

“They Make Us Old Before We’re Old”: Designing Ethical Health Technology with and for Older Adults

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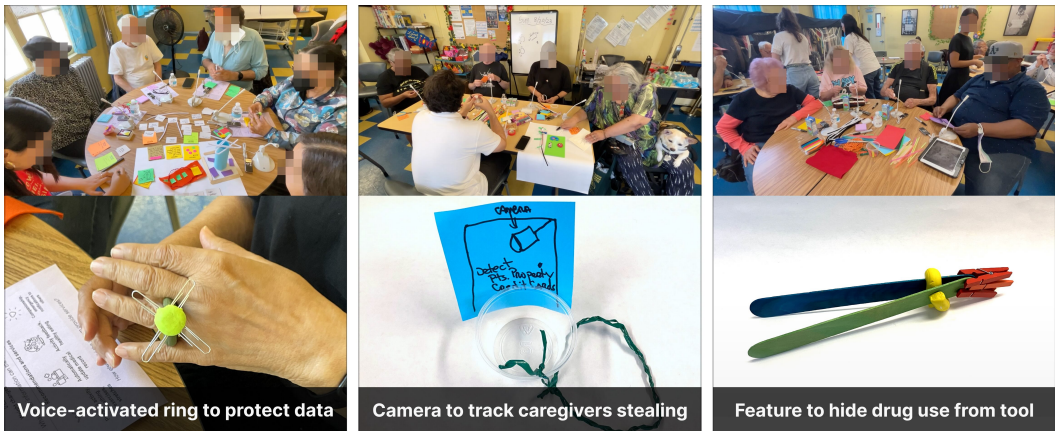


Fig. 1. Photos of the three teams who participated in our workshop and examples of their modifications to ambient intelligence: a voice-activated ring to protect data, a camera to track caregivers stealing from patients, and a feature to block a health tool’s recognition of drug use.

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ACM 2573-0142/2024/11-ART478
<https://doi.org/10.1145/3687017>

Voice-first ambient interfaces (VFAIs), such as Alexa, can uniquely meet the health needs of older adults. However, inequitable technology may worsen health disparities and decrease independence, calling for participatory methods to increase the agency of older adults in the design processes of these technologies. We adapt and conduct a participatory design workshop to focus on ambient interfaces for home health with 13 diverse older adults in San Francisco’s Tenderloin neighborhood. Using the prototypes they made as discussion catalyzers, participants shared different perspectives entailing stigmatized topics that can be difficult to discuss, such as drug use, sex, isolation, and dementia. They deliberated on the negative implications of VFAIs, such as a justified concern for surveillance, in conjunction with their positive implications, such as receiving always-available “non-judgmental” support. Similarly, the risk of leaking drug use data was considered alongside the benefits of sharing important medical information with clinicians. We synthesize our findings into design considerations, such as how we might address varying levels of trust in different stakeholders and reduce stigma that may hinder users from fully benefiting from VFAIs’ capabilities.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**; *Sound-based input / output*; *Empirical studies in accessibility*; • **Social and professional topics** → **Seniors**.

Additional Key Words and Phrases: aging; ambient intelligence; conversational agents; cultural relevance; ethics; field study; home health; identity; LGBTQ+; marginalization; older adults; participatory design; qualitative methods; race; surveillance; value sensitive design; value tensions; voice assistants; workshop

ACM Reference Format:

Jianna So, Samantha Estrada, Matthew Jörke, Eva Bianchi, Maria Wang, Nava Haghighi, Kristen L. Fessele, James A. Landay, and Andrea Cuadra. 2024. “They Make Us Old Before We’re Old”: Designing Ethical Health Technology with and for Older Adults. *Proc. ACM Hum.-Comput. Interact.* 8, CSCW2, Article 478 (November 2024), 30 pages. <https://doi.org/10.1145/3687017>

1 Introduction

Inequitable technology worsens existing health disparities [29, 91, 106], which are impacted by many aspects of our identities, such as race [25, 75, 83], socioeconomic status [67, 76], sexual orientation [54], and their intersections. Older adults (65+) in particular face undue barriers when navigating multiple health conditions through coordination with multidisciplinary health teams [47, 74], which often entails interaction with electronic health records and other digital tools not designed for their needs. As the global older adult population is projected to almost double by 2050 [78], it is crucial to design equitable health technology tailored to the unique needs of older adults and their existing systems of care.

Voice-first ambient interfaces (VFAIs), such as Alexa and Siri, have a large potential to fill existing gaps in healthcare. VFAIs have been shown to improve accessibility [52], affordability [72], and emotional support [16] in healthcare experiences. The ubiquity of these devices amplifies their potential for benefit worldwide. In the United States, it is estimated that almost half of the population, 157 million people, will use voice assistants by 2026 [90]. Acting as a speech-first interface between users and the built environment, VFAIs can be especially beneficial for people with diverse needs, such as those with disabilities [81] or low technology literacy [80]. The market is also recognizing this potential—in 2021, 21% of adults used VFAIs for a health need [51]. On the other hand, VFAIs have also exacerbated the risks for technological harm. As VFAIs have become more mainstream, they have started to shift digital norms, making it feel normal to have always-on microphones connected to the Internet in our private spaces [88], and possibly leaving many behind in this shift. For older adults, VFAIs may perpetuate algorithmic bias in diagnosis [14], enable user profiling through digital healthcare surveillance [42], and potentially display inconsistent, flippant, or hollow empathy [21]. Additionally, VFAIs in care settings that operate “continuously and unobtrusively” leave a range of individuals, including patients, doctors, nurses, staff, and family, unable to properly consent to the collection or use of their data [63]. As VFAIs are increasingly

marketed to older adults to provide connection and support [1, 44, 71], the potential harms and benefits of this technology create an urgent need for participatory research [70, 82, 87] that centers the voices of people who will be impacted by these technologies.

