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The **Essential Guide** to

Older Adult-Centered Design:

Supporting Personal Health Information Management

UW SOARING

SOARING Design Book*

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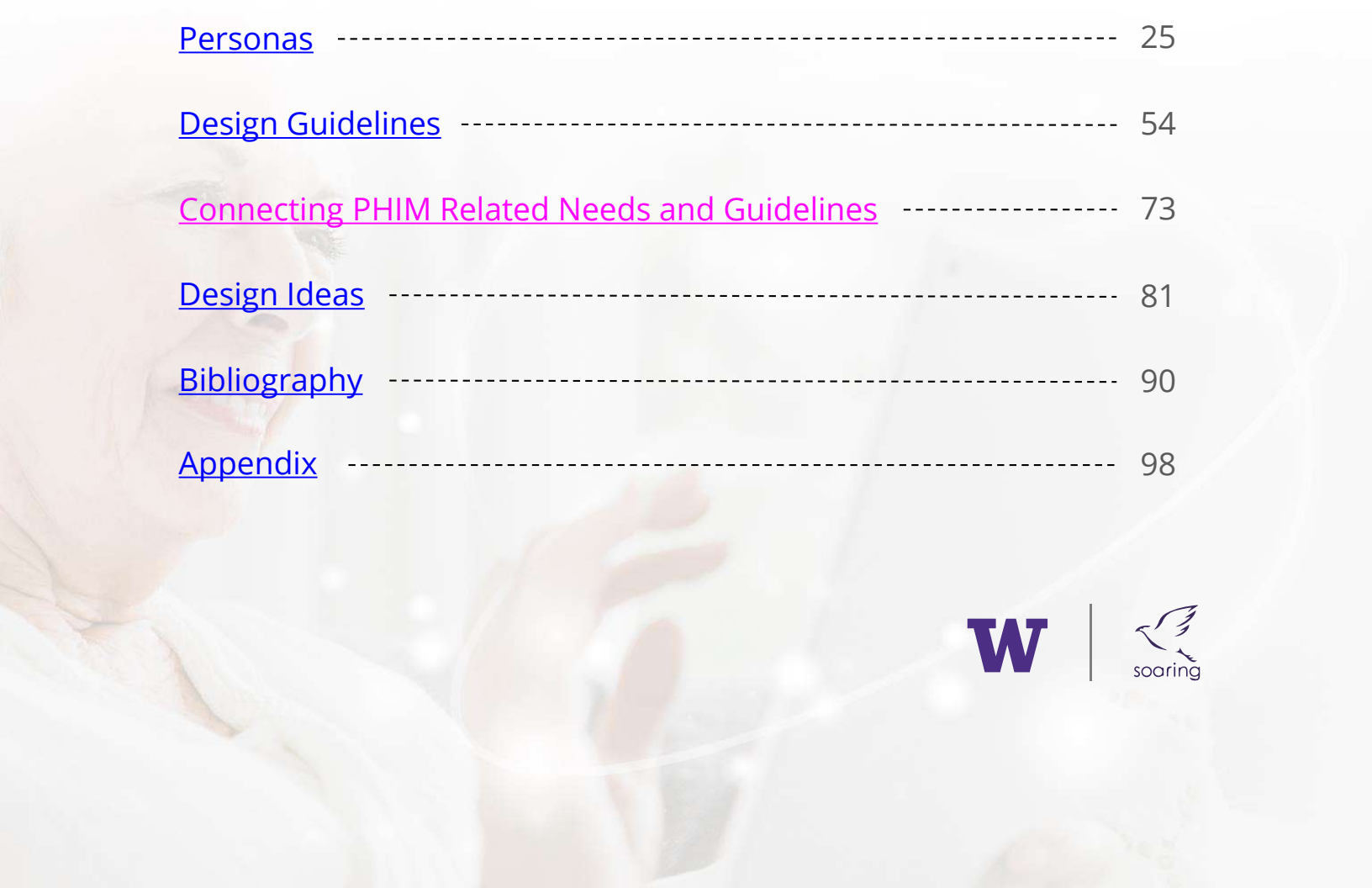
Introduction

The aging population in the United States is large and growing. By 2060, more than a quarter of the US population will be 65 years or older[1]. Compared to other age groups, older adults are more likely to have multiple chronic conditions, which may lead to more doctor visits and taking more medications[2]. As a result, older adults and their caregivers may need to manage and organize more personal health information. This includes activities like keeping a list of medications, maintaining a calendar of appointment times, or organizing health records. We refer to the act of accessing, organizing, and utilizing personal health information as personal health information management (PHIM)[3]. PHIM helps older adults take an active and engaged role in their health care and overall wellness and can ultimately lead to better health outcomes[3].

Health information technologies have the potential to help people access, organize, and manage their personal health information. For example, an online system connected to a patient's health record, known as a patient portal, allows individual patients to view lab results, message their doctors, and refill prescriptions.

Contrary to popular perceptions that older adults are not interested in new technologies, research has shown that older adults will adopt new technologies if they are easy to use and are useful[4]. For example, today more older adults own smartphones and are using the internet than in prior years[5]. However, few older adults make use of patient portals or other health technology systems.
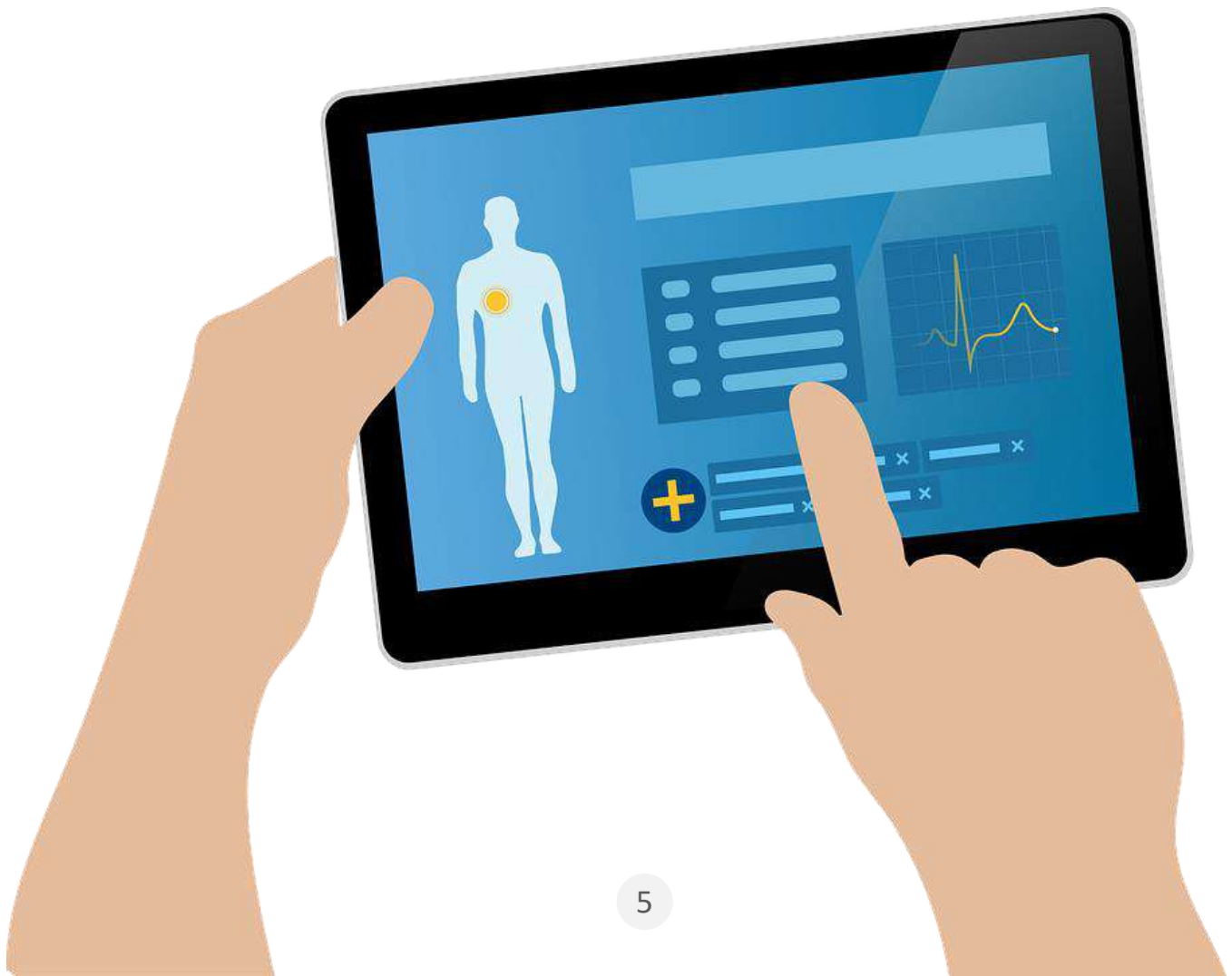
Reasons for this lack of health information technology (HIT) use include limited access to technology, lack of technological ability, and privacy concerns. In addition, most HIT systems were not designed to meet the needs of older adults. With improved design, HIT systems may more effectively address the needs of older adults and their caregivers.

The goal of the SOARING study described here is to better understand the PHIM practices of older adults so that designers can design systems that better meet their needs, including maintaining their independence and making informed health decisions. This guide was created to provide designers and developers with guidance on how to best design health technologies for a wide range of older adults.

Who is this book for?

This guide was created for assisting health information designers and developers, researchers, user experience professionals, and anyone interested in technologies for an aging population. The following pages provide an overview of the current state of older adult technology use, and health information management. You will also find personas and design guidelines that can be used to inform decisions in the design process.

Who are we?

We are a multidisciplinary group of researchers focusing on better understanding and describing the health information management needs and practices of older adults through the AHRQ funded SOARING study (Studying Older Adults & Researching Information Needs & Goals). The aim of the SOARING study has been to better understand and describe how older adults manage their health information and the role that caregivers and providers play in PHIM activities. The ultimate goal of SOARING is to improve the design of health technologies that support the health, well-being, and independence of older adults. Throughout this 5-year project, we adopted an ecological approach, looking at older adults in the context of their environment, social connections, and tasks related to health information management. We gained an understanding of PHIM through human-centered interviews, focus groups, and surveys with older adults, family members, friends, and providers. The findings from our research provided the foundation for the personas, scenarios, and design guidelines found in the following pages. For more information about the SOARING study and researchers, visit the study website: http://www.SOARINGstudy.org/

Background

Health information technologies (HITs) are electronic systems that allow people, including health care providers and patients, to access, use, and store their health information[6]. Examples include patient portals, electronic health records, and monitoring devices that track blood glucose or diet. HIT has the potential to help older adults with PHIM, through improving access, organization, and use of health information.

Access to personal health information (PHI) is increasingly available through patient portals (e.g., MyChart). However, research suggests that older adults face barriers to the adoption of these systems. These barriers include physical or cognitive limitations[5, 7], limited access to the internet and computers, lack of experience in using digital technologies[8, 9, 10, 11], and concerns about privacy and security in using health management tools[7, 8, 9, 10, 12, 13, 14].

Low health literacy among older adults also contributes to the low rate of HIT adoption[15, 16]. Health literacy is the ability to understand health information in order to make informed decisions[17]. It is estimated that 29% of Americans who are 65 years or older have below basic health literacy, which is a higher percentage than other age groups[18].
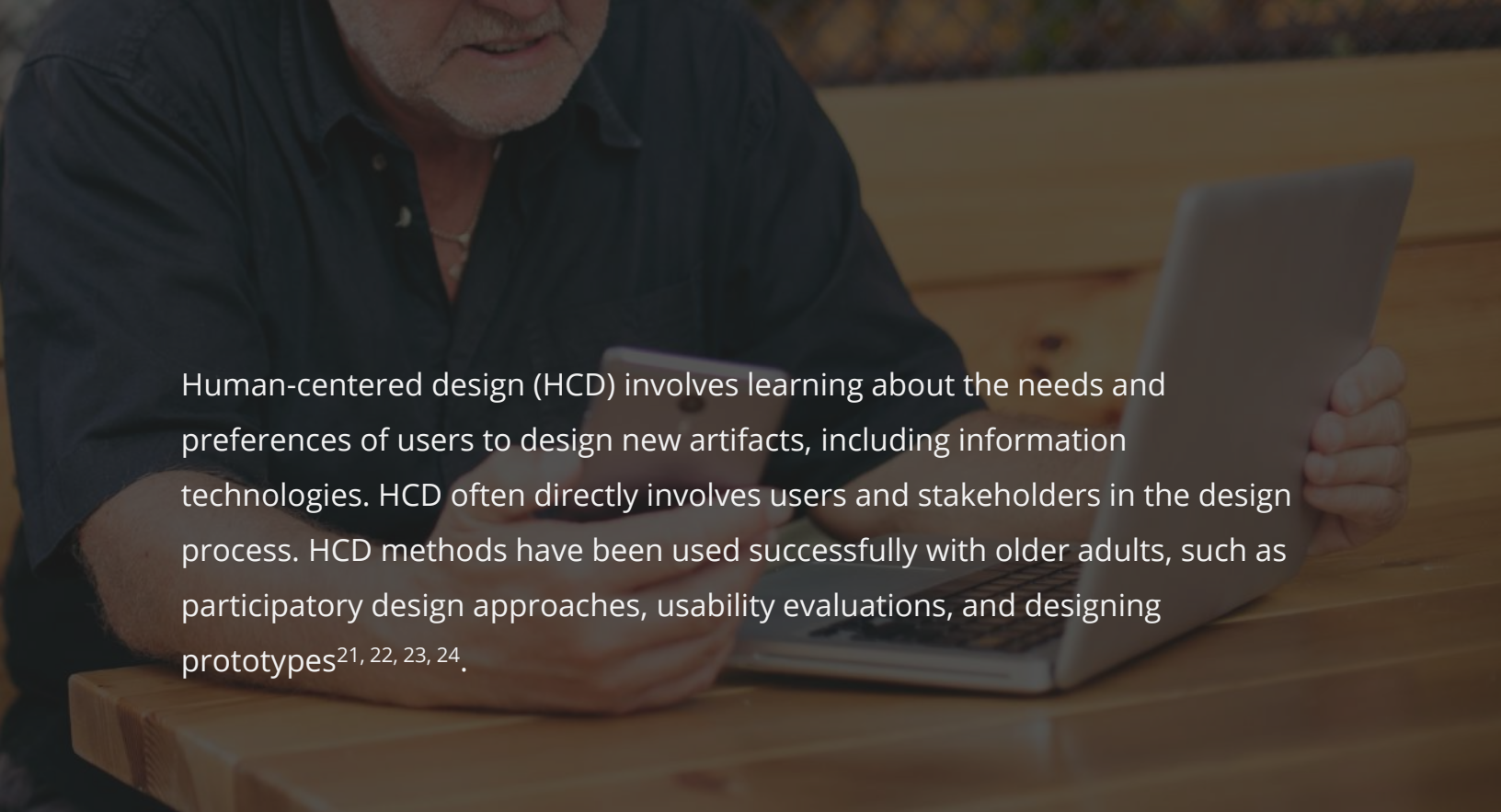
Despite these concerns, a growing number of older adults are willing to try HIT, if they support their diverse needs, and are perceived as useful and beneficial[4, 7, 19]. In fact, 30% of the older adults we studied in the SOARING study had used patient portals.

The SOARING Project

To inform the design of more effective health technologies for older adults, the SOARING project followed a human-centered design approach to learn about the PHIM needs and practices of older adults. The human-centered design approach places people at the center of the design process to make sure products are useable and meet people's needs and goals and addresses their challenges and pain points[20].

