014.01.010>
- Vines, J., Clarke, R., & Wright, P. (2013). Configuring participation: on how we involve people in design. In *CHI 2013: Changing Perspectives, Paris, France* (Vol. 20, pp. 429–438). [https://doi.org/10.1016/S0142-694X\(98\)00026-X](https://doi.org/10.1016/S0142-694X(98)00026-X)
- Vines, J., Pritchard, G., Wright, P., Olivier, P., & Brittain, K. (2015). An Age-Old Problem: Examining the Discourses of Ageing in HCI and Strategies for Future Research. *ACM Transactions on Computer-Human Interaction*, 22(1), 1–27. <https://doi.org/10.1145/2696867>
- Vines, J., Wright, P., Silver, D., Winchcombe, M., & Olivier, P. (2015). Authenticity, Reliability and Collaborative Approaches to Sharing Knowledge about Assistive Living Technology. In *Proceedings of the ACM Conference on Computer Supported Cooperative Work, CSCW* (pp. 82–94). <https://doi.org/10.1145/2675133.2675222>
- Wallace, L. S., Angier, H., Huguet, N., Gaudino, J. A., Krist, A., Dearing, M., ... DeVoe, J. E. (2016). Patterns of electronic portal use among vulnerable patients in a nationwide practice-based research network: From the OCHIN Practice-based Research Network (PBRN). *Journal of the American Board of Family Medicine*, 29(5), 592–603. <https://doi.org/10.3122/jabfm.2016.05.160046>
- Walsh, G., Foss, E., Yip, J., & Druin, A. (2013). FACIT PD: A Framework for Analysis and Creation of Intergenerational Techniques for Participatory Design. In *Proceedings of the SIGCHI*

Conference on Human Factors in Computing Systems (pp. 2893–2902). New York, NY, USA: ACM. <https://doi.org/10.1145/2470654.2481400>

Waycott, J., Vetere, F., Pedell, S., Kulik, L., Ozanne, E., Gruner, A., & Downs, J. (2013). Older adults as digital content producers. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 39–48). New York, NY, USA: ACM.

<https://doi.org/10.1145/2470654.2470662>

Weber, R. (2004). Editor's Comments: The Rhetoric of Positivism versus Interpretivism: A Personal View. Source: *MIS Quarterly* (Vol. 28).

Weppner, W. G., Ralston, J. D., Koepsell, T. D., Grothaus, L. C., Reid, R. J., Jordan, L., & Larson, E. B. (2010). Use of a shared medical record with secure messaging by older patients with diabetes. *Diabetes Care*, *33*(11), 2314–2319. <https://doi.org/10.2337/dc10-1124>

Wethington, E. (2005). An Overview of the Life Course Perspective: Implications for Health and Nutrition. *Journal of Nutrition Education and Behavior*, *37*, 115–120.

World Health Organization. (n.d.). Fact file: Misconceptions on ageing and health.

World Health Organization. (2018). *Ageing and health*.

Wyche, S., Sengers, P., & Grinter, R. E. (2006). Historical analysis: Using the past to design the future. In *Lecture Notes in Computer Science (including subseries Lecture Notes in Artificial Intelligence and Lecture Notes in Bioinformatics)* (Vol. 4206 LNCS, pp. 35–51).

https://doi.org/10.1007/11853565_3

Yip, J. C., Foss, E., Bonsignore, E., Guha, M. L., Norooz, L., Rhodes, E., ... Druin, A. (2013). Children initiating and leading cooperative inquiry sessions. In *Proceedings of the 12th International Conference on Interaction Design and Children* (pp. 293–296). New York, NY, USA: ACM. <https://doi.org/10.1145/2485760.2485796>

Yip, J. C., Lee, K. J., & Lee, J. H. (2019). Design partnerships for participatory librarianship: A conceptual model for understanding librarians co designing With digital youth. *Journal of the Association for Information Science and Technology*, *71*(10), 1242–1256.

<https://doi.org/10.1002/asi.24320>

Yip, J. C., Sobel, K., Pitt, C., Lee, K. J., Chen, S., Nasu, K., & Pina, L. R. (2017). Examining

Adult-Child Interactions in Intergenerational Participatory Design. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (pp. 5742–5754). New York, NY, USA: ACM. <https://doi.org/10.1145/3025453.3025787>

Young, R., Willis, E., Cameron, G., & Geana, M. (2014). “Willing but unwilling”: attitudinal barriers to adoption of home-based health information technology among older adults. *Health Informatics Journal*, 20(2), 127–135. <https://doi.org/10.1177/1460458213486906>

Zettel-Watson, L., & Tsukerman, D. (2016). Adoption of online health management tools among healthy older adults: An exploratory study. *Health Informatics Journal*, 22(2), 171–183. <https://doi.org/10.1177/1460458214544047>

Zhang, Y., Fleischmann, K. R., Gao, J., & Xie, B. (2015). A systematic review of the literature on consumers’ use of patient portals: Preliminary results. *Proceedings of the Association for Information Science and Technology*, 52(1), 1–4. <https://doi.org/10.1002/pra2.2015.1450520100142>