Thus, we conduct participatory design research with a diverse group of older adults to collectively speculate about technological futures entailing VFAs for home health. We employ strategies to mitigate participatory design shortcomings. For example, participatory design methods may unintentionally restrict the narratives that marginalized participants (e.g., Black, LGBTQ+, or low-income) are comfortable sharing [37], create power differentials between participants and facilitators [28], or be overly technosolutionist [60]. We worked with a community partner to bridge the interests of researchers and the community, leveraging our community partner for participant recruitment and conducting the workshop in a familiar community space, and we adapted a recent participatory and speculative design workshop method [34]. The workshop introduces implication design, a design approach for embedding a technology's ethical implications in its design to allow participants without technical or design expertise to collectively navigate value tensions. This in turn allows us to collectively anticipate and communicate ethical implications of the VFAs our research group is building *for* older adults *with* older adults.

Our study took place at a senior center in San Francisco's Tenderloin neighborhood over the course of four days. We enrolled 13 older adult participants who generated over 50 prototypes with a focus on VFAs for home health. The primary purpose of conducting the workshop with this community was to preemptively surface these implications, so that we can consider them as we develop these technologies. The secondary purpose was to evaluate how well this method works with an older adult community, as this community was not the focus of the original development of the workshop format but is one that the workshop intends to serve. We investigate three main research questions:

- RQ1: Ethical implications.** What does an older adult community anticipate to be the ethical implications of a VFAI to support older adults' health and wellbeing needs?
- RQ2: Design considerations.** What design modifications can be made to VFAs to address these ethical implications?
- RQ3: Workshop method.** How well does this workshop method work with an older adult community?

In addressing our RQs, we make two main contributions and one minor contribution to the CSCW literature. First, we describe the ethical implications our participants anticipated (RQ1). Using prototypes as discussion catalyzers, participants navigated value tensions between key ethical implications of VFAs. They deliberated on the negative implications of VFAs, such as a justified concern for surveillance, in conjunction with their positive implications, such as receiving continual "non-judgmental" support. Similarly, the risk of leaking drug use data was considered alongside the benefits of sharing important medical information with clinicians. They surfaced needs related to stigmatized topics that can be difficult to discuss, especially in group settings, such as drug use, sex, isolation, and dementia. Second, based on these value tensions, we present design considerations for creating ethical VFAs for home health (RQ2). For example, we consider how, through the design of VFAs, we might address varying levels of trust in different stakeholders, and how we might reduce stigma that may hinder users from fully benefiting from VFAs' capabilities. Finally, we make a minor contribution through adaptations to the workshop created by Haghghi & Jörke et al. [34] for older adult participants based on collaboration with the senior center, such as splitting the workshop into multiple days and enlarging printed materials, and reflections on how our community-based method was especially effective to enable participants' honest engagement.

We begin by situating our paper within related work on health technology for older adults, values in design, and design workshops with older adults. Then, we describe our methods for carrying out the four-day workshop with community partners. Next, we present our findings from two main health technology scenarios presented to participants: Toilet Buddy and a VFAI for home health. Finally, we discuss our findings by first reflecting on the method we employed, then exploring the challenges associated with the ethical implications and value tensions of using VFAIs for home health, and lastly introducing design considerations for VFAI development and research.

As a whole, through this work we anticipate and communicate ethical implications of VFAIs to support older adults' health and wellbeing needs, and generate design considerations that reflect these implications and possible mitigations in the technology itself.

2 Related Work

We situate our study by first highlighting recent literature around health technology for older adults. Then, we present relevant literature on values in design. Lastly, we review design workshops as a research method in the context of designing with and for older adults.

2.1 Health technology and VFAIs for older adults

In recent years, there have been multiple efforts in CSCW to include older adults' perspectives in the design of health technology, namely to improve self-management of their health and coordination with their care teams. In terms of self-management, home monitoring data allows older adults to actively manage their own healthcare and understand their condition in relation to others' [12]. Technology can also improve communication with formal healthcare teams, such as in shared decision making with older adults' clinicians around chronic disease [35], and informal healthcare support, such as through securely sharing activity data to keep older adults' children aware of their condition [57]. Integrating information across formal and informal care networks can further coordinate care, as has been shown with older adults' psychiatrists and family members in depression management [105]. Most relevant to our work, conversational agents have been explored to support care coordination, though they pose usability issues for older adults that limit their full potential in healthcare settings [109].

Within health technology, VFAIs have been increasingly explored for use in older adults' care experiences, with such work displaying VFAIs' critical benefits and risks. VFAIs have been used to improve older adults' experiences with managing their health information [7, 49], pain treatment [89], diabetes care [4], and activity data [12]. Additional relevant literature focuses on the value of VFAI for marginalized older adults. Chen et al. [13] report that older adults with mobility impairments saw VFAI as an opportunity to verbally interact with their environment, such as providing users a way to access control panels if the user cannot move to reach them. Mathur et al. [65] designed a VFAI to support medication management for older adults with mild cognitive impairment. While other medication reminder strategies, such as alarms, depend on whether the user remembers taking the medicine, the authors' VFAI performed check-ins around medication through a conversational agent. This prevented over-medication by encouraging users to double-check their medication intake. More recently, Cuadra et al. [20] explored how VFAIs can support aging-in-place for older adults, highlighting their potential to provide consistent health management for multiple comorbidities and support low-literate users through multimodal interaction. However, past work highlights the harm of VFAIs as well. Harrington et al. [39] conducted a study around the value of voice assistants to help Black older adults as they seek health information. When interacting with the voice assistant, participants performed "cultural code switching" by rewording their interactions with the voice assistant, limiting their freedom of expression and negatively affecting their search for information. In care settings generally, VFAIs pose risks to individual and community privacy,

as people in the vicinity of the technology become users without consent over their participation or the use of their data [63]. As VFAs become ubiquitous and their impact is amplified accordingly, this research showcases both the diverse potential and shortcomings of VFAI tools to support older adults' health needs and the need to design such tools ethically.