RESEARCH

ANALYZE

VALIDATE

IDEATE

Human- Centered
Design Process

PROTOTYPE

SKETCH &
WIREFRAME

WIREFRAMES
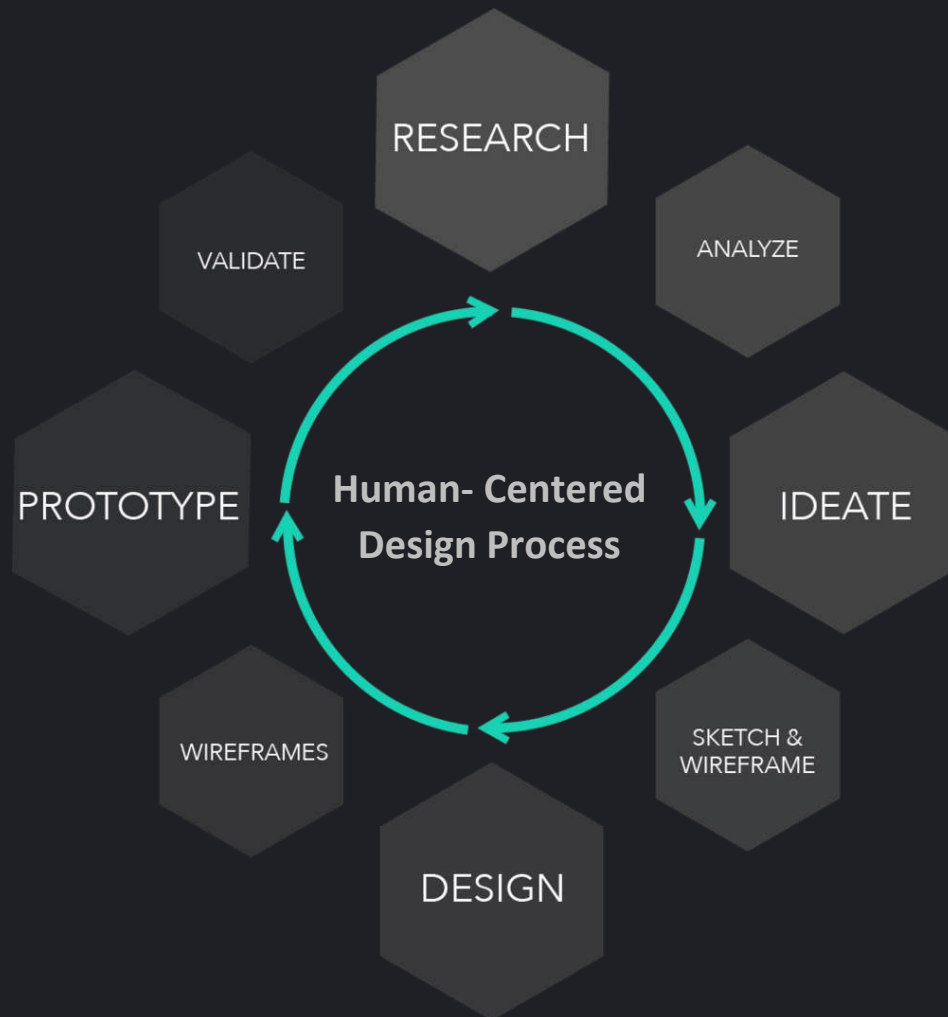
DESIGN

Human-centered design (HCD) involves learning about the needs and preferences of users to design new artifacts, including information technologies. HCD often directly involves users and stakeholders in the design process. HCD methods have been used successfully with older adults, such as participatory design approaches, usability evaluations, and designing prototypes[21, 22, 23, 24].

As part of our research, we had in-depth conversations with 88 older adults about their PHIM practices. We held these conversations in their residences, which helped us to observe and understand their PHIM practices in context. We also interviewed 52 family and friends of older adults and 27 health care providers to understand how others are involved in older adult PHIM. We then categorized and analyzed our findings, translating them into personas, scenarios, and design guidelines. These HCD tools convey the diversity of older adults and highlight important considerations for the design of HIT.
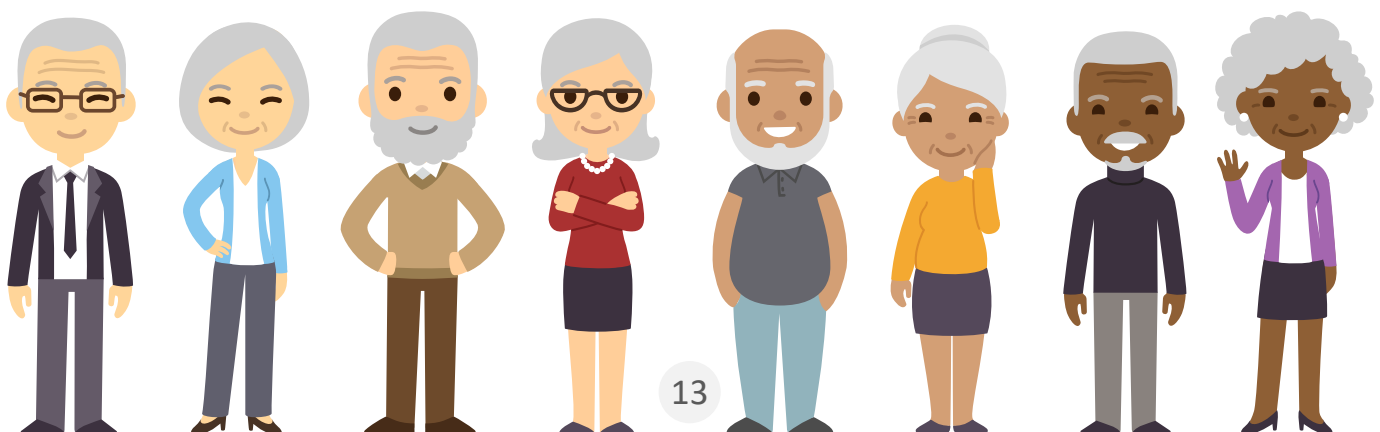
Key Learnings

Through our focus groups and interviews with older adults, we learned that older adults often view health information management as connected to personal goals of achieving wellness and staying healthy[3]. Family, friends, and health care providers often play a supportive role in older adult decision-making and health information management[25].

Wellness

Wellness plays a role in the way older adults perceive and manage their health and personal health information. Specifically, older adults discussed staying healthy through personal practices that allow them to maintain their physical, cognitive, and emotional well-being. They also discussed the value of being connected to their community and personal networks[3]. These findings highlight the importance of PHIM tools for older adults that support wellness goals.
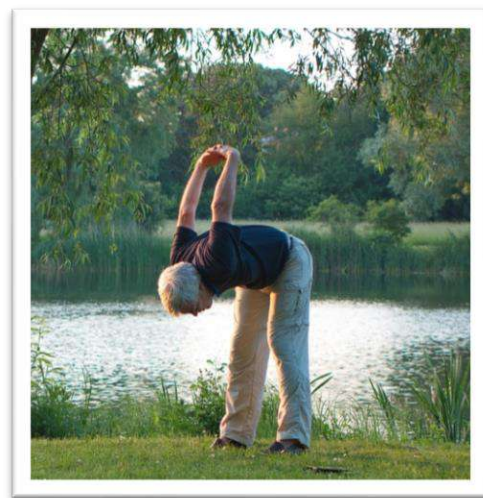
Information Sharing

Older adults share health information with family and friends and often receive support for PHIM practices. Family and friends help older adults maintain wellness, prepare for and attend their medical appointments, and assist with decision-making and activities of daily life. In the context of the dynamic aging process, our studies showed that family and friends were often engaged in what we called "monitoring," or looking for information related to the older adult's health status to understand when and how to support the older adult's PHIM needs[25].

Living Situation

We interviewed older adults who lived in private residences, retirement communities and assisted living facilities, as well as older adults who were homeless or previously homeless. Through this research, we learned that living situations have a significant impact on the ways that older adults manage their health information. For example, older adults who live in an assisted living facility may rely on the staff to store their health information and so may discard physical documents such as doctors' visit summaries. In contrast, older adults who live in an independent residence may keep and file all of their health-related documents.

The Role of Providers

Older adults frequently state a preference for information from their providers over other sources[26, 27]. We also interviewed providers, specifically medical providers (family practice and internal medicine physicians, geriatric specialists and fellows, medical residents, and nurse practitioners), social workers, assisted living staff, and pharmacists. We learned that providers collect, provide, interpret, and reconcile health information with older adults. Providers also help to refer older adults to different resources, give support for developing health plans and goals, and work with older adults to manage health information and medications in particular. Providers often communicate and share information with family and friends and other providers in order to carry out these activities[28].

Personal Health Information Management Activities

We translated our findings into types of health information management activities: organizing personal health information, tracking or recording health information (weight, blood pressure, etc.), sharing health information (with family, friends, and providers), seeking information about health questions/issues, and planning for health-related emergencies[29]. There are a variety of needs and approaches that older adults take in carrying out these activities. The next section outlines the different activities and approaches older adults take, to ensure designers consider these diverse approaches when designing PHIM tools.

PHIM Activities Overview

Seeking

Level of initiative in obtaining health information

Sharing

Including others (family/friends) in communication and management of health-related information

Planning

Preparing and maintaining information in case of a health-related emergency
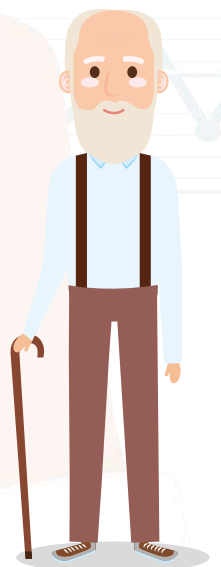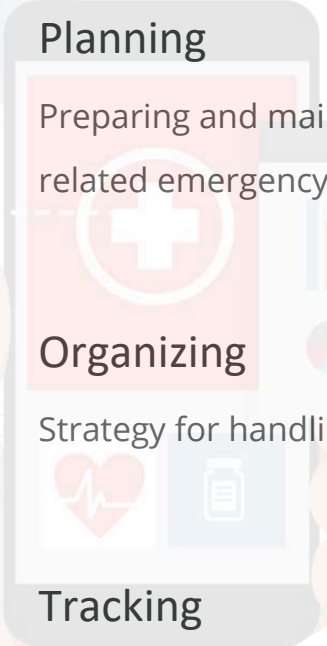
Organizing

Strategy for handling health-related print materials

Tracking

Generating or logging of health-related measures.

Example: Blood sugar log

Seeking

Level of initiative in obtaining health information

Active	Combined	Passive

Active ⬡ Consistently demonstrates initiative in obtaining health information

Combined ⬡ Demonstrates inconsistent initiative in obtaining health information
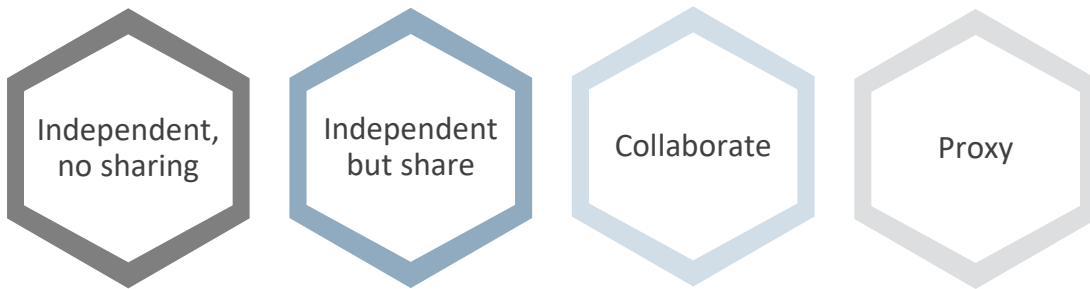
Passive ⬡ Demonstrates little to no initiative in obtaining health information

Sharing

Including others (family/friends) in communication and management of health information

Independent, no sharing	Independent but share	Collaborate	Proxy

Independent, no sharing — Manages health information independently, does not share health information with others

Independent but share — Manages health information independently, but shares health information with others

Collaborative team / partnership — Manages health information with others
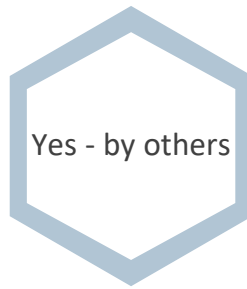
Proxy — Does not manage health information on their own. Instead, health information is managed by others (residence staff, family members, or other individuals)

Planning

Preparing and maintaining information in case of a health-related emergency.

Yes - by self

Yes - by others

No planning

Yes - by self

Prepares or maintains information in case of a health-related emergency

Yes - by others

Another person prepares and/or maintains, on behalf of the older adult, information in case of a health-related emergency

No planning

Neither the older adult nor another person prepares and/or maintains information in case of a health-related emergency

Organizing

Strategy for handling health-related print materials.

Filing

Piling

Toss

Filing — Accumulates printed materials with a systematic process

Piling — Accumulates printed materials without a systematic process

Toss — Does not accumulate printed materials

Tracking

Generating and logging health-related information. Example: Blood sugar levels

| Consistently | Sometimes | Never |

Consistently — Regularly generates and logs health-related information

Sometimes — Occasionally generates and logs health-related information

Never — Doesn't generate or log any health-related information

Personas

Personas and scenarios are instrumental to human-centered design[30]. Personas are representations of potential users whose needs and goals should be considered by designers. Scenarios are narratives that describe the persona's perceptions, goals, and technology needs[30]. They serve as tools for evoking empathy and communicating contextual information about users and stakeholders to designers[30, 31].

The personas in this guide were designed to capture common themes that emerged from the SOARING data, and represent older adults in a variety of living situations, with varied health issues and levels of support. By showcasing the different ways older adults seek, share, manage, and organize their health information, personas offer a look at older adults' access to and experience with technology.

Developing the personas and scenarios

The key findings from the SOARING project served as the foundation for the personas presented in this guide. Our findings were incorporated into elements of the personas, such as their goals, information needs, technology usage, and health information management activities. This information aims to help designers get an overview of how older adults manage their health information. For example, we found that one of the key characteristics of older adult PHIM is living situation. Older adults who live independently may take a more independent approach to managing their health information. Therefore, we included the connection between PHIM and living situation when developing the personas and scenarios.

Following the human-centered design process, the personas went through several iterations. We received feedback from experts in the field of health informatics, nursing, medicine, biostatistics, and human computer interaction. We also received feedback from older adults, user experience designers, and students.

The idea of *connected personas* grew out of our understanding of older adult information sharing and the role that others play in supporting older adult PHIM activities.

As demonstrated in the SOARING project results, family, friends, and providers frequently support older adults. They often help with health-related tasks such as organizing medications, finding answers to health-related questions, or making informed decisions. To reflect the complexity of this supportive network, we created friend, family, and provider personas that are connected to each older adult persona. We have called them connected personas. The connected personas represent the ways that family, friends, and providers support or want to support the older adult. They also describe the goals, needs, and challenges faced by family/friends and providers and give a sense of their relationship with the older adult.

A set of connected personas includes an older adult persona and at least one supportive family, friend, or provider persona. We believe that these connected personas provide value to designers by offering a broader picture of an older adult's PHIM than individual personas alone. In the following section, we briefly introduce each connected persona set.

Introducing Older Adult and Connected Personas

We have six sets of connected personas that consist of an older adult as well as family, friends, or provider personas. These connections represent the network of people that support the older adult with managing their health information. They convey the relationships that family, friends, and providers have with the older adult.

The older adult persona represents the primary user with respect to HIT design. The connected personas of family, friends, and providers are supplementary to the older adult. The purpose of the connected personas is to provide a broader context and a more holistic picture of the ways older adults manage their health information. The exception to this is Mary Memory, who is experiencing increased memory challenges due to Alzheimer's Disease. It is unlikely that she will be a primary HIT user, and therefore her PHIM needs may be best served by meeting the needs of her caregivers and providers.

Below is a brief description of each set of connected personas. The full set of personas is available in the Appendix.

Persona Set Overview

Paula Private's Set

Irving Independent's Set

Alice Assisted's Set

Rosa Retirement's Set

Arty Active's Set

Mary Memory's Set

Paula Private's Set

Paula Private

Henry Husband

Felicia Family Physician

Description

Paula Private is an older adult who likes her privacy. At the moment she would not like to share her diagnosis of pre-diabetes with her spouse, Henry Husband. Paula Private is also a patient of Felicia Family Physician.

Paula Private

Older Adult

Paula Private wants to keep her family happy and maintain her independence. She was diagnosed as pre-diabetic and does not want to share this news with her husband because of his dominating personality. She is comfortable searching the internet and using email, but has difficulty using the patient portal. She wishes there was some way that she could privately track and manage her health information.

Persona Needs

- She wants to privately manage health information

- She has difficulty using the patient portal

Suggested Design Guidelines

- **Support control over privacy of health information:** Explore ways older adults can share information while maintaining privacy.

- **Provide training:** Tailor technology trainings to the needs of older adults to help them use HIT tools to the fullest.

Henry Husband

Family and Friends

Henry Husband has been married to Paula for 50 years. He wants Paula to be healthy. He would like to be more involved with her health care but wants to respect her privacy. He wishes there was a way he could know about her health without repeatedly having to ask her. Henry has helped Paula with setting up her patient portal but has not accessed her account.

Persona Needs

➢ He wants to help Paula but also respect her privacy

Suggested Design Guidelines

➢ **Facilitate supportive relationships:** Consider features that allow family and friends to ask permission to access the older adult's health information[25].

Felicia Family Physician

Provider

Felicia Family Physician has many limited English-speaking patients and so has interpreters available at the time of their appointments. However, Paula has refused interpreters because she is concerned that health information may get back to her community.

Persona Needs

➢ She wants access to health information translated into languages other than English for her patients

Suggested Design Guidelines

➢ **Connect to reliable resources:** Consider resources that are tailored to the older adult and to the role and needs of family and friends[26,29], such as translated materials.

Irving Independent's Set

Irving Independent

Sarah Social Worker

Description

Irving Independent lives on his own in a low-income housing apartment. Sarah Social Worker visits him and helps him to organize his health information. He appreciates her help but would like to manage his health information on his own.

Irving Independent

Older Adult

Irving Independent is living in a low-income housing apartment. When he was homeless, he had difficulty managing his health information, and turned over his PHIM to his social worker. He wants to eventually manage and organize his health information on his own. Irving has access to computers at the library, which he uses to look up information to answer questions about his health. However, his arthritis often prevents him from using the computer.

Persona Needs

➢ He wants to manage his health information on his own but values the support of his social worker

➢ His arthritis is a barrier to using a computer

Suggested Design Guidelines

➢ **Anticipate changes over time in PHIM:** Older adults may experience shifts in responsibility over their health information at different points in time. They may go between active and passive management of their health information.

➢ **Support physical abilities:** Older adults may experience vision or hearing loss or in Irving's case, arthritis as they age.

Sarah Social Worker

Provider

Sarah Social Worker is a geriatric social worker. She has been working with Irving since he moved into his apartment. She helped him locate lost health records. She hopes that she can find ways to support his PHIM needs.

Persona Needs

➢ She wants to balance Irving's desire to manage his health information on his own while giving him the support he needs

Suggested Design Guidelines

➢ **Support PHIM in different living situations:** An older adult's living situation (e.g. independent home, homelessness, etc.) influences how they manage their personal health information. Consider the living situation when designing solutions to support older adults.

Alice Assisted's Set

Alice Assisted

Kevin and Kathy Kids

Frieda Friend

Pam Pharmacist

David Director

Description

Alice Assisted recently experienced a fall and broke her hip. She transitioned from an independent apartment to assisted living to receive more supportive care, but she values her independence and would like to return to her own apartment as soon as she can. Kathy and Kevin Kids are relieved that she is in assisted living because they are concerned she needs more help. David Director and Pam Pharmacist are working to make this a smooth transition for Alice. Alice talks about her health issues with Frieda Friend, a long-time friend.

Alice Assisted

Older Adult

Alice Assisted has transitioned from living independently to assisted living after breaking her hip. The facility manages her health information and though she appreciates it, she is struggling with the loss of autonomy. Alice has not used much technology but expresses interest in it and wants computer training.

Persona Needs

➢ She wants to regain some autonomy in managing her health information

➢ She has an interest in technology but needs training

Suggested Design Guidelines

➢ **Support PHIM in different living situations:** An older adult's living situation (e.g. independent home, homelessness, etc.) influences how they manage their personal health information. Consider the living situation when designing solutions to support older adults.

➢ **Provide training:** Help older adults use health information technology to the fullest.

Kevin and Kathy Kids

Family and Friends

Kevin and Kathy Kids are siblings and their mom is Alice. They worked together to coordinate Alice's care after she broke her hip. Their goal is to support their mom's independence, but they are ready to step in to provide more support as needed.

Persona Needs

➢ They want to support their mom's autonomy

➢ They want to be ready to step in when their mom needs more support

Suggested Design Guidelines

➢ **Support flexibility:** 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[25, 41].

Frieda Friend

Family and Friends

Frieda Friend has been a close friend to Alice for over 30 years. When they are together, they talk about their health issues and medications. Frieda does not have a lot of insight into Alice's health information management but is willing to support her and her family in whatever way that she can.

Persona Needs

➢ She wants to know how she can support Alice and her family when they need it

Suggested Design Guidelines

➢ **Support across the social network:** Design features for family and friends to coordinate among themselves to ensure they provide effective help[25, 41].

Pam Pharmacist

Provider

Pam Pharmacist is a clinical pharmacist that works with the assisted living facility. She wants to provide older adults with information that is clear and simple. During Alice's transition into assisted living, Pam did not have access to her hospital records so her medication list was incomplete. She was able to get the information, but it was time-consuming.

Persona Needs

➤ She wants access to an accurate list of medications for Alice

Suggested Design Guidelines

➤ **Encourage sharing across providers:** Consider potential solutions for providers to exchange and update older adults' health information. This information exchange can be especially critical for medications[28, 33].

David Director

Provider

David Director works with incoming residents and their families to ensure that the transition to assisted living is smooth. He has been trying to help Alice settle into their facility by supporting her need for autonomy. For example, they acknowledge and discuss her preferences in family meetings.

Persona Needs

➢ He wants to help Alice transition into assisted living and support her independence

Suggested Design Guidelines

➢ **Support the facilities and communities that help older adults manage their health information:** Older adults living in retirement communities and assisted living facilities typically receive support to manage personal health information[29]. Consider ways to keep older adults and families involved and informed while supporting these facilities.

Rosa Retirement's Set

Rosa Retirement

Diana Daughter

Gary Geriatrician

Description

Rosa Retirement lives in a retirement community where they support her with some of her needs like transportation to doctor appointments. Her adult child, Diana Daughter, helps her to organize her medications. She is a patient of Gary Geriatrician because he specializes in the care of older adults.

Rosa Retirement

Older Adult

Rosa Retirement wants to maintain her independence for as long as possible. She takes an active role in her healthcare, writing down questions for her doctor and using the internet to look for answers to health-related questions. Rosa uses email and she has tried to use her patient portal but no longer uses it because she forgot her password.

Persona Needs

➢ She uses the internet to look for answers to health-related questions, but is concerned about the quality of the information

➢ She does not use a patient portal because she forgot her password

Suggested Design Guidelines

➢ **Connect to reliable resources:** Link older adult users to resources about health information that are reliable and accurate.

➢ **Make login easy:** Older adults express challenges logging into systems and remembering passwords[38]. Explore login options that balance ease of use and privacy[38].

Diana Daughter

Family and Friends

Diana Daughter is involved with Rosa's health care. She works full-time but takes her mother to most doctor appointments. She also helps Rosa to organize and manage her health information. Although Diana is actively involved with Rosa's health and PHIM, she's concerned about missing signs of her mother's health declining.

Persona Needs

- ➢ She wants to continue to have an active role in Rosa's health care

- ➢ She is concerned about missing signs of her mother's health declining

Suggested Design Guidelines

- ➢ **Allow family and friends to share information with providers:** Consider ways that loved ones can share information by allowing them to upload information, such as their Power of Attorney forms, to the older adult's medical record.

- ➢ **Support flexibility:** 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[25, 41].

Gary Geriatrician

Provider

Gary Geriatrician wants his patients to be active in their health care. His schedule is such that he often finds that he runs out of time to address all his patients' concerns. This recently happened with his patient Rosa and her daughter Diana. He wishes he could have spent more time with them. Gary wishes he had more training on how to effectively use patient portals. He would like it if the patient portal could allow patients to share health data like blood pressure numbers.

Persona Needs

➢ He wants to see data trends and points of health information like blood pressure numbers from patient tracking

Suggested Design Guidelines

➢ **Incorporate ways to capture and share information:** Some older adults use devices such as blood glucose meters or activity trackers to collect personal health information. Consider features that allow older adults to easily capture, upload, and share this information with their healthcare providers or caregivers while assuring their privacy and control over where their information goes[29] .

Arty Active's Set

Arty Active

Felicia Family Physician

Description

Arty Active is an active participant in managing his health and health care. Felicia Family Physician has a range of patients at different ages. One of her goals is to build long lasting relationships with patients.

Arty Active

Older Adult

Arty Active wants to continue to be healthy and live independently. He is an active participant in his health care and has stopped seeing providers who dismiss his questions about health and nutrition. He wishes that providers could share health information with one another rather than always relying on him to convey the information. He is comfortable with technology and is an avid user of the patient portal.

Persona Needs

➢ He prefers that providers share his information with one another rather than always relying on him to convey his personal health information to them.

Suggested Design Guidelines

➢ **Encourage sharing across providers:** Consider potential solutions for providers to exchange and update older adults' health information.

Felicia Family Physician

Provider

Felicia Family Physician provides care to both Arty and Paula. Arty once messaged her through the patient portal about chest pains he had experienced. Although he was alright, she wished she had been alerted about his chest pain sooner so that she could have responded promptly.

Persona Needs

➢ She wants to be notified through a system which identifies urgent situations communicated through the patient portal, or other means.

Suggested Design Guidelines

➢ **Guide effective use:** Technology can be used in unintended ways. For example, secured messaging systems are typically used for non-emergency questions. However, health care providers have reported receiving urgent messages form older adults[28]. Anticipate and avoid unintended uses of health information technologies.

Mary Memory's Set

Mary Memory

Oliver Out-of-State Son

Nancy Nursing Supervisor

Description

Mary Memory is living with Alzheimer's Disease. She is transitioning to a memory care unit because her condition has worsened. She would like her son, Oliver Out-of-State to be more involved. He would like that too, but because he lives out of state and works full-time it is difficult. Nancy Nursing Supervisor has tried to keep Oliver updated about his mother.

Mary Memory

Served persona: Older Adult

Mary Memory has Alzheimer's disease. She is transitioning from assisted living into a memory care unit. She does not use technology, and her health information is managed by the assisted living facility. She wants her son Oliver to be more involved in her health care and in decision-making. She wishes that there was a convenient way for him to be kept up-to-date about her health, including having access to her health information.

Persona Needs

➢ She wants her son Oliver to be kept up-to-date about her health and have access to her health information

Suggested Design Guidelines

➢ **Facilitate supportive relationships:** Consider features that allow family and friends to ask permission to access the older adult's health information or allow the older adult to reach out to family members to ask for support in managing health-related activities[25].

Oliver Out-of-State Son

Served persona: *Family and Friends*

Oliver Out-of-State Son lives in another state from his mother and is working full-time. He wants to find ways he can be more involved in her care and decision making. Being far away has been difficult and he has felt helpless in her transition to the memory care unit.

Persona Needs

➢ Despite living far away, he wants to play a more active role in his mother's care.

Suggested Design Guidelines

➢ **Connecting with health care providers:** Some personal health records, such as Epic MyChart, support secure messaging with healthcare providers. With the advances in technology, there are ways that patients and providers could connect, such as through devices that track health information. Explore easy to use and effective mediums to facilitate communication[29].

Nancy Nursing Supervisor

Served persona: *Provider*

Nancy Nursing Supervisor aims to have a great relationship with residents and families. She tried to contact Oliver to fill him in on his mother's increasing memory challenges. However, they kept missing each other. At their annual conference Oliver was surprised to see his mother's condition had worsened. Nancy explained everything that had happened. Oliver agreed that it was necessary to move his mom into the memory care unit.

Persona Needs

➢ She wants more effective ways to communicate with family members about residents' status.

Suggested Design Guidelines

➢ **Support the facilities and communities that help older adults manage their health information:** Older adults living in retirement communities and assisted living facilities typically receive support to manage personal health information. Consider ways to keep older adults and families involved and informed while supporting these facilities[29].
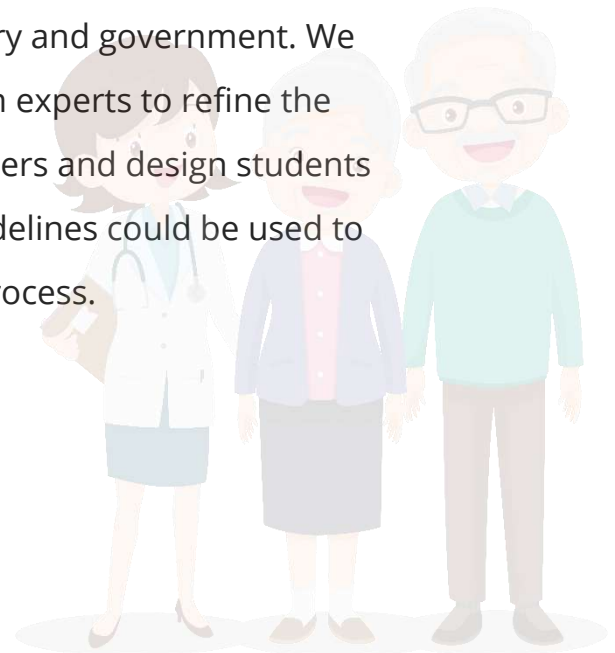
Design Guidelines

Designing HIT for Older Adults

While the personas illustrate specific cases across a variety of older adults, the following guidelines address broader considerations for designing HIT for older adults. The design guidelines, like the personas and scenarios, are based on our findings from the SOARING project. They are also based on literature from academic publications and best practices from industry and government. We used an iterative process of feedback from experts to refine the guidelines. We also gained input from designers and design students regarding how our personas and design guidelines could be used to better inform the design process.

These design guidelines aim to address the specific needs and experiences of older adults. We hope these guidelines will support designers and practitioners in developing HITs that empower older adults to successfully manage their personal health information. The design guidelines are organized into groups that offer considerations about the user experience of technologies, ways to support the older adult's PHIM, and encourage designers to involve older adults in their design process.

Guidelines List

A   Tailor the User Experience for Older Adults

B   Encourage Use of Technology

C   Help Older Adults Play an Active Role in Their Health

D   Facilitate Help from Friends, Family, and Healthcare Providers

E   Involve Older Adults in Your Design Practices

F   Recruit and Collaborate with Older Adults

A

Tailor the User Experience for Older Adults

Broad Design Guidelines

1

Design for diversity

The older adult population is not homogeneous. People differ across living situations, health issues, backgrounds and privacy needs[29]. Consider approaches like inclusive design to reach people across a wide range of situations and with differing abilities[32].

2

Recognize a range of experiences with technology

Older adults have varying levels of comfort with technology. In some cases the lack of experience and training may be a barrier to use[5]. Consider varying levels of confidence, experience, and in-person into your design process.

Support physical abilities

3

Older adults may experience vision or hearing loss as they age, as well as other physical challenges like dexterity. Increase font size [33, 34, 35] to at least 16 or 18 points[36]. If you offer sound, allow users to adjust the volume. Avoid frequencies above 400Hz[33]. Consider voice assistance for people living with physical challenges.

Address accessibility

4

Use accepted web accessibility guidelines to inform your design process so that older adults of every ability can use your health information technology. The World Wide Web Consortium (W3C) Web Accessibility Initiative (WAI) provides a list of accessibility standards for websites, web applications, and tools for older adults[36].

58

Deliver a consistent experience

5

Consider ways to deliver a consistent experience between mediums. For example, in our focus groups, older adults talked about inconsistencies between online and printed text. Older adults specifically noted that the font size displayed on a screen was much larger than in print[38].