2.2 Values in design

Towards further eliciting older adults' perceptions of health technologies, we draw on a rich body of literature on values and ethics in design. Value-sensitive design (VSD) defines values as "what is important to people in their lives, with a focus on ethics and morality" [31]. More recent scholarship characterizes values as situated in local contexts and shaped by lived experience [45, 55]. In this work, we aim to understand what older adults value in the design of ambient intelligence technology, with an emphasis on older adult communities with lived experiences that are marginalized in the design of technology.

We adapt a workshop-based method that aims to enable participants of diverse backgrounds to navigate value tensions in collectively speculated worlds [34]. Beyond surfacing values, navigating value tensions allows participants to directly grapple with difficult design trade-offs and conflicts in stakeholder values. Haghghi & Jörke et al. [34] draw from methods in VSD (e.g., stakeholder analysis [32] and card-based value elicitation [30]), but also from speculative design [27], participatory design and co-design [70, 93], as well as game design and role-play [18].

2.3 Design workshops with older adults and marginalized groups

There is a long history of design workshops that aim to include marginalized voices in the design of technology, including people of color [37, 38, 101], queer people [23, 36], people with disabilities [24, 43, 62], low-literacy communities [2, 5], low-income communities [38, 43, 86], survivors of sex trafficking [33] and migrants [26]. Such workshops have been especially effective in designing alongside older adults [22, 38, 56, 104]. As we further adapt workshop methods for older adult participants, we seek to avoid deficit models that focus on the risks and vulnerabilities that come with age [69]. Instead, such "deficits" can be understood as opportunities for society, services, and technologies to better meet older adults' needs, similar to social models of disability [9]. Light et al. [58] call for CSCW research on older adults to be driven by the goal to "age well" by preserving older adults' agency in managing their health, aligning with our approach.

These principles guide the inspiration we draw from past workshop methods for older adults. Rogers et al. [85] framed design workshops with retired older adults as a way to learn from their "wisdom" instead of their "frailty." Participants were given approachable electronic toolkits with Arduino micro controllers, allowing them to more directly contribute to the design of technology than what craft materials allow. Relevant to our work, Harrington et al. [38] conducted design workshops through a community center for low-income African American older adults around their health experiences. Notably, participants were hesitant to talk about their personal health in a community setting, preferring to talk about the health of the larger community when in the presence of others. In contrast, in our study, many participants were open about their personal health stories, though some were still hesitant to share detailed experiences about taboo or stigmatized topics. Lindsay et al. [59] highlight other key challenges when practicing participatory design with older adults, such as "maintaining focus and structure in meetings" and "envisioning intangible concepts". The authors suggest addressing these challenges by rooting workshop scenarios in participants' lives and encouraging facilitators to use accessible language, creating a "common frame of reference" between participants and facilitators. In addition to having the structure of our workshop abide by those recommendations, the physical aspects of our workshop seemed to effectively mitigate these challenges. Additionally, other work argues that older adults resist designing for themselves during

design workshops, focusing instead on the perspective of other older adults [79], a challenge we also dealt with and further discuss in this paper. These methods and findings helped us adapt our workshop for older adults by limiting abstractions in prompts, stressing the validity and wisdom of participants' lived experiences, respecting their comfort around disclosure, and deemphasizing facilitator involvement when possible.

3 Methods

We now introduce our workshop's participants. Then, we share the workshop method we employed along with the modifications made to adapt the original workshop [34] to our older adult population. Finally, we describe our video and transcript analysis procedure. All procedures and methods were approved by our university's institutional review board.

3.1 Participants

To create a welcoming brainstorming space in participatory design, establishing trust is key [108]. To build a foundation of trust as researchers who are not older adults, we partnered with a senior center in an urban area of the United States. The study's location, San Francisco's Tenderloin neighborhood, has a long history of LGBTQ+ advocacy, a vibrant arts and music scene, and a welcoming community for immigrants, but also high rates of poverty, crime, sex work, and drug use [8, 40]. Participants in the workshops were recruited by the senior center's staff, with many of them having participated in the center's technology literacy program. We hoped this would further establish trust based on shared community experiences and technology familiarity. 13 participants attended the workshop in total, with ten participants attending all four days. No more than two people were absent for each workshop— P13 was absent on day one, P9 was absent on day four, and P12 was absent on days three and four. This high retention rate was likely due to the workshop being held in a convenient location and our compensation structure. Participants were compensated after each workshop session, with additional compensation provided for attendance of all four days. On the first day, participants were grouped into three teams of four to five members. Researchers sought to balance teams in terms of racial and gender diversity to minimize existing power differentials in co-design [46]. Some participants requested to sit with people they were familiar with, allowing teams to build on existing rapport. Participants stayed in the same groups, except when individuals moved across groups to maintain even group sizes when members were absent.

Participant demographics are provided in Table 1. Our team accommodated participants' differing needs. For example, P13 was a blind artist, so one researcher was assigned to be P13's dedicated aide in the prototyping process. This researcher described the materials available and assisted with some physical tasks such as cutting tape, writing, and selecting materials. Two participants came with service animals, which often animated the workshop by barking.

3.2 Collective speculation workshop

As discussed above, we adapted the procedure and materials from Haghghi & Jörke et al. [34], which we refer to as the collective speculation workshop. Workshop materials were available in the authors' public website and were adapted to fit our research goals (working with older adults and VFAIs). We chose this method because of its focus on enabling "participants of different backgrounds to collectively navigate value tensions" and mitigating power dynamics, which we found to be particularly relevant to our participant population.