Anticipate changes over time in PHIM

6

Older adults may need to shift responsibility for management of their health information to others at different points in time. Consider ways to facilitate changes between active and passive management of their health information.
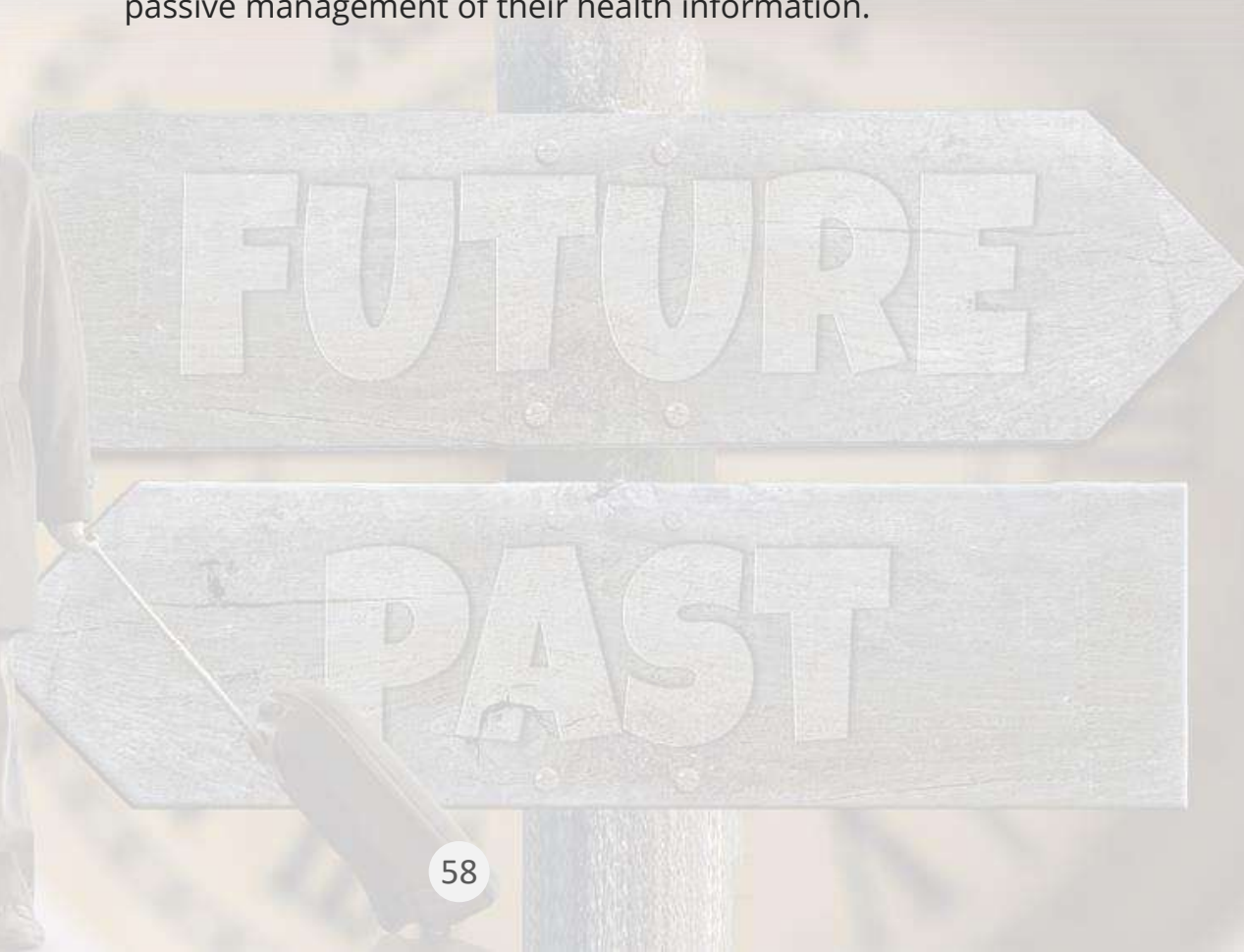
Specific Design Guidelines

Offer multiple platforms

7

Older adult users may want to access health information technology from more than one platform, such as a laptop or a mobile device. Design for the devices or platforms that older adults use.

Make login easy

8

Older adults may have challenges logging into systems and remembering passwords[37]. Explore options that balance ease of logging in and privacy[37]. For instance, in our focus groups, older adults brainstormed login ideas such as using voice assistants and face ID.

Streamline navigation

9

Make navigation simple, especially for older adults with memory challenges. Avoid visual clutter and complexity. Offer consistent and obvious paths to information. Keep navigational steps to a minimum[26, 33, 34].

Offer navigation cues

10

Help older adults orient themselves within the technology. Let users know where they are by using elements like navigational breadcrumbs and descriptive page titles that can be located via search[36].

Use plain language

11

Nine out of ten adults have trouble understanding and using health information when it is complex and unfamiliar[38]. Facilitate understanding - keep sentences short and concise, avoid jargon[28, 34, 37, 39], and use active voice[34, 40].

B

Encourage Use of Technology

Extend current practices

1

Many older adults have established systems to manage their health information, such as files of printed materials. Although there is potential for a digital solution, the benefits should outweigh current practices[4]. Consider incorporating features that extend or exceed their current tools such as, keeping an option to print online information.

Guide effective use

2

Technology can be used in unintended ways. For example, secured messaging systems are typically used for non-emergency questions. However, healthcare providers have reported receiving urgent messages from older adults[28]. Anticipate and avoid unintended uses of health information technologies.

Offer tips

3

Consider offering bite size tips and tutorials that educate and encourage older adults to play an active role in managing their health information and could also provide tips on how to use your tool. Consider involving healthcare professionals such as home health care nurses in the design process to share tips with older adults during home visits[39].

Provide training

4

Help older adults use health information technology to the fullest. Older adults have expressed preferences for in-person training and printed instructions. Consider training options that best meet the learning needs of older adult users. Consider multiple options to serve a wide range of users.

C

Help Older Adults Play an Active Role in Their Health

1

Connect to community resources

Older adults, friends and family, and providers want access to information about community resources for older adults (support groups and social services). Provide links to local services and organizations[25, 29].

2

Incorporate ways to capture and share health information

Some older adults use devices such as blood glucose meters or activity trackers to collect personal health information. Consider features that allow older adults to easily capture, upload, and share this information with their healthcare providers or caregivers while assuring their privacy and control over where their information goes[29]. For example, devices could capture and automatically upload information or be manually typed-in or spoken using a voice assistant[29].

3

Make it easy to update information

Health information, such as medications or emergency information, can change over time. Consider implementing periodic reminders for older adults to review and update their information. Ensure that changes can be made easily and efficiently.

4

Support information accuracy and efficient transfer

Older adults are sometimes the conduit of their health information between providers. They have expressed concern that they might share wrong information. Consider ways that older adults can convey accurate information to their providers[28].

5

Connect to reliable resources

Older adults and their loved ones may want to learn more about a health condition or treatment options. Link older adult users to resources about health information that are reliable and accurate. Consider resources that are recommended by providers and are tailored to the older adult and to the role and needs of family and friends[26, 29].

Help to synthesize health information

6

There is a wealth of health information that older adults and their loved ones may encounter. Consider ways your health information technology can present resources in one place and help older adults compare and understand this information[26].
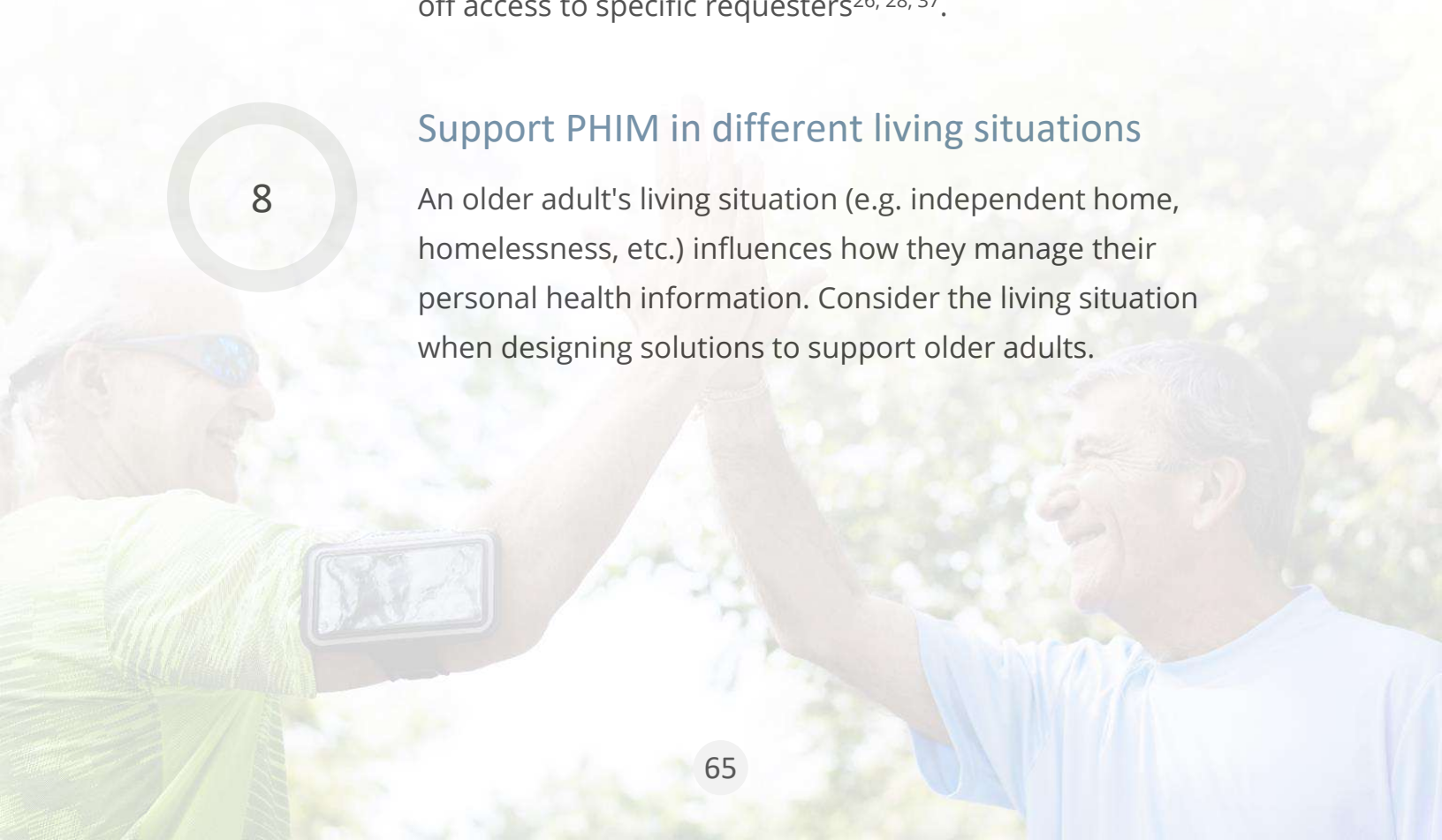
Support control over privacy of health information

7

Many older adults want to determine who has access to their personal health information. Explore ways older adults can share information while maintaining control over access. For example, when friends and family request information, features could enable older adults the ability to turn on and off access to specific requesters[26, 28, 37].

Support PHIM in different living situations

8

An older adult's living situation (e.g. independent home, homelessness, etc.) influences how they manage their personal health information. Consider the living situation when designing solutions to support older adults.

D

Facilitate Help from Friends, Family, and Healthcare Providers

Support flexibility

1

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[25, 41].

Facilitate supportive relationships

2

Consider features that allow family and friends to ask permission to access the older adult's health information or allow the older adult to reach out to family members to ask for support in managing health-related activities[25].

Support across the social network

3

Design features for family and friends to coordinate among themselves to ensure they provide effective help[25,41].

Connecting with healthcare providers

4

Some personal health records, such as Epic MyChart, support secure messaging with healthcare providers. With the advances in technology there are ways that patients and providers could connect such as through devices that track health information. Explore easy to use and effective mediums to facilitate communication[29].

Allow family and friends to share information with providers

5

Family and friends could help share health information with healthcare providers on behalf of an older adult, such as their medical and social history. Consider ways that loved ones can share information by allowing them to upload their Power of Attorney forms to the older adult's medical record or generate an updated list of contact information, including time preferences, and preferred modes of communication[25,26].

Encourage sharing across providers

6

Consider potential solutions for providers to exchange and update older adults' health information. This information exchange can be especially critical for medications[28, 39].

Support the facilities and communities that help older adults manage their health information

7

Older adults living in retirement communities and assisted living facilities typically receive support to manage personal health information. Consider ways to help those facilities while keeping older adults and their families involved and informed[29].

E

Involve Older Adults in Your Design Practices

Empower older adults

1

Involve older adults throughout the technology design process. Brainstorm and design with older adults. Get feedback and do usability testing with older adults on design iterations at different stages of the process. Seek input from older adults to create health information technologies that best meet their needs[42].

Don't forget non-users

2

Some older adults prefer not to use technology and worry that the touchpoints they currently use with organizations, such as telephone, could be negatively impacted by new technologies[37]. Gain an understanding of the whole user journey of older adults and the impact health information technology could have on different touchpoints.

Involve stakeholders

3

Family, friends, and healthcare providers often play a critical role in an older adult's personal health information management. Incorporate feedback and ideas from these stakeholders into the design process to ensure you fully assess and meet personal health information management needs[26, 41].

F

Recruit and Collaborate with Older Adults

Reach out to senior communities

1

Studies show that one of the best ways to recruit older adults is building partnerships with local senior organizations and senior centers[35, 43, 44, 45]. Consider building relationships with older adults by volunteering at those organizations. Doing so can build trust, especially in places where older adults are asked to participate in numerous research studies[44].

Consider transportation needs

2

Some older adults have difficulty securing reliable transportation[46]. When conducting studies with older adults, find a location that is convenient for older adults to participate, such as their local senior center[45].

71

Keep scheduling flexible

3

The cost of transportation and conflicting commitments can make scheduling challenging. Be open to adapting to the days and times that work best for older adults[45].

Show appreciation

4

Offer incentives to show gratitude for the time and feedback that older adult participants provide, such as gift cards, or other gifts[46].

Accommodate for older adults' needs

5

Adapt materials to older adult needs, such as using large font for printed study materials[44]. Consider the length of participation to avoid fatigue and interference with scheduled activities.

Use techniques that work

6

Depending on the older adult audience, have a few options to facilitate brainstorming or obtain feedback. Be ready to adapt techniques. Some older adults may prefer a discussion or providing written notes to sketching or low-fidelity prototyping[45].

Connecting PHIM Related Needs and Guidelines

We created a table of personal health information management (PHIM) and user experience needs based upon findings from our SOARING interviews and focus groups. The needs are organized first by role, with older adults' needs listed first, followed by family and friends, and then health care providers. For each need, we have listed relevant guidelines which are linked to the appropriate section of the design guidelines.

Older Adult Needs	Design Guidelines to Meet Needs
Play an active role in their own health care	A. Tailor the User Experience for Older Adults (A1-A11) B. Encourage Use of Technology (B1-B4) C. Help Older Adults Play an Active Role in Their Health (C1-C8) D. Facilitate Help from Friends, Family, and Healthcare Providers (D2, D4, D6, D7) E. Involve Older Adults in Your Design Practices (E1, E2) F. Recruit and Collaborate with Older Adults (F1-F6)
Easy to remember passwords	A. Tailor the User Experience for Older Adults (A1-A11) B. Encourage Use of Technology (B1, B2, B3) E. Involve Older Adults in Your Design Practices (E1, E2) F. Recruit and Collaborate with Older Adults (F1-F6)
Support organizing and managing their health information	A. Tailor the User Experience for Older Adults (A1-A11) B. Encourage Use of Technology (B1-B4) C. Help Older Adults Play an Active Role in Their Health (C2,C3, C4, C5, C6, C7, C8) D. Facilitate Help from Friends, Family, and Healthcare Providers (D2, D7) E. Involve Older Adults in Your Design Practices (E1, E2) F. Recruit and Collaborate with Older Adults (F1-F6)

Older Adult Needs	Design Guidelines to Meet Needs
One place to access and store health information	A. Tailor the User Experience for Older Adults (A1-A11) B. Encourage Use of Technology (B1-B4) C. Help Older Adults Play an Active Role in Their Health (C2, C3, C4, C5, C6, C7, C8) D. Facilitate Help from Friends, Family, and Healthcare Providers (D4, D5,D6, D7) E. Involve Older Adults in Your Design Practices (E1, E2) F. Recruit and Collaborate with Older Adults (F1-F6)
Understand medical terms and health information	A. Tailor the User Experience for Older Adults (A1-A11) B. Encourage Use of Technology (B1,B2,B3) C. Help Older Adults Play an Active Role in Their Health (C2, C4, C5, C6, C8) D. Facilitate Help from Friends, Family, and Healthcare Providers (D2) E. Involve Older Adults in Your Design Practices (E1, E2) F. Recruit and Collaborate with Older Adults (F1-F6)
Decide between electronic and manual tools to do tasks i.e., paper calendar vs. electronic calendar	A. Tailor the User Experience for Older Adults (A1-A11) B. Encourage Use of Technology (B1-B4) C. Help Older Adults Play an Active Role in Their Health (C3, C7, C8) E. Involve Older Adults in Your Design Practices (E1, E2) F. Recruit and Collaborate with Older Adults (F1-F6)

Older Adult Needs	Design Guidelines to Meet Needs
Manage and organize medications	A. Tailor the User Experience for Older Adults (A1-A11) B. Encourage Use of Technology (B1,B2,B3) C. Help Older Adults Play an Active Role in Their Health (C3, C4, C6, C7, C8) E. Involve Older Adults in Your Design Practices (E1, E2) F. Recruit and Collaborate with Older Adults (F1-F6)
Easily track health information such as, blood glucose levels, and share it with their health care providers	A. Tailor the User Experience for Older Adults (A1-A11) B. Encourage Use of Technology (B4) C. Help Older Adults Play an Active Role in Their Health (C2, C4, C8) E. Involve Older Adults in Your Design Practices (E1, E2) F. Recruit and Collaborate with Older Adults (F1-F6)
Find trustworthy online information about health, such as fitness and healthy eating	A. Tailor the User Experience for Older Adults (A1-A11) B. Encourage Use of Technology (B1-B4) C. Help Older Adults Play an Active Role in Their Health (C1, C5, C6, C8) E. Involve Older Adults in Your Design Practices (E1, E2) F. Recruit and Collaborate with Older Adults (F1-F6)
Have control over health information, for example, being able to choose who has access to their health information	A. Tailor the User Experience for Older Adults (A1-A11) B. Encourage Use of Technology (B1-B4) C. Help Older Adults Play an Active Role in Their Health (C7, C8) D. Facilitate Help from Friends, Family, and Healthcare Providers (D2, D4, D7) E. Involve Older Adults in Your Design Practices (E1, E2) F. Recruit and Collaborate with Older Adults (F1-F6)

Family and Friend Needs	Design Guidelines to Meet Needs
Gain access to their older adult loved one's health information	D. Facilitate Help from Friends, Family, and Healthcare Providers (D1, D2, D4, D5) E. Involve Older Adults in Your Design Practices (E3)
Understand when to step in to help their older adult loved one while respecting their independence	A. Tailor the User Experience for Older Adults (A6) C. Help Older Adults Play an Active Role in Their Health (C1, C5, C6, C8) D. Facilitate Help from Friends, Family, and Healthcare Providers (D1, D3, D7) E. Involve Older Adults in Your Design Practices (E3)
Update health care providers with their older adults loved ones' health information	C. Help Older Adults Play an Active Role in Their Health (C3, C8) D. Facilitate Help from Friends, Family, and Healthcare Providers (D1, D4, D5, D7) E. Involve Older Adults in Your Design Practices (E3)

Family and Friend Needs	Design Guidelines to Meet Needs
Involved with decision-making of their older adult loved one's health	C. Help Older Adults Play an Active Role in Their Health (C1, C6, C7, C8) D. Facilitate Help from Friends, Family, and Healthcare Providers (D1,D2, D3, D4, D5, D7) E. Involve Older Adults in Your Design Practices (E3)
Find resources that help them support their loved ones, for example, housing options for an older adult that needs memory care or ways to stay healthy	C. Help Older Adults Play an Active Role in Their Health (C1, C5, C6, C8) E. Involve Older Adults in Your Design Practices (E3)

Provider Needs	Design Guidelines to Meet Needs
Find best mode to communicate with family members	D. Facilitate Help from Friends, Family, and Healthcare Providers (D4, D5, D7) E. Involve Older Adults in Your Design Practices (E3)
Know older adult's contextual factors, i.e., living situation	A. Tailor the User Experience for Older Adults (A6) C. Help Older Adults Play an Active Role in Their Health (C8) D. Facilitate Help from Friends, Family, and Healthcare Providers (D4, D5, D6, D7) E. Involve Older Adults in Your Design Practices (E3)
Identify urgent messages from older adults in the health information management systems	B. Encourage Use of Technology (B2, B3, B4) D. Facilitate Help from Friends, Family, and Healthcare Providers (D4) E. Involve Older Adults in Your Design Practices (E3)

Provider Needs	Design Guidelines to Meet Needs
Access older adult's health information, i.e., medical and social history, durable power of attorney, mediations	C. Help Older Adults Play an Active Role in Their Health (C3, C4, C8) D. Facilitate Help from Friends, Family, and Healthcare Providers (D4, D5, D6, D7) E. Involve Older Adults in Your Design Practices (E3)
View health information shared by older adults, such as blood pressure data, and to be able to see trends and unusual data	C. Help Older Adults Play an Active Role in Their Health (C2, C4) E. Involve Older Adults in Your Design Practices (E3)
Share health information resources in different languages to older adults and their family members	A. Tailor the User Experience for Older Adults (A1, A4) C. Help Older Adults Play an Active Role in Their Health (C1, C5, C6, C8) D. Facilitate Help from Friends, Family, and Healthcare Providers (D7) E. Involve Older Adults in Your Design Practices (E3)

Design Ideas

We have developed four design ideas based on the design guidelines to serve as an inspiration when designing for older adults. Each illustrated design idea has a scenario that provides context to the older adult PHIM needs and potential solutions.

1. Sharing health information with loved ones

Scenario

Jean is an 81-year-old who lives independently. She calls her daughter Carol to catch up on the day's events. Jean tells Carol that she went to the doctor that morning but is frustrated because she can't remember all the details of her visit. Jean would like to share information from the patient portal with Carol. However, Carol does not have access.

Design Idea

Carol investigates information about Jean's patient portal and finds there is a sharing feature, where family and friends can request access to health information. Carol sends a request to Jean so that she can see the latest doctor visit summary.

Jean receives Carol's request and accepts it.
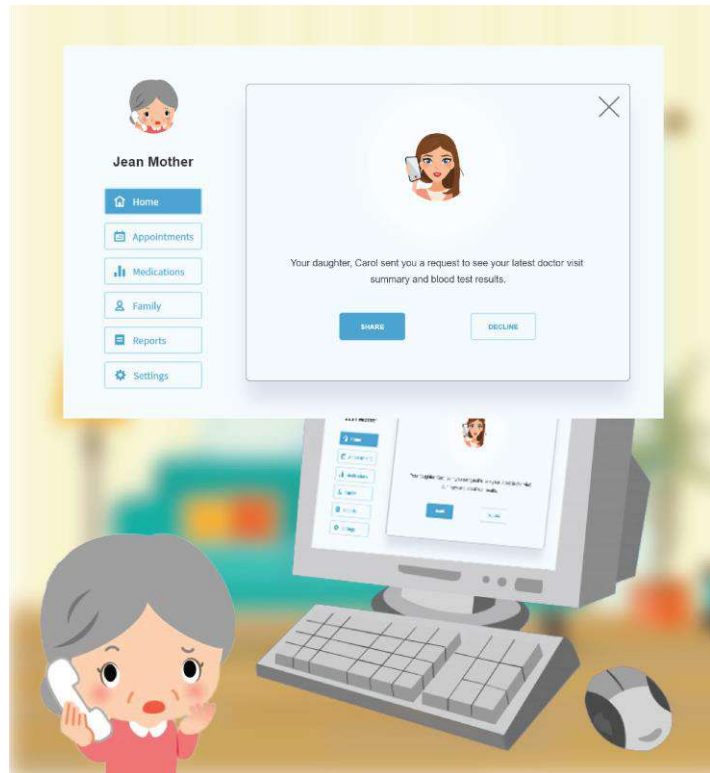
Carol is notified that Jean has accepted her request and now has access to Jean's visit summary. Carol calls Jean to continue their conversation about Jean's appointment.

2. Easy access to reliable resources

Scenario:

John is a 76-year-old retired plumber. He is reviewing his last medical visit summary about the pain in his elbow. He sees his diagnosis is gout.
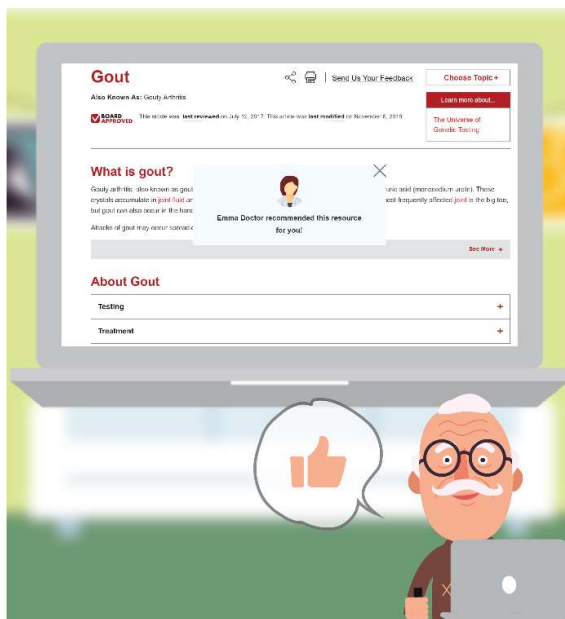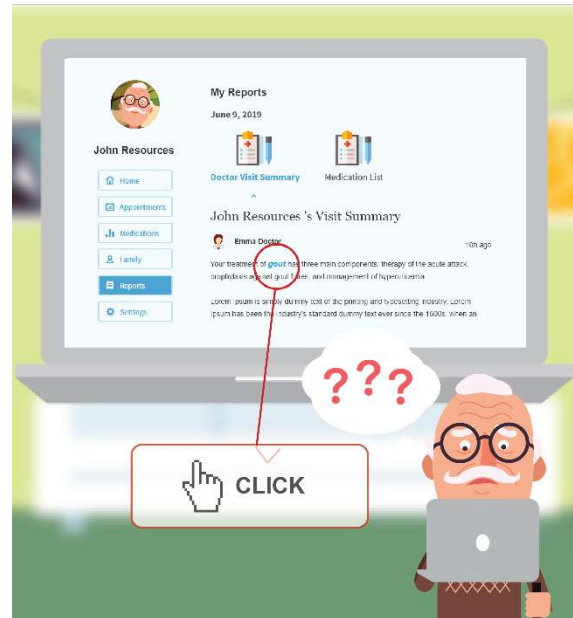
Design idea:

John notices that the word 'gout' is highlighted and clicks on it . A separate web page opens to a well-known credible resource which his primary care doctor, Dr. Turner, recommended. The resource provides an in-depth explanation about gout that pertains to his symptoms. John reads it and feels better informed.

He returns to his online medical visit summary and notices that there are links to recommended community and online resources that he can also check out. He finds out about foods to eat to prevent a gout attack.
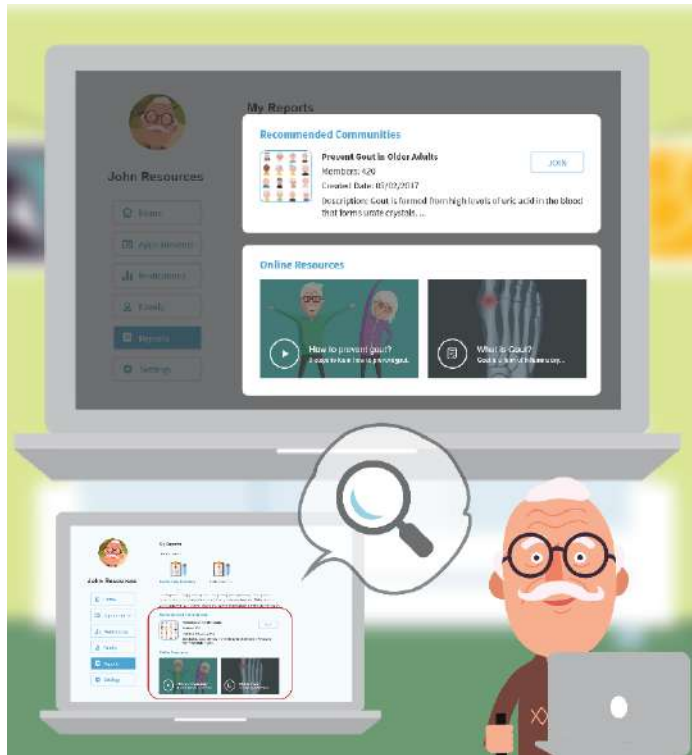
Character vector created by BSGStudio - all-free-download.com

3. Support decision making

Scenario:

Sheri has been concerned about her mother, Julie, a 68-year-old widower. Over the last month, she has noticed that her personal hygiene has declined and that she has been struggling with managing her medications.

Sheri talks with Julie about this and she reluctantly accepts that she needs some support throughout the week.

Pill box vector by www.vecteezy.com.

Design idea:

Sheri goes online to search for options and comes across a tool that allows her to specify the service that Julie needs help with and what her budget will allow for.
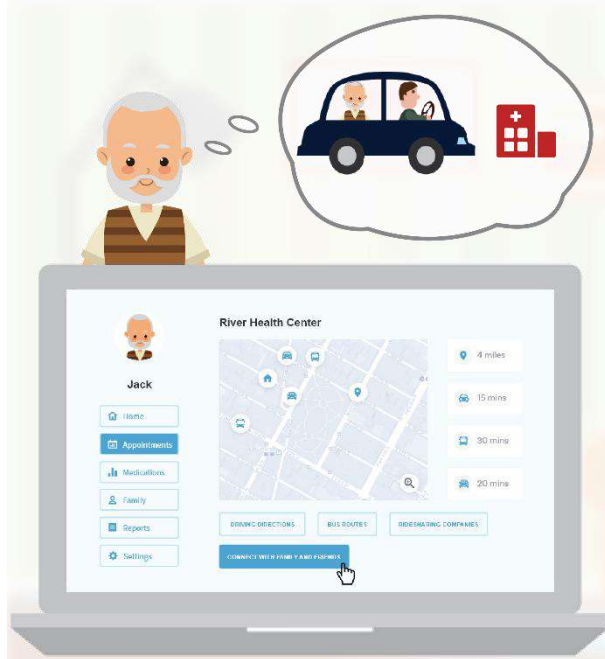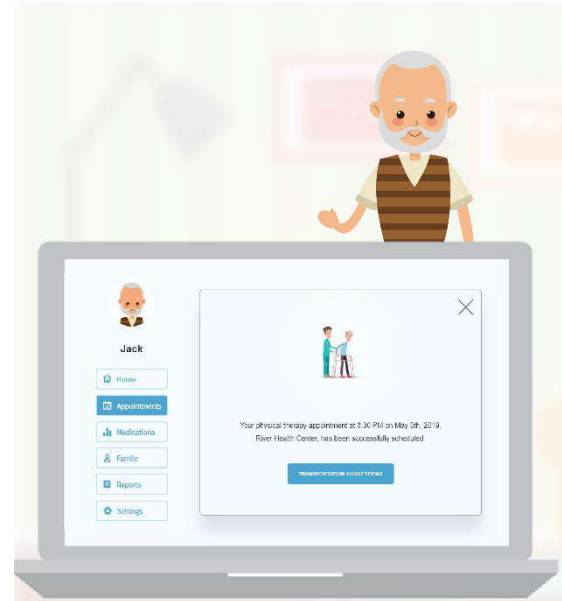

The tool returns with a list of service options with related costs. She and Julie compare them together.