The workshop was adapted for our older adult participants through collaboration with the senior center over the span of four months. These workshop modifications accommodated participants' varying abilities (e.g. holding the workshop over multiple days, enlarging printed materials, and

Age	Mean = 70.2, Median = 69, SD = 8.25
Gender	Men: 7, Women: 6
Race	Black: 4 (1 multi-racial), White: 9 (2 multi-racial), Asian: 2 (1 multi-racial)
LGBTQIA+ Identity	LGBTQIA+: 6, Not LGBTQIA+: 7
Highest degree level	Highschool diploma or GED: 3, Some college: 4, Associate's degree: 1, Bachelor's degree: 4, Master's degree: 1
Annual income	\$10,000 - \$14,999: 3, \$15k - \$19k: 1, \$20k - \$24k: 3, \$25k - \$34k: 3, \$35k - \$49k: 2, Decline to answer: 1
Living with a disability	Living with a disability: 5, Not living with a disability: 6, Prefer not to disclose: 2
Confidence with computing devices	Mean = 4.15, Median = 4, SD = 0.90 (out of a 1 to 5 scale where 1 = not confident and 5 = very confident)
Confidence with speech-based computing devices	Mean = 3.15, Median = 3, SD = 1.52 (out of a 1 to 5 scale where 1 = not confident and 5 = very confident)

Table 1. Participant Demographics ($N = 13$)

modifying prompts), their physical comfort (e.g. spacing out tables to reduce noise from other groups), and transparency regarding the data captured during the study (e.g. making the use of audio and video recording equipment clear before and during the workshop).

3.2.1 Procedure. The original workshop was designed as a single six hour session, but our partner institution expressed that would be too much time in one sitting for older adult participants. Thus, we split the workshop into four 90 minute sessions that took place every day of the work week except for Wednesday, which served as a rest day. Each of our four sessions corresponded to a section from the original workshop design, described in full detail in Haghghi & Jörke et al. [34].

- **Day 1: Warm-up Activity.** Facilitators introduced the workshop and established norms to create a welcoming environment. Participants completed a warm-up activity, in which participants used craft materials to create speculative prototypes. To prepare for Day 2, facilitators introduced the VFAI scenario as the topic for the rest of the workshop. Participants brainstormed contexts and direct stakeholders for the technology within their teams.
- **Day 2: Anticipation Round.** Teams narrowed down contexts by having another team vote on the top context. For the chosen context, each team brainstormed use cases for the VFAI technology. Teams swapped use cases and voted on another team's top use case. Participants then brainstormed positive and negative implications for the given use case using the Tarot Cards of Tech [3].
- **Day 3: Implication Design Round.** Facilitators introduced the concept of *implication design* defined by [34] as "a design approach towards embedding a technology's ethical implications in its design." Participants practiced implication design by creating design modifications based on their negative implications from Day 2 using craft materials.
- **Day 4: Action Round:** Participants engaged in implication design through a role playing activity based on their chosen context, use case, stakeholders, and implications. Within each team, participants took turns as a "moderator", specifying the team's context to their own lived experiences. The moderator drew a positive implication card and negative implication card. Participants sorted stakeholders between the two implication cards based on whether

the stakeholder might be more excited about the positive implication or more concerned about the negative implication. All team members designed a modification to maintain the positive implications while communicating and/or protecting against the negative implications.

The workshop was conducted with a team of six facilitators, who reintroduced themselves to participants before each workshop. The main facilitator presented slides and maintained schedule. Each group had an individual facilitator to guide team activities. Two facilitators handled recording, documentation, and participant accommodations.

Prior to the study sessions, participants consented to the study and recording methods. After each session, participants filled out an exit survey regarding their experience for the day, including Likert scale and open-ended questions about their experiences and what could be improved. The last day's exit survey asked participants what ethical considerations they considered most important.

3.2.2 Materials. We now describe workshop materials by each of the two main scenarios: Toilet Buddy and a VFAI for home health. Toilet Buddy served as an introduction to ambient interfaces, while the VFAI for home health scenario was the main focus of the workshop. For more details, refer to our supplementary material. For access to workshop materials directly, refer to our [website](#).

Warm-up Exercise: Toilet Buddy The following warm-up exercise was adapted directly from Haghghi & Jörke et al. [34]. On Day 1, we introduced Toilet Buddy (TB), a smart toilet.

To improve the health and wellbeing of the senior center, the senior center has launched Toilet Buddy in all of their bathrooms: an intelligent toilet that cares about you and your wellbeing. Toilet Buddy monitors your nutrition information, vitamin deficiencies, and stress levels to provide customized nutrition plans and health recommendations over time. Toilet Buddy cares about your emotional wellbeing too and is always there to chat if you ever need to vent.

Based on research that shows avoiding technosolutionism better surfaces community perspectives instead of researchers' interests [37], we introduced Toilet Buddy as a hypothetical example without sharing that the technology already exists to make space for participants' gut reactions to ambient technology. This activity was key to begin with, especially as co-creation of technology increases older adults' acceptance of it [15]. Moreover, as discussed in [34], Toilet Buddy was intentionally designed to be provocative to encourage creative speculation and increase participants' comfort speaking about sensitive topics. Participants were asked to discuss and prototype around Toilet Buddy, with a general prompt to "create modifications for toilet buddy that address concerns and amplify benefits." Constraints were added, such as "you have to use magic" and "you can only use technology from 100 years ago."

Voice First Ambient Interface (VFAI) Scenario On Days 2-4, the following scenario around a VFAI was focused on:

Imagine having a device that can speak with you the same way humans can. It has been programmed by your doctor to ask questions related to your health and wellbeing. It learns as much as it can about you, and provides that information to your doctor so they can adapt your care. It also makes recommendations personalized to your needs, and serves as a companion, actively listening to anything you want to tell it.

This scenario was written by the research team and modified based on feedback from community partners. For example, the scenario above originally described "cognition" as a part of health and had specific examples of functionality, but the language was simplified to focus on the voice-interaction and high-level goals of the system to make it more approachable for participants. Given this scenario, each team focused on a chosen context and use case for a specific stakeholder. During prototyping,

participants were asked to modify the VFAI in relation to positive and negative implications for various stakeholders. Certain rounds had constraints similar to Day 1, including “add something to the device,” “add something to the body,” and “add a digital (screen-based) intervention.”

Kits, cards, and guiding slides Each team was provided with a kit, including crafting supplies, printed handouts, and the Tarot Cards of Tech [3]. We also adapted the slide deck from Haghighi & Jörke et al. [34]. By our partner’s recommendation, we enlarged fonts and images and simplified the language in all workshop materials (e.g., slides, handouts, and card decks). Items that could serve as reference, such as a system information sheet with reminders of the scenario and prompts for brainstorming, were printed and handed to each individual participant.

3.2.3 Room, technology, and recording setup. The room was set up with careful attention to participant comfort and awareness that their participation was recorded. We conducted the study in a conference room at the senior center that participants had previously attended technology literacy workshops in, where we split participants into three tables, spaced apart as much as possible to reduce noise from other groups. As the workshop was conducted during the summer, we placed fans around the room since some participants expressed feeling too hot to concentrate on their first post-session survey. However, this came with some trade-offs as some participants disliked feeling the fan’s breeze, and the fans created additional background noise affecting the quality of the audio. Guiding slides were displayed on a TV mounted at the front of the room. Before each session, participants were reminded that their video and audio would be recorded and analyzed. Each table was video recorded using a recording device mounted on a tripod. We separately recorded audio for each participant using a digital voice recorder (KerLiTar K-R01) connected to a microphone (SimplePC Microphone, 3.5mm), which was placed in front of each participant for the entirety of each session. We then merged and reduced the background noise in these individual files by group using Adobe Premier Pro to prepare them for analysis.

3.3 Data analysis

We simultaneously used the videos, audio recordings, and audio transcriptions for analysis. We used techniques from video analysis [19, 48, 64, 94–96, 102], such as playing the video at variable speeds or replaying insightful behaviors (expressed through body language, movements, facial expressions, etc.), to study non-verbal cues during the discussions, prototype iterations, and design modifications. Using thematic analysis [6], a minimum of two researchers analyzed the 12 videos.

Five authors coded the data, with the first and second authors performing most of the analysis. After open-coding [50] half of the sessions across all four days of the workshop at least once, the second and last authors clustered codes. Then, the first and second author consolidated broader themes and additional specific codes based on the initial coding. For example, codes related to “family” and “relationships” were grouped into a “community concern” theme, while codes such as “harm” were broken down into “policing” and “drug use”. The first and second authors reached agreement on codes and interpretation of each annotated quote, resolving conflicts through discussion. For example, one coder did not realize that a facilitator had misunderstood a participant’s description and ideal vision of a welfare check, another coder pointed that out, and they together decided to correct the interpretation of the participant’s quote. These additional themes and codes were used to code the rest of the videos, then eventually guided the organization of written findings.

Our codebook included four categories: perceptions of the technology, health and wellbeing, ethical considerations, and workshop (insights originated from the style and structure of the workshop). There were 96 codes across the different categories. The number of instances of a certain code provided insight into the importance of the theme, which permeated across participants and the days of the workshop. Codes like privacy and user control (both under the ethical considerations

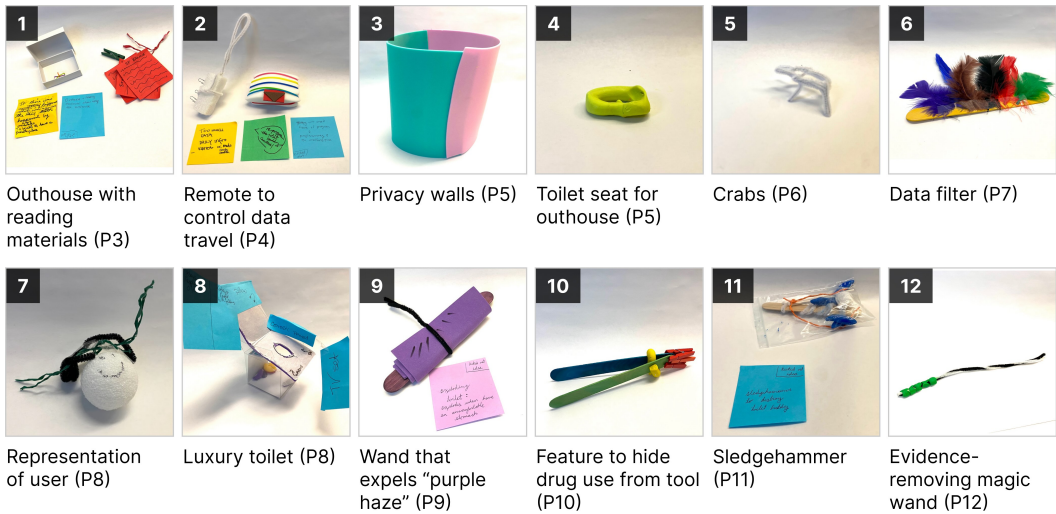


Fig. 2. Participants' final prototypes in response to the Toilet Buddy warm-up scenario. A screen-readable list of prototype labels is in Appendix A.1

category) generated 78 and 67 tagging instances respectively, out of a total 1,137 instances. Privacy-related codes included “personal identification,” “surveillance,” and “intrusive.” User control related codes included “data security,” “information filtering,” and “tech glitch.”

4 Findings

Even though the Toilet Buddy scenario was just a warm-up activity, participants' discussion around it surfaced important design values that shaped and influenced their ideas during the VFAI scenario. Thus, we present findings from both scenarios. Through the Toilet Buddy scenario, participants resisted ambient AI-powered technology based on a fear of judgement and desire for independence. In the VFAI scenario, participants explored safety features that would make them comfortable using the tool. While maintaining privacy concerns, participants eventually envisioned the VFAI as a mediator between other stakeholders in their care teams and as a direct provider of care.

4.1 Toilet Buddy

The following sections highlight the main themes of the Toilet Buddy activity, including participants' initial rejection of Toilet Buddy, their worry about Toilet Buddy's judgement, their interest in Toilet Buddy's potential to help with private matters, and their desire for Toilet Buddy to augment care instead of replace it.