4. Reaching out for support

Scenario:

Jack scheduled a physical therapy appointment. He received a confirmation message that his appointment was set.

Design idea:

Jack noticed a button that said "Transportation Suggestions". He clicked it and saw there were several suggestions for transportation, such as driving directions, bus routes, and even links to ridesharing companies. He also noticed an option to connect with family and friends to help organize a ride to his appointment.

Jack's son Zachary has said he would like to help Jack get to his appointments. Jack selects the "Connect with Family and Friends" option, then selects Zachary, writes a message, and then presses "send", which sends a request to his son.
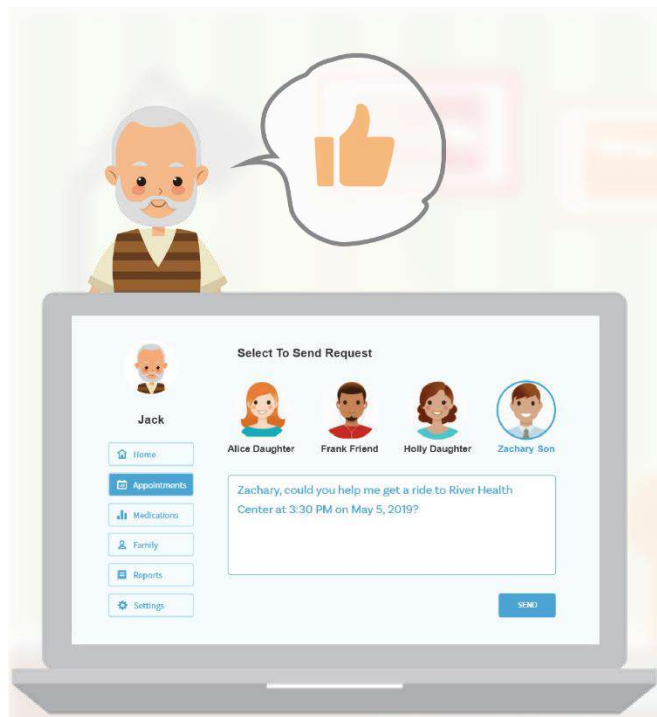
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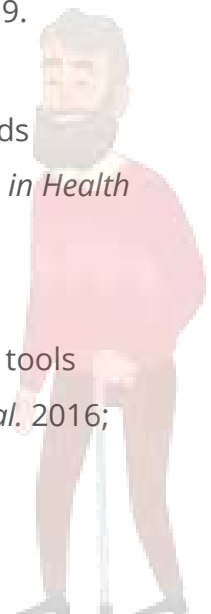
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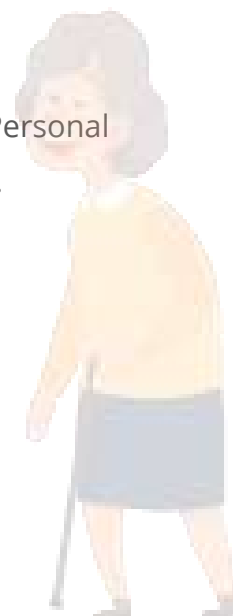
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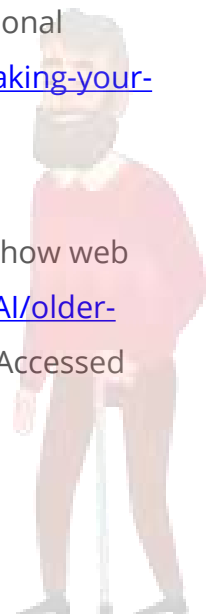
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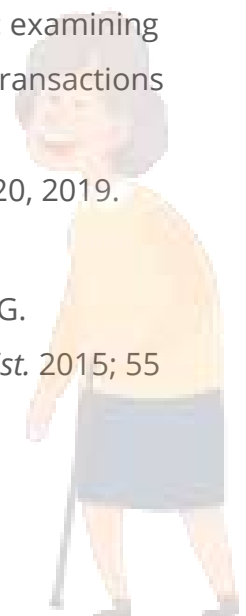
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Appendix

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The following pages contain six complete sets of connected personas, each consisting of an older adult persona, and related family, friend, and/or provider personas. These connected personas provide a holistic perspective to understanding the complexity of ways in which older adults manage their health information in the context of their supportive network. The persona set Mary Memory is slightly different from the others - because of her memory challenges related to Alzheimer's Disease, her health information is managed primarily by her family and providers.

Paula Private

"I wish to be a master filer and can choose what information to share with my partner."

Age: 71
Gender: Female
Race: Asian
Relationship Status: Married to Henry
Living Situation: Private residence
Income Level: Upper middle
Education: Post-graduate

Activities

Volunteer   **Socialize**   **Workout**   **Family**   **Technology**   **Cooking**
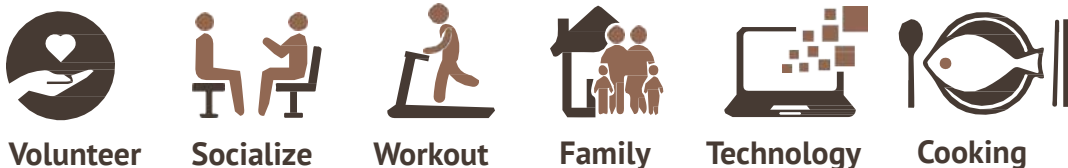
Health

Health Conditions: pre-diabetes, high blood pressure

Cognitive impairment: None
Physical Ability: Gets tired easily
Insurance: Medicare
Medication management: Manages by self

Goals

Life Goals
- Keep her family happy
- Stay active and have a positive attitude
- Maintain independence

Health Goals
- Lower blood pressure
- Control her blood sugar level
- Lose weight

Current Challenges

- Gain understanding of newly diagnosed condition -- prediabetes
- Avoid feeling pressure from her husband's advice and insistence to do things his way
- Maintain control over her health information and decision-making
- Organizing paper materials related to her health

Needs and Considerations

- Would like to have health information in one place, like patient portals where she accesses past after-visit summaries and lab reports
- Wants to choose what information to share with others
- Wants to manage and track her health conditions

Technology Access

✓ Laptop   ✓ Desktop   ✓ Smartphone

✓ Tablet   ✓ E-book reader   Smart TV

Technology Use

	Never	Sometimes	Freq.
Phone calls			✓
Texting			✓
Web browsing			✓
E-mail			✓
Creating docs		✓	
Social media		✓	
Patient Portal		✓	

Paula Private

Scenario

Paula was recently **diagnosed with prediabetes**. She was disappointed because she thought she was doing a good job managing her weight and food intake. Paula **did not tell her husband,** Henry, about the diagnosis. Paula and Henry have been married for over 50 years. They currently live in a private residence and **manage their health and health information on their own**. Paula admits that Henry has strong opinions especially when it comes to her health. Unlike Henry, Paula has a mild personality and likes to please others. She often does whatever Henry suggests, which is why she is keeping her diagnosis of prediabetes to herself until she can figure out the best way to manage it.

Paula is logging her weight once a week and stores it in a folder in her desk drawer. Now, Paula also **wants to track her blood sugar levels.** She has **difficulty using the patient portal,** but still prefers to use it. She is hesitant to ask Henry for help because she's afraid that he would find out more than she wants him to know. She is nervous that he might try taking over by telling her what she should do, if he finds out her new diagnosis. Paula wishes there was a way to track and manage her health information in one place and to also keep it private at times.

Health Information Management Style

Seeking:
Active

Sharing:
Independent shares with others

Tracking:
Sometimes

Emergency Planning:
Done by self

Organizing:
File printed materials

Paula's desk drawer
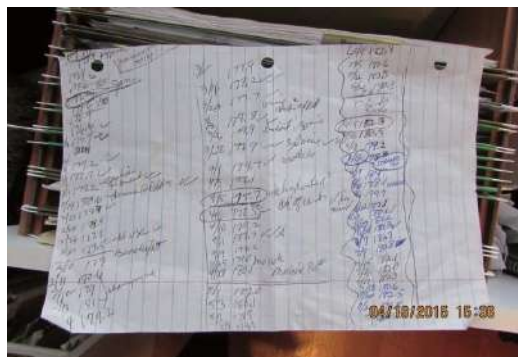
Paula's old weight log

Henry Husband

"I want to keep my partner healthy and happy."

Age: 72
Gender: Male
Race: Asian
Relationship Status: Married to Paula
Employment Status: Retired
Education: Graduate degree
Relationship to Older Adult: Husband
Living Situation of Older Adult: Private residence

Support Activities

Obtaining health information

Sharing healthy activities

Preparing for change

Goals

- Be able to offer solutions to any health questions that Paula might have
- Keep Paula and himself healthy
- Understand Paula's health issues and be there to support her

Current Challenges

- Obtain enough information to support Paula with her health while also respecting her privacy
- Find resources which help him understand medical information

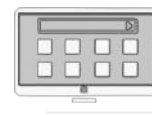## Technology Access

✓ Laptop   ✓ Desktop   ✓ Smartphone

✓ Tablet   E-book reader   Smart TV

Access to Paula's patient portal: **No**

Needs and Considerations

- Wants to interpret medical terms and health information, i.e. lab results
- Wants to find reliable resources about fitness and healthy eating
- Know how to be actively involved with Paula's health

Scenario

Henry has been married to Paula for over 50 years. They enjoy doing social and family-related activities together. Henry **supports Paula in tasks such as picking up medications and attending doctor appointments**. When Henry takes her to doctor appointments, he often waits for her in the waiting room. Paula shares with him what happens in those appointments, but Henry **feels like she leaves out some details.**

Henry has also talked with Paula about working towards a healthier lifestyle. He doesn't want to be too pushy but feels he has a lot to contribute to help her feel better and avoid potential future illnesses. Henry **wishes there was a way for him to know more about her health without having to repeatedly ask her.** He wants to respect Paula's privacy, but also wants to be prepared to support her. Henry also **wants to know where he can find resources** to help him understand medical information he may encounter. He has set up his own patient portal and feels comfortable using it. He also helped Paula set up her patient portal but he has not accessed it since setting it up.

"Messaging through the portal is a great way to communicate but it has increased my workload a lot."

Age: 45
Gender: Female
Race: Asian
Job Type: Physician
Speciality: Family Medicine
Education: Medical Doctor
Time in Practice: 8 years
Working with Older Adult: 8 years
Patient Panel: 30% are older adults
Technology experience: Very experienced

Goals

- Maintain a work and life balance
- Promote preventive health care
- Build a long lasting relationship with patients
- Provide interested patients with information about how to set-up and use the patient portal

Current Challenges

- Overwhelmed by high volume of portal messages from patients and caregivers
- Patients use the patient portal to send newsy or casual messages
- Lack of language interpreters available
- Find acceptable ways to communicate with English as a second language patients

Information Needs

- Identify urgent messages in the patient portal
- Wants to see trends and unusual values of health data like blood pressure
- Access to more translated health information for patients

Strategies

- Review after-visit summary with patients
- Ask patients for preferred method of communication
- Rely on family members for language translation

Scenario

Felicia's days are packed with appointments. She enjoys receives messages her through the patient portal but, is **often overwhelmed by the amount of messages she receives** everyday, forcing her to respond to them at home. Furthermore, Felicia once missed an urgent message from her patient, Arty, as she had no way of determining which messages were urgent. On the other hand **some patients have sent messages about things that are unrelated to their health** like, current news. Felicia does respond to them but keeps it brief. She tries to hint that messages are for health related questions or concerns.

Felicia has many limited English speaking patients so she **tries to ensure that her patients have interpreters available** at the time of their appointment. It does not always happen. However, some patients, like **Paula refuse to use interpreters** at their appointment due to privacy concerns. Some patients are concerned that their health information may get back to their community.

Support Activities

Medication Management

Connect patients to health resources

Communicate with caregiver

Irving Independent

"I don't wanna live to be that age if I'm dependent on someone for everything."

Age: 69
Gender: Male
Race: Native American
Relationship Status: Divorced
Living Situation: Apartment in low-income housing
Income Level: Low
Education: Some college

Activities

Newspaper **Socialize** **Chess** **Music**

Health

Health Conditions: Bipolar, arthritis, diabetes, back pain, sleep apnea

Cognitive Impairment: No
Physical Ability: Mildly impaired
Insurance: Medicaid and Medicare
Medication management: Manages by self

Goals

Life Goals
- Not to be a burden on his family
- See his grandchildren grow up
- Be independent

Health Goals
- Be more physically active
- Keep mentally healthy
- Eat healthy

Current Challenges

- Lost health records while previously homeless
- Reliant on social worker to manage his health information, he wants to be able to manage his health information on his own
- Arthritis limits his physical activity and ability to go to the library to use the computer

Needs and Considerations

- He receives papers from his doctor, but they are handled by social worker that file them for him
- Some health-related papers from recent appointments are stored in a box in his dresser
- He wants to figure out what works for him regarding physical calendar vs. phone calendar and features

Technology Access
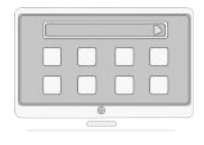
Laptop	Desktop ✓	Smartphone
Tablet	E-book reader	Smart TV

Technology Use:

	Never	Sometimes	Freq.
Phone calls		✓	
Texting	✗		
Web browsing		✓	
E-mail		✓	
Office tasks	✗		
Social media	✗		
Patient Portal	✗		

Irving Independent

Scenario

Irving lives in a low-income housing apartment. Prior to living there he was homeless. Irving is glad to have a place of his own; it provides him with a sense of security and stability. **While being homeless, he had a difficult time managing his health information, in fact at one point, he lost all his health records**. Irving has not done any emergency planning yet, but hopes to do so soon. He does not care to track any health information, instead he prefers to listen to his body.

Irving typically goes to the library to use their computers and access the Internet. However, recently **he has had to stay home because his arthritis** has been too painful. Irving is disappointed that he cannot go because it has limited his access to information. When he has questions about his health, he often searches the web. He also gets health information by listening to the radio and from his doctor. Currently, a social worker visits him and helps him handle his health materials by filing them for him. Irving appreciates the help and enjoys chatting with the social worker but he also **wants to manage his health information on his own.** He is nervous about this desire and afraid that this will feel overwhelming. Irving wants to find an easy way to manage his health information without the involvement of the social worker.

Health Information Management Style

Seeking:
Both actively and passively

Sharing:
Collaborative

Tracking:
Never

Emergency Planning:
No emergency planning

Organizing:
Pile
(Keeps in a pile until his social worker comes to visit)

Pill boxes in kitchen

Box in the drawer

Flyer for elder services

Sarah Social Worker

"Something where I can get accurate medical history would be incredibly helpful"

Age: 41
Gender: Female
Race: White
Job Type: Social Worker
Job Title: Geriatric Social Worker at a Senior Center
Education: Master Social Work
Time in Practice: 12 years
Working with Older Adult: 4 years
Patient Panel: 100% are older adults
Technology Experience: Very experienced

Support Activities

Obtaining health information Decision-making Preparing for change Socializing Managing Medication Managing Records

Goals

- Help clients to age in place
- Assist clients to determine their needs and goals
- Connect clients to community resources
- Help clients adapt to changes result from life circumstances such as unemployment

Current Challenges

- Balancing Irving's desire to manage his health information on his own and giving him necessary support
- Clients often report inaccurate information that leads to misunderstandings that gets corrected by others like, family
- Support clients' through crisis situations, such as a inadequate housing

Information Needs

- Understanding of medical history and diagnoses
- Awareness of client's living circumstances
- Access to client's online health records

Strategies

- Email providers with quick questions instead of scheduling in-person visits
- Makes phone calls to figure out missing information
- Uses different methods for younger and older clients (printed material for older, technological approaches for younger)

Scenario

Sarah is an advocate for her clients and **supports them with a range of things to help improve their quality of life.** This includes, helping them find accurate information on the internet, determining what questions to ask the doctor, figuring out bills, setting up transportation, making sure they take their medication and supporting them when they need someone to talk to. A challenge, especially if a client has memory issues, is knowing what s/he says is accurate. Sarah **wishes she had online access to her clients' health information** especially when clients have memory issues. In these cases, it can be especially difficult to get accurate information.

Sarah was paired with Irving when he began to live in low-income housing. Since Irving was previously homeless, he **lost his health records**. Together they have retrieved necessary information from the doctors. **Sarah is helping him create a plan for the future**. Sarah prints everything for him. They have made great progress and she hopes she can continue to be of help to him.

Alice Assisted

"To go from living alone to living with a group of people is a real shock to your system."

Age: 81
Gender: Female
Race: White
Relationship Status: Widowed
Living Situation: Independent to assisted living in continuous care facility
Income Level: Middle
Education: College graduate

Activities

Bible Study   Socialize   Choir   Family   Physical Therapy

Health

Health Conditions: Broken hip, Stroke, Diabetes
Cognitive Impairment: No
Physical Ability: Difficulty with mobility
Insurance: Medicare
Medication: Managed by assisted living facility

Goals

Life Goals
- Stay healthy
- Be in good physical condition
- Spend time with family and friends

Health Goals
- Recover from broken hip
- Be active again and maintain exercise routine
- Improve balance and prevent falls
- Better manage diabetes

Current Challenges

- Experiencing a loss of autonomy in transitioning from independent living to assisted living
- Lacks confidence in using technology
- Difficulty with physical mobility prevents her from doing activities she used to do

Needs and Considerations

- Living in an assisted living facility, the staff manage her health information, she feels a loss of autonomy
- Wants to stay involved with her healthcare
- Desire to return to independent living

Technology Access
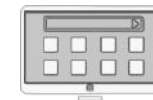
Laptop   Desktop ✓   Smartphone ✓
Tablet ✓   E-book reader   Smart TV

Technology Use:

	Never	Sometimes	Freq.
Phone calls			✓
Texting	✗		
Web browsing	✗		
E-mail	✗		
Office tasks	✗		
Social media	✗		
Patient Portal	✗		

Alice Assisted

Scenario

Prior to living in assisted living, Alice lived independently in a private apartment at a continuous care facility. Several months ago, Alice fell and broke her hip. As a result, she now **uses a walker** and has difficulty with activities like bathing. She also has a hard time continuing with activities that she formerly enjoyed like, singing in the church choir and leading a bible study group.

Her **children**, Kathy and Kevin, **are worried about her** and urged her to move to an assisted living facility. This facility **manages her health information**, tracks her blood glucose levels, organizes her health-related materials, and plans for emergencies. Although she appreciates their support, Alice is **struggling with the loss of her autonomy** as in the past she managed this information on her own. She keeps a wall calendar of her appointments.

Alice maintains a close friendship with Frieda, whom she has known for over 30 years. Her son, Kevin, takes her to most of her doctor appointments and church. Alice gets a copy of her visit summary from her doctor but often forgets to give it to the staff at the facility. While she has all this support, **she wants to keep up with her health conditions** and be included in any decision-making. She has heard about patient portals but **does not feel comfortable with technology,** so she would like some assistance in setting up an account and using a computer.

Health Information Management Style

Seeking: Passive

Sharing: Health info managed by proxy

Tracking: Never

Planning: Done by others

Organizing: Toss (Assisted living manages printed materials)

Wall calendar

Walker

Exercise handout

Frieda Friend

Age: 75
Gender: Female
Race: White
Relationship Status: Married
Employment Status: Retired
Education: Graduate degree
Relationship to Older Adult: Friend
Living Situation of Older Adult: retirement community
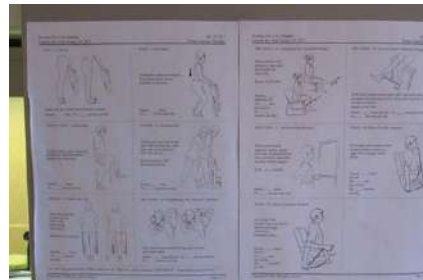
"Just talking and listening are probably the largest health related activities we do together"
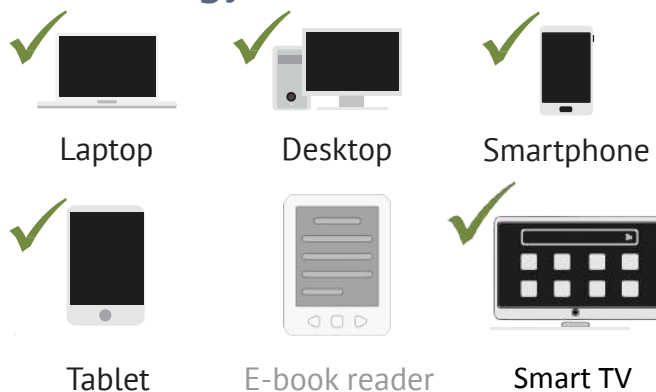
Goals

- Continue to share a close friendship
- Be a sounding board for health related questions
- Encourage each other to engage in healthy activities

Current Challenges

- Maintain her health condition
- Figure out whether Alice needs help in her health care

Technology Access

✓ Laptop   ✓ Desktop   ✓ Smartphone

✓ Tablet   E-book reader   ✓ Smart TV

Access to Alice' patient portal: **No**

Needs and Considerations

- Know whether her friend would like her to play a bigger role in her health care
- Wants to learn ways she and Alice can stay healthy
- Wants to know what health information online she can trust

Scenario

Frieda and Alice are close friends and have been friends for over 30 years. They are both retired and in the past have spent time together going on walks, going to seminars, running errands, and sharing meals. When Frieda and Alice are together they **casually talk about their health**, especially since Alice's recent hip injury. They share questions about medications and sometimes **Frieda looks up answers to Alice's questions online.** However, sometimes they wonder what information they can trust. They also **talk about** the things that happen at their **doctor appointments** and **give each other advice** about their health. Frieda does not have much awareness about Alice' emergency planning or how she manages her health information.

Health topics of conversation are often mixed with other news and shared interests. Frieda does not think she needs access to Alice's health information, but would do so if Alice asked her. Frieda believes Alice's son would be her primary caregiver, but she is **willing to help her friend** and her friend's family in any way that she can.

Support Activities

Sounding Board

Sharing healthy activities

Preparing for change

Kevin and Kathy Kids

> *"The most challenging thing is mom's privacy. It's hard to know how to support her."*

Race: White
Living situation of older adult: Independent to assisted living

Kevin
Ages: 62 **Gender:** Male
Relationship Status: Married
Employment Status: Retired
Education: Bachelor's Degree
Relationship to Older Adult: Son

Kathy
Ages: 57 **Gender:** Female
Relationship Status: Divorced
Employment Status: Self-Employed
Education: Bachelor's Degree
Relationship to Older Adult: Daughter

Support Activities

Sounding Board **Obtaining health information** **Preparing for change** **Decision-making** **Transportation**

Goals

- Understand when to help or step in
- Support their mom's independence
- Continue to have good communication and coordination of their mom's health care

Current Challenges

- Concerned about mom's balance issue and nervous about her falling again
- Want their mom to maintain autonomy but also share important health events

Technology Access

✓ Laptop ✓ Desktop ✓ Smartphone
✓ Tablet E-book reader ✓ Smart TV
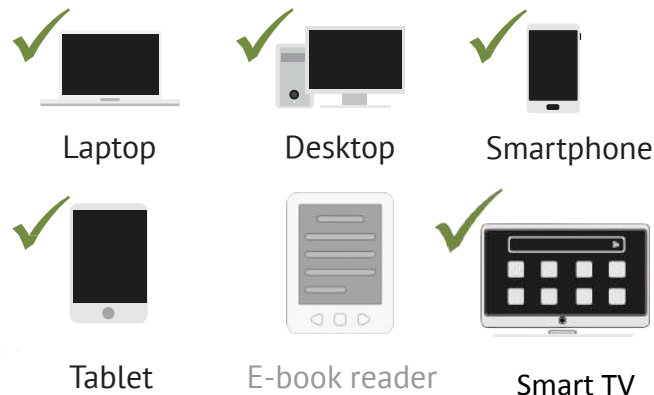
Access to Alice' patient portal: **No**

Need and Considerations

- Wants to access to Alice's health information
- Would like to set up online system with mother's visit summaries or health care provider contact information
- Find ways to increase support for their mom but respect her independence

Scenario

Kathy and Kevin are siblings who are close to their mother, Alice. Kevin sees her several times a week, **takes her to doctor appointment**s and they spend Sundays together going to **church**. He also **helps her manage her finances.**

Kathy lives about an hour and half away and so calls Alice a couple times a week and **visits** **every other week.**

Kathy and Kevin coordinated care for their mom after she broke her hip. They are **relieved that Alice is in an assisted living facility.** They know that she has a desire to move back to independent living once she has recovered. However, they are **worried that she'll fall again.** They anticipate she may need to stay in assisted living care due to some recent incidents.

Alice has been soiling the bed because she could not get to the toilet in time. Kevin and Kathy learned about this from the assisted living staff and not from Phyllis. **They wonder if there is other information that their mom has kept from them.** They sense they may need to step up support soon. They want to know how and when to step in.

Pam Pharmacist

"I would love to see the older adults at home and communicate with them directly."

Age: 52
Gender: Female
Race: White
Job Type: Pharmacist
Speciality: Clinical Pharmacist
Education: Doctor of Pharmacy
Time in Practice: 30 years
Working with Older Adult: 15 years
Patient Panel: 85% are older adults
Technology experience: Intermediate

Goals

- Help older adults stay healthy by providing personalized care
- Give older adults information and materials that are clear and simple

Current Challenges

- Difficulty providing just the right amount of information in the right way to older adults
- Older adults' health data, medication list and hospital discharge notes are unclear or incomplete
- Knows little about how patients manage their medications in their home environment

Information Needs

- Accurate and current medications and side effects
- Wants access to older adults' medication lists after being discharged from the hospital
- Understand factors, such as their home environment in order to provide informed recommendations

Support Activities

Drug Reconciliation

Navigating between Patient and Doctor

Chart Review

Patient Counseling

Strategies

- Simplifies information about medication side effects for patients by making them specific to their individual risk
- Creates a risk profile for patients based on the number of medications and sends that to assisted living facility and also relays that information to the patient.
- Encourage patients to set up a reminder system of when to take medications and the dosage

Scenario

Pam is a **clinical pharmacist** with a specialty in geriatrics. Pam has noticed that many of the older adults lack strategies to manage their health information. They often rely upon their caregivers and doctors a lot. Many of the older adults defer to the physicians for decision-making as opposed to seeking out answers to their health questions.

One of Pam's patients, Alice, recently broke her hip and moved into an assisted living facility. Pam **did not have access to Alice's hospital records,** making her medication list incomplete. Pam was able to get the **information** but it was **time-consuming** to get it.

Also, because of her impaired mobility, Alice could not come into the pharmacy. So, Pam **communicated with the assisted living staff instead.** She gave the specifics of Alice's medications and how it should be administered but she was **worried about the information being miscommunicated.**

David Director

"Older adults don't want to take that step of moving, we work hard at making it feel like home here."

Age: 53
Gender: Male
Race: American Indian/Alaskan/White
Job Type: Director
Speciality: Director of Resident Care, Assisted Living facility
Education: Masters
Time in Practice: 13 years
Working with Older Adult: 20 years
Patient Panel: 100% are older adults
Technology experience: Intermediate

Support Activities

Obtaining health information

Decision-making

Preparing for change

Goals

- Support residents in maintaining highest level of independence
- Address any family concerns, medical issues or other major problems
- Hire the most qualified staff and ensure full staff is present 24/7
- Ensure the transition into assisted living for residents and families is smooth

Current Challenges

- Residents struggling to make the transition into assisted living
- Communicating new information to everyone involved (staff, stakeholders and other providers)
- Family members disagree on what's best for the resident

Information Needs

- Full medical and social history to make the best care plan
- List of updated medication list both prescribed & over the counter
- Know who has access to the resident's chart
- After visit summaries especially if there are medication changes

Strategies

- Identifies initiatives for the year
- Holds regular leadership meetings
- Uses a picture-based system of residents to help staff recognize each resident
- Email families to keep them updated about their loved ones' latest happenings

Scenario

David manages the delicate balance between ensuring that residents feel a sense of autonomy and supporting their needs. He **values the intake process** where he works with residents and their family members on a care plan that includes defining their health needs, preferences and finances. David believes that these efforts help to make the transition go smooth. But there are **challenges in getting health records from providers** in a timely manner and **miscommunication among staff members a**bout the arrival of a resident. He wishes that their system could help to gather information and keep staff updated.

David also **supports residents who have a difficulty** transitioning to assisted living. One resident, Alice is struggling. She wants to go back to living on her own but it is unlikely that will happen. David and his staff tried to ease her transition by making sure they acknowledge her desires in family meetings. They have also offered to set up her computer so she can use it to get health information. For now, she has declined but is interested. To help residents transition, they have also tried to make the facility feel and look like home rather than a hospital.

Rosa Retirement

" I feel safe living in community but I hate living in an isolated apartment."

Age: 86
Gender: Female
Race: African American
Relationship Status: Widowed
Living Situation: Retirement Community
Income Level: Middle
Education: Post-graduate

Activities

Socialize   **Theater**   **Reading**   **Family**   **Clinic**   **Walk**

Health

Health Conditions: High blood pressure, acid reflux

Cognitive Impairment: Yes, minor memory challenges

Physical Ability: Normal

Insurance: Medicare

Medication management: Manages in partnership with daughter

Goals

Life Goals
- Stay independent as long as possible
- Leave daughter and son an inheritance

Health Goals
- Exercise and eat healthy
- Remember to take all medications

Current Challenges

- Allowing her daughter to be more involved in helping her manage her health care and health information
- Organizing so many pills
- Concern about the loss of independence because of increasing health issues

Needs and Considerations:

- Wants to be able to store and access all her health information
- Feels overwhelmed by the amount of medication she needs to take
- Wants to access trustworthy information online
- Interested in using a patient portal, but difficulty remembering her passwords

Technology Access

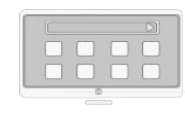✓ Laptop   ✓ Desktop   ✓ Smartphone

Tablet   E-book reader   Smart TV

Technology Use:

	Never	Sometimes	Freq.
Phone calls			✓
Texting		✓	
Web browsing		✓	
E-mail			✓
Office tasks		✓	
Social media		✓	
Patient Portal		✓	

Rosa Retirement

Scenario

Rosa keeps her space clean and organized. She has a filing cabinet and files absolutely everything just in case she needs it. She started **using a pillbox that her daughter fills for her** because she can't remember when to take the pills. In addition to her medication, she also takes vitamins. Rosa has used a patient portal but no longer has access to it because **she forgot her password** and doesn't know how to get a new one. **She checks her blood pressure and writes it down on paper that she keeps on her mirror.**

Rosa is very happy with both the staff and facility where she lives. They clean for her every two weeks, but she makes the bed herself, does laundry, and irons as she **feels it is important to do things for herself.** Her daughter drives her around and Rosa uses the facility van. For every appointment**, Rosa develops a list of written questions for her doctor.** Sometimes she will ask the nurses at her facility or look on the Internet for answers to health-related questions. Rosa sometimes gets frustrated and sad about reduction in her mobility, memory, and overall independence but tries to focus on being grateful for the help from her daughter and the retirement community.