4.1.1 Initially rejecting Toilet Buddy. When the concept of Toilet Buddy was introduced, many participants audibly gasped or laughed, suggesting discomfort or shock. P5 immediately yelled out “*Too much information! TMI!*”, while P8 called it “*big brother.*” Participants started to suggest ways to opt out of the tool completely. When prompted to modify Toilet Buddy with an idea that would get them kicked out of the senior center, P1 said he would “*just take a hammer and destroy it all.*” P11 created a sledgehammer to smash Toilet Buddy as well (see Prototype 11 in Figure 2). Participants' first instinct was to reject or destroy Toilet Buddy, initially focusing on negative implications before considering positive implications. This shock around Toilet Buddy was rooted in privacy concerns

around how the tool would collect and share information. P4 assumed that using Toilet Buddy would mean “*everybody in the family can see, if it’s there at home,*” suggesting that it no longer made a home a private space. This prompted various security mechanisms: P1 suggested making Toilet Buddy password protected, P10 explored using urine identification, P6 preferred adding facial recognition, and P5 added walls to block her data from leaving Toilet Buddy (see Prototype 3 in Figure 2).

4.1.2 Worrying about Toilet Buddy judging people. Once satisfied with securing data privacy in the system, participants started to worry around how the tool might judge users. P6 considered Toilet Buddy’s potential to determine if a user drank too much and P8 worried that Toilet Buddy would know “*she’s not following her diet.*” P10 expressed concern about Toilet Buddy voicing judgement directly, saying “*I don’t want it to nag.*” P9 wanted to control the data that Toilet Buddy could judge by creating a wand (see Prototype 9 in Figure 2) to flush a “*purple haze,*” a reference to past drug use, out of his system before his waste was analyzed. The concept of judgement was further applied to Toilet Buddy contributing to gossip within the senior center, as P5 suggested that Toilet Buddy could expose user information around around diabetes, alcohol and drug use, and sexually transmitted disease. P6 imagined Toilet Buddy telling users “*don’t have sex with so and so, they have crabs.*” These prototypes captured the data privacy concerns participants have around formal and informal judgement when obligated to provide their data to health tools.

Given these concerns, participants designed artifacts that expressed a desire to control the use of their data. P10 proposed being able to control Toilet Buddy’s data analysis to “*stop anybody from knowing what I had eaten or [if the waste] had any drugs in it.*” P7 modeled a data filter after a dream catcher (see Prototype 6 in Figure 2) to avoid unwanted interactions with Toilet Buddy, meant to “*stop evil.*”

4.1.3 Using Toilet Buddy for help with private matters. Though Toilet Buddy was seen as a tool that subjects users to judgement, it was also seen as a form of non-judgemental support for private matters. P8, who used a wheelchair, shared a desirable feature for technology like Toilet Buddy to check whether she has changed her undergarments for the day. She used Alexa as an example of how voice interaction is beneficial, sharing that when talking to Alexa the device might hold her accountable for not changing: “*She’ll ask me, “Well, did you change today?” I’ll say, “Oh, yeah, I did.” And then this Alexa will say, “Oh, no, you didn’t.”* Similarly, P10 shared that he wanted Toilet Buddy to privately tell him whether he needs a colonoscopy, a decision that would usually require an appointment with a doctor to check his rectum. In these cases, Toilet Buddy was seen as a shame-free support tool.

4.1.4 Augmenting versus replacing care. While discussing both negative and positive implications of Toilet Buddy, participants shared that they feel a general loss of agency when the responsibility of their health is put in others’ hands and began to see tools like Toilet Buddy as another instance of this happening. Faced with the idea of AI-powered tools augmenting their healthcare teams, P6 compared using Toilet Buddy to his experience using older adult care services by saying, “*I think a lot of senior services do the opposite of what they should. They make us old before we’re old.*” Participants viewed the use of health services and technology as a sign of declining function, signaling how health tools perpetuate deficit models of aging.

P6 reiterated the importance of independence and how many tools and services do the opposite, comparing it to using a walker: “*If you start using a walker, then you become dependent on it.*” As the conversation moved into selecting a use case for the next activity, P6 again reiterated this feeling, applying it to dependence on caregivers as well:

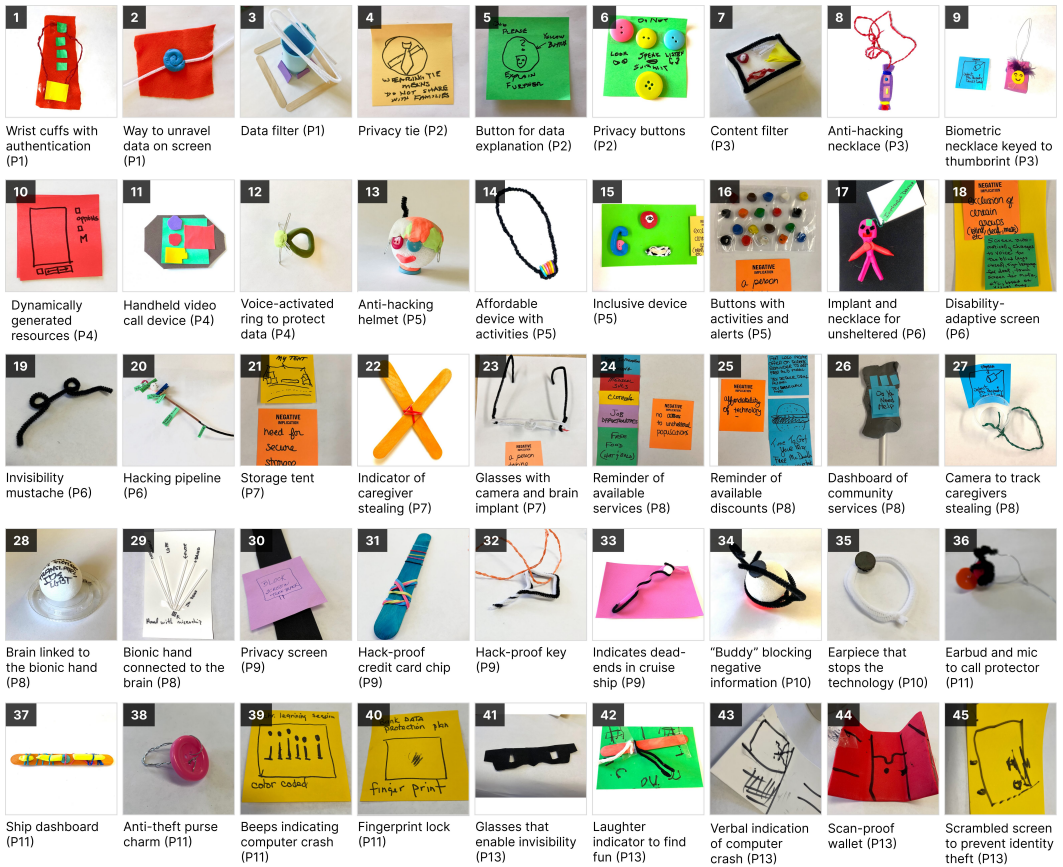


Fig. 3. Participant prototypes in response to the VFAI scenario. A screen-readable list of the prototype labels is available in Appendix A.2.

“The way I see it, this [technology] is actually doing the opposite of what I’m supposedly trying to achieve. Instead of making you independent, it makes you dependent. [Even] other people involved in my well-being, family members, et cetera, they also will become dependent. It alleviates their responsibility. They become dependent on the technology to take care of me instead of them.”

Whether it was about their own abilities or their family members, participants worried that Toilet Buddy would replace rather than augment human interactions, creating technological dependence. P10 compared Toilet Buddy to a Japanese interactive robot, describing how lonely senior center residents might benefit from AI-powered tools that are *“able to answer questions back again and actually have conversations.”* P5 continued to resist against this progression of tech in consideration of human values, emphasizing that *“we’re losing human companionship, human touch with this . . . we’re going backwards.”* P5 poignantly questioned the trade-offs being made between dependence vs. companionship, or privacy vs. support: *“Where do you draw the line, or is there a line to be drawn?”*

When the workshop moderator revealed that technology like Toilet Buddy already exists, participants’ shock from the beginning of the exercise turned into curiosity about how to answer this question, setting the stage well for the second part of the workshop.

Group #	Context	Use case	Direct Stakeholders
1 (P1–P4, P13)*	Living alone	Monitor vitals of older adult, send vitals to doctors	Older adult, caregiver
2 (P5–P8)	Living alone	Assist caregiver of older adult living alone	Older adult, doctors
3 (P9–P12, P13)*	Hotel, cruise ship	Provide navigation and social interaction assistance	Older adult, staff

Table 2. The specific context, use cases, and direct stakeholders chosen by each group. *P13 did not show up on the first day, and was in Group 1 for Day 2, and in Group 3 for Days 3–4. P12 was not present for Days 3–4.

4.2 Voice-first ambient interface (VFAI) for home health

During days 2–4 of the workshop, discussion focused on the VFAI for home health. Each team further customized the scenario by choosing a context and use case (see Table 2). Participants created prototypes to address positive and negative implications of the VFAI (see Figure 3). Building on concerns from Toilet Buddy around privacy, participants focused on establishing user agency in the tool, building in safety features to make them comfortable with opting into the system. Once this agency and safety was established, participants felt more comfortable envisioning the tool in their lives and began to treat the VFAI as part of their support team. The workshop scaffolding for eliciting positive and negative ethical implications helped participants deepen their discussions around ethical implications past expected concerns around agency and surveillance. Participants saw potential for the VFAI to act as a mediator, protecting users from untrustworthy stakeholders while further connecting users to dependable stakeholders. Throughout the workshop, participants saw potential for VFAI to support older adults who are living with a disability, isolated, and unsheltered, beyond what existing resources can provide. However, they stayed skeptical of the technology, underscoring the need to design digital technology more justly.

4.2.1 User agency: establishing control as a pre-condition to using the VFAI. For many participants, having clear user agency was a pre-condition to using the VFAI. In this section, we describe different forms of agency surfaced by participants, including multiple layers of security, keeping track of data, and the ability to become invisible to technology.

Establishing control over system access and user data. While building on privacy concerns from the Toilet Buddy scenario, participants created prototypes to establish control within the VFAI, starting with ensuring secure access. P1, P2, P9, and P11 created keys to access the system, in a mix of digital and physical formats. P2 said that a physical key would provide “*absolute control*” in the system while P1 preferred a digital key to prevent breaking or losing it. P1 designed wrist cuffs with a double authentication button to prevent unauthorized access (see Prototype 1 in Figure 3). P3 used fingerprint recognition in a biometric necklace that would be “*electronically wired as another safety intervention*” (see Prototype 9 in Figure 3).

Participants also wanted to keep track of how their data was used. In considering healthcare related data being sent to different stakeholders in their care team, P1 was interested in receiving information about whom the data was sent to, what those individuals did with it, and how their own care plan changed. He shared his desire to understand the system and its use of his data:

[I want] a way of continuing the knowledge... I'm that person that's giving it all. Now, if I know how the tech is used, then I understand what's going to the doctor, to the nurse, to the social worker, too. I would like to have some information back.

This concept of tracking the communication of user data was especially relevant around how such data might be used to critically evaluate users, with P5 and P7 worried about sensitive healthcare data being sent to employers and insurance companies. Moreover, participants joked about how modern practices around healthcare data are to hide adverse outcomes, such as hiding the risks of misdiagnosis instead of addressing them. These jokes highlight an underlying need to keep healthcare providers accountable for questionable communication practices. Overall, these protective features show participants' needs to establish mental security around privacy concerns.