Health Information Management Style

Seeking: Active

Emergency Planning: Done by others

Sharing: Health info managed by self but shares

Organizing: File printed materials

Tracking: Consistently

Tracking blood pressure

Rosa's desk drawer

Rosa's pill boxes

Diana Daughter

"Keep my senses open for some kind of change"

Age: 59
Gender: Female
Race: African American
Relationship Status: Married
Employment Status: Full-time employed
Education: Bachelor's degree
Relationship to Older Adult: Daughter
Living Situation of Older Adult:
Retirement community

Goals

- Support her mom's health and daily life
- Be prepared for a health crisis
- Continue to be involved with her mom's health care

Current Challenges

- Concerned about missing signs of her mother's health declining
- Disagreements with her brother about what is best for their mother
- Help Rosa with her health information without relying on her for details
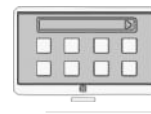
Technology Access

✓ Laptop   ✓ Desktop   ✓ Smartphone

✓ Tablet   E-book reader   Smart TV

Access to Rosa's patient portal: **No**

Support Activities

Obtaining health information   **Managing records**   **Communicating with providers**   **Medication Management**   **Transportation**

Needs and Considerations

- Wants to understand the status of my mom's health
- Needs to communicate with her mom's health providers
- Wants to find out about housing options for aging adults due to mother's memory decline

Scenario

Diana is the daughter of Rosa, who lives in a retirement community. Diana is involved in Rosa's health care. She takes her to most doctor appointments, asks questions, and helps organize her health information into files. When Rosa has questions, they search the Internet together or look through the handouts that doctors have given to her at past appointments. Diana **fills her mother's pill boxes every week.**

Diana doesn't access Rosa's patient portal since **she attends her appointments and talks to Rosa about her health.** Although she works hard at helping her mother, **Diana's brother,** who lives in a different state, **doesn't think she does a good job** with this and is constantly hounding her for more information and to "do more" for their mother. Her brother even once advocated to move their mother closer to him so he could take over care duties.

"How can you do assessments of people's lives when you've got such a small window?"

Age: 70
Gender: Male
Race: White
Job Type: Physician
Speciality: Geriatrician
Education: Medical Doctor
Time in Practice: 45 years
Working with Older Adult: 40 years
Patient Panel: 95% are older adults
Technology experience: Intermediate

Support Activities

Medication Management

Support Medical Understanding

Review and sort health materials

Goals

- Want patients to be engaged and active in their health care
- Have open communication with caregivers and maximize the information they provide
- Learn about external factors such as, stressors at home that could impact a patient's health

Current Challenges

- Not enough time in appointments to discuss all of patient concerns
- No access to patient information from providers at other healthcare organizations
- Difficult to know what is current among patient's paper management systems

Information Needs

- Accurate and current information such as medications and contact lists from patients
- Know patient's health care proxy or durable power of attorney
- Data trends and points of health information like blood pressure numbers from patient tracking

Strategies

- Prints out medication list to review with patient
- Use visual aids to explain diagnosis or medical conditions
- Ensures patients understand their current condition, he asks them to teach-back that what's been explained in the appointment.

Scenario

Gary's patients have multiple health conditions and are managing a lot of medications. In appointments, Gary **reviews medication lists with his patients but runs out of time to address other concerns.** This recently happened with his patient, Rosa who had come to the appointment with her daughter, Diana. Rosa came prepared with questions but they did not have time to go over them. So **he gave her pamphlets** and briefly reviewed the after-visit summary with them. He told Rosa and Diana to call with any questions. Gary **wishes he could spend more** time with his patients.

Gary has recommended the patient portal to patients but he often hears that patients don't really use it. He **wishes he could get training on how to use the system more effectively.** He also wishes the system would allow patients to share pictures of their living situation. Gary and his staff **struggle to get information about medication and patient's health conditions from other providers.** He would love if the portal allowed him to receive and share information with other providers. Patients are often surprised when they find out that Gary does not have access to all of their health information.

Mary Memory

"I'd like to keep my marbles rolling- as they say. We don't know what tomorrow brings."

Age: 90
Gender: Female
Race: White
Relationship Status: Widowed
Living Situation: Assisted living, in continuous care facility
Income Level: Low middle
Education: Some college

Health

Health Conditions: Alzheimer's disease, Moderate and Falls

Cognitive Impairment: Yes
Physical Ability: Normal
Insurance: Medicare
Medication management: Managed by assisted living facility

Goals

Life Goals
- Live as long as possible and as comfortably as possible
- Improve her mood
- Don't want to feel like a burden to family

Health Goals
- Go for walks with friends and family
- Maintain physical health
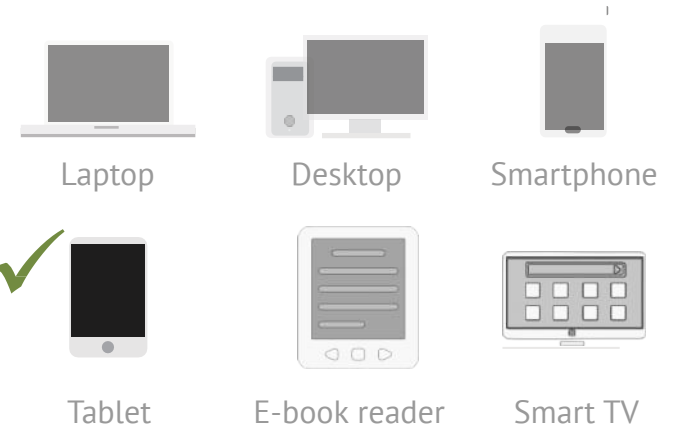- Communicate her preferences for care and write it down so everyone knows them

Current Challenges

- Memory impairs her communication with others
- Has difficulty remembering things like doctor appointments
- Health information goes directly to assisted living facility and not to her or her son, Oliver
- Oliver lives out of state and is busy so he often misses health events that happen

Activities

Socialize   **Family**   **TV**   **Music**

Needs and Considerations

- Anticipating the later stages of Alzheimer's disease
- She is unable to manage her health information
- Desire to have Oliver, her son involved with her health care and decision making

Technology Access

Laptop   Desktop   Smartphone

✔ Tablet   E-book reader   Smart TV

Technology Use:

	Never	Sometimes	Freq.
Phone calls	✗		
Texting	✗		
Web browsing	✗		
E-mail	✗		
Office tasks	✗		
Social media	✗		
Patient Portal	✗		

Mary Memory

Scenario

Mary lives in assisted living care environment within a continuous care facility. She is **getting ready to transition into a memory care unit** because her Alzheimer's disease has gotten worse. She experiences more instances of confusion about where she is. The staff has noted that several times a week she has not wanted to bathe and gets frustrated and angry when encouraged to do so. Also, recently she has seemed to be suspicious and sometimes combative.

Mary has a **calendar to help her remember appointments** but **the staff has been responsible for all of her health information management**, including posting the POLST form and installing a pull cord in her apartment for emergency situations. They also manage her medications.

Mary appreciates the support from the staff but also **wishes her son, Oliver, could be more involved.** He lives in a different state and works full-time. Mary knows that Oliver has tried to stay abreast of her health condition but he is not able to visit or call frequently. She **wishes there was a convenient way for him to be more involved** and keep updated on her health.

Health Information Management Style

Seeking: Passive

Planning: Done by others

Sharing: Health info managed by Proxy

Organizing: Toss printed materials
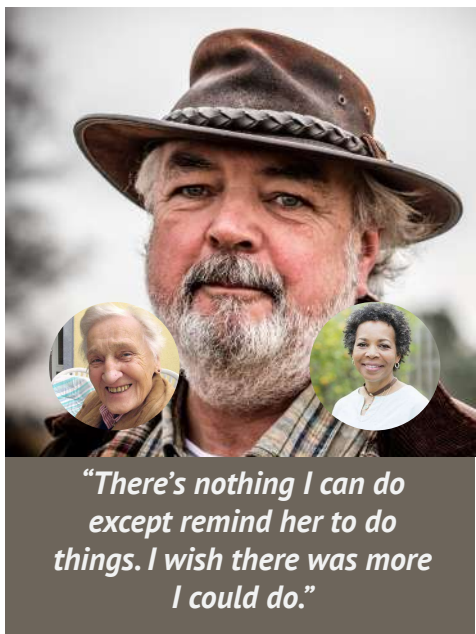
Tracking: Never

Calendar of appointments

Physician's instruction form

Emergency pull cord

Oliver Out-of-State Son

"There's nothing I can do except remind her to do things. I wish there was more I could do."

Age: 58
Gender: Male
Race: White
Relationship Status: Divorced
Employment Status: Hourly employee
Education: Bachelor's degree
Relationship to Older Adult: Son
Living situation of Older Adult: Assisted Living in continuous care facility

Support Activities

Researching health information

Sharing health information

Communicating with staff

Goals

- Be a source of support to his mom
- Develop a good relationship with the assisted living staff and his mom's doctors
- Maintain his mom's dignity as her memory declines

Current Challenges

- Not enough time to be actively involved in Mary's health information management
- Not sure when and how he should become more involved in Mary's health care

Technology Access

✓ Laptop ✓ Desktop ✓ Smartphone

✓ Tablet ✓ E-book reader ✓ Smart TV

Access to Mary's patient portal: **No**

Needs and Considerations

- Stay informed about his mom's daily well-being
- Find ways he can support his mom from afar
- Access to his mom's patient portal
- Find how he can be involved in decision-making of his mom's health

Scenario

Oliver and his mother, Mary, have always had a close relationship. As her memory has started to decline, Oliver has begun to feel a bit helpless. She is now in the process of **transitioning to the memory care** unit at the continuous care facility. He is mostly satisfied with the facility. **They manage her health and her health information.** They make sure she gets her medication at the right times and keep copies of information from her doctor appointments. The facility has also helped manage Mary's emergency plan.

Since **Oliver lives in another state and works full-time,** he isn't able to attend Mary's appointments, so he has to rely on the staff to communicate everything. Oliver does help Mary answer **health-related questions by searching the internet or by asking others**, but he's not sure if it helps. He is happy that the facility supports Mary, but, **wonders how he could play a bigger role** in his mom's care from a distance.

Nancy Nursing Supervisor

"Some family members are hard to get a hold of, they know their mom or dad is being cared for and so don't respond right away"

Age: 50
Gender: Female
Race: African American
Job Type: Nursing
Specialty: Nursing Supervisor, Assisted Living
Education: Master of Science in Nursing
Time in Practice: 20 years
Working with Older Adult: 25 years
Patient Panel: 100% are older adults
Technology experience: Very experienced

Support Activities

Care planning

Administrative support

Communicate with family

Goals

- Establish a good relationship with residents and their families
- Ensure the facility meets state regulations
- Provide services that maximize resident's independence

Current Challenges

- Residents' fear that sharing notes from doctors could impact their autonomy, so they choose to not share them
- Residents with memory challenges are unable to sign forms and sometimes it is difficult to get a hold of a family member to be present
- Keeping staff trained and updated on the system

Information Needs

- Care notes from doctor appointments and changes to medications
- Needs to ensure that they are in compliance with regulations, example, nurses' notes are up to date
- Family's preferred mode of communication

Strategies

- Discuss resident happenings in care team meetings
- Conduct an annual conference with resident and family members
- Contact family about any changes to resident's health

Scenario

Nancy does her best to keep families updated about their loved ones. However, she understands that **family members have competing priorities.** Sometimes it is **difficult to reach them**. This was the case with Mary's son, Oliver. Mary's memory challenges have gotten worse. Nancy **tried to get in touch with Oliver**. She tried to catch him by phone but they kept missing each other. At their annual conference, **Oliver was surprised that his mom's condition had declined as fast as it did**. Nancy explained everything that had been happening with Mary. He agreed that it was necessary to move his mom from assisted living into their memory care unit.

Nancy is in constant communication with **her staff.** She has learned that something that **frustrates them** is the **electronic health record system**. It is inefficient because they have to enter the same information in multiple places. This has lead to errors and inconsistent information. Also a number of **staff have limited computer experience** which has made learning how to use the system much more difficult.

Arty Active

"I want to stay as healthy as I can and live in my home for as long as I can."

Age: 63
Gender: Male
Race: Latino
Relationship Status: Single
Living Situation: Private residence
Income Level: Middle
Education: Graduate degree

Activities

Check the stock market

Socialize

Learn Mandarin

Yoga

Travel

Health

Health Conditions: Elevated blood pressure, tendinitis
Cognitive Impairment: None
Physical Ability: Normal
Insurance: Blue Cross Blue Shield
Medication management: Manages by self

Goals

Life Goals
- Be able to travel
- Continue to live independently
- Stay in touch with family and friends

Health Goals
- Maintain good health
- Improve quality of sleep
- Continue to be physically active

Current Challenges

- Information is disjointed and he has to fill in the gaps with multiple providers. He's worried about giving the wrong information to providers.
- Wants to be active in his healthcare but some providers seem resistant
- Concerned about how aging increases his health risks
- Has had difficulty finding health resources related to traveling such as getting medications abroad

Needs and Considerations

- Wants health information to be accessible to providers across different organizations
- Wants to figure out what information he needs to keep printed copies versus stored online
- Would like an easy way to share tracking information with providers
- Enthusiastic participant in his health care

Technology Access

✓ Laptop
✓ Desktop
✓ Smartphone
✓ Tablet
✓ E-book reader
✓ Smart TV

Technology Use:

	Never	Sometimes	Freq.
Phone calls			✓
Texting			✓
Web browsing			✓
E-mail			✓
Office tasks			✓
Social media		✓	
Patient Portal			✓

Arty Active

Primary Persona: Older adults

Scenario

Arty is an active and healthy senior. He has **elevated blood pressure** and made a management plan with his doctor to make lifestyle changes. When Arty started to train for a half marathon he developed knee pain, which his doctor says is **tendinitis**. Arty has noticed that he sees his primary care doctor more often and is also now seeing a physical therapist for his knee. He realizes that he'll probably need increased support as he grows older. Currently, he **lives independently** and wants to do so for as long as he can. He eats healthy and has just joined a yoga studio.

He is an **active participant in his own health care** and has ended relationships with providers who were dismissive of his health concerns. Arty wishes that providers could access and share information with each other, rather than relying on him. He is concerned that he might pass on inaccurate information.

Arty is an **avid user of the patient portal** and also **keeps paper copies** of information including, post-visit summaries. He wonders if paper records are necessary if the information is available online. Arty also wants a way to **easily share information he tracks** (i.e., blood pressure log) with his providers.

Health Information Management Style

Seeking: Active

Planning: Done by self

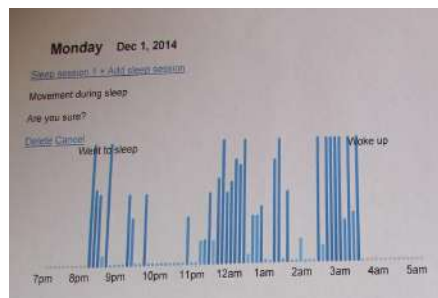**Sharing:** Independent, doesn't share

Organizing: Files mostly online

Tracking: Consistently

Blood pressure log

Sleep log

"Messaging through the portal is a great way to communicate but it has increased my workload a lot."

Age: 45
Gender: Female
Race: Asian
Job Type: Physician
Speciality: Family Medicine
Education: Medical Doctor
Time in Practice: 8 years
Working with Older Adult: 8 years
Patient Panel: 30% are older adults
Technology experience: Very experienced

Support Activities

Medication Management

Connect patients to health resources

Communicate with caregiver

Goals

- Maintain a work and life balance
- Promote preventive health care
- Build a long lasting relationship with patients
- Provide interested patients with information about how to set-up and use the patient portal

Current Challenges

- Overwhelmed by high volume of portal messages from patients and caregivers
- Patients use the patient portal to send newsy or casual messages
- Lack of language interpreters available
- Find acceptable ways to communicate with English as a second language patients

Information Needs

- Identify urgent messages in the patient portal
- Wants to see trends and unusual values of health data like blood pressure
- Access to more translated health information for patients

Strategies

- Review after-visit summary with patients
- Ask patients for preferred method of communication
- Rely on family members for language translation

Scenario

Felicia's days are packed with appointments. She enjoys receives messages her through the patient portal but, is **often overwhelmed by the amount of messages she receives** everyday, forcing her to respond to them at home. Furthermore, Felicia once missed an urgent message from her patient, Arty, as she had no way of determining which messages were urgent. On the other hand **some patients have sent messages about things that are unrelated to their health** like, current news. Felicia does respond to them but keeps it brief. She tries to hint that messages are for health related questions or concerns.

Felicia has many limited English speaking patients so she **tries to ensure that her patients have interpreters available** at the time of their appointment. It does not always happen. However, some patients, like **Paula refuse to use interpreters** at their appointment due to privacy concerns. Some patients are concerned that their health information may get back to their community.

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https://www.soaringstudy.org/

Thank You

the **Essential Guide** to
Older Adult-Centered Design:

Supporting Personal Health Information
Management