Becoming invisible to the technology. Aside from designing for secure use of the technology, participants designed multiple prototypes with features around opting out of the system entirely. P13 addressed this by creating glasses that cloaks a user's presence completely (see Prototype 41 in Figure 3), including body temperature and location data, once they "*have enough confidence to not depend on it constantly.*" P10 similarly addressed this through an ear piece that protects the user from the tool's "*sight,*" saying "*if you turn it on, they don't know where you are*" (see Prototype 35 in Figure 3). Through these ideas, participants maintained desires around not wanting to use the tool at all, which were continually referenced even as benefits were discussed.

4.2.2 Centralized care: improving communication with expanded care teams. After establishing security within the system, participants starting surfacing more positive implications and imagining opting into the VFAI, valuing it as a mediator to improve communication with their care team. However, they also worried about how VFAs might connect them to inadequate services.

Navigating disjointed care teams. Many participants described their experiences in having decentralized care teams consisting of doctors, nurses, family members, caregivers, hospice workers, and more. They shared that miscommunication with these teams is hard to avoid. P8 discussed how she has multiple doctors for her cancer since her "*cancer is all related.*"

I have so many major health problems going on and I have a variety of people, like my primary is here, but all my serious all my serious doctors are at [anonymous hospital]. My hematologist, my cardiac, my liver doctor, I'm trying to get them to a roundtable."

She shared that miscommunication with her care team once made her incorrectly believe that she was on a heart transplant list, suggesting that such events can be addressed through the VFAI by keeping doctors aware of a user's medical history from different providers. Relatedly, P1 added a feature to the VFAI to print reports of users' consolidated health information. P3 further modified P1's idea to send these reports to healthcare professionals, hoping they would cross-reference personal records with internal patient records to prevent miscommunication.

Communicating with caregivers. Aside from communication with doctors and nurses, participants sought to improve communication with their caregivers. P10 added features to enhance communication around scheduling appointments, going to the doctor, understanding medical conditions and prescriptions, fulfilling material needs such as toilet diapers, and coordinating transportation. He specified that the scheduling feature would be helpful in a situation in which a family wants to visit in place of the caregiver, showing a need to integrate family into the care experience and communicate this preference to the caregiver. Additionally, P13 wanted to notify stakeholders of his location in the case of personal absences or emergencies. In these cases, the VFAI was considered a mediator to support both caregivers and older adults with indirect tasks around health needs.

Sharing data on a need-to-know basis. In the context of a larger care team, previously discussed concerns around data privacy were addressed through features that enabled selective sharing. As P2 said, "*what I give to my doctor, I may not want my family to have.*" P5 designed multiple buttons

that controlled others' access to different types of information, such as sending medical information to doctors to prevent misdiagnosis and sending financial information to bankers (see Prototype 16 in Figure 3). P8 discussed using voice interaction for this sharing process in order to receive tailored support, such as accessing her therapist when she is "*feeling an episode*." P5 responded to this saying that even though she is "*so negative when it comes to AI*," she would be okay with this situation. When participants could be in full control of their data, communication functionality in the VFAI was highly valued.

Avoiding failing services. Beyond their care team, participants stressed the ineffectiveness of some services that the technology might connect them to. For example, P1 said that he would not be interested in sharing his data with security staff at his apartment complex since he does not feel protected by them, saying "*honest to God, if we do [have them], I don't see them*." Considering other services meant for protection, P10 pointed to an existing tool for older adults: a button worn around the neck that alerts the fire department when the user presses it during an emergency. However, P5 shared a distrust with the technology's perceived benefit of being connected to the fire department. She did not trust that it could properly support their community, saying, "*they don't know diddly squat*" about older adults' unique needs. A few participants discussed their similar lack of trust in In-Home Supportive Services (IHSS), a support program for older adults with disabilities provided by the government. Participants said that the way IHSS workers are evaluated as government workers leads them to feel as if IHSS workers primarily care about fulfilling their tasks rather than truly caring for a patient. If fire departments, home security staff, or other services meant to support local residents were already failing, any additional support a VFAI could provide to communicate with them was perceived to be useless.

4.2.3 Safety and security: protecting users from other people. Participants continued modifying the VFAI to provide safety in relation to various stakeholders. Based on mistrust in technology and services, participants created prototypes to protect users from hackers and untrustworthy caregivers.

Establishing physical and emotional support against hackers. In considering the need for protection, many participants were worried about the risk and stress of being hacked. As P11 expressed, "*nothing is unhackable*." P8 was concerned about the tool being an avenue for hackers to fake user data itself, such as putting false urine test results into the data of someone who is being monitored during drug recovery. Multiple participants seemed to value physical interactions with the technology in the event of being hacked, such as P5's helmet that prevented hacking (see Prototype 13 in Figure 3). P3 focused on addressing the emotional and mental distress caused by being hacked by making a necklace to regulate her mental state (see Prototype 8 in Figure 3). She explained the "*panic*" button on her device functioned to help a user calm down and "*come back to life after you've been hacked, because I don't come back to life*." As we observe, participants wanted protection beyond their data, also considering the emotional distress of being hacked.

Protecting against untrustworthy caregivers. Multiple participants created prototypes to guard against untrustworthy caregivers. As an existing protection, some participants relied on family members, stakeholders perceived to be more trustworthy. P5 shared that her son is her caregiver by saying, "*I can talk to [my son] about my issues. I trust him. He cares about me, he cares about my health, and I don't have to worry about being taken advantage of*."

The potential to be taken advantage of was discussed with rich examples as participants created prototypes. P6 talked about examples of caregivers stealing medicine for severe pain instead of giving them to their patient, with P8 saying that this is a problem in her workplace. P7 considered this through a robot that records the people around the user with clear notification when "*bad*

things,” such as stealing, happen (see Prototype 22 in Figure 3). P8 addressed this in a prototype with a doorway camera to detect caregivers’ money at the start and end of caregiver appointment (see Prototype 27 in Figure 3). If the tool detected a difference in the caregivers’ money when leaving, indicating money was stolen, it would tell the caregiver “*improper amount of money, please go back*” and lock the door. In these cases, VFAI was seen as trustworthy protection against untrustworthy stakeholders.

4.2.4 Equity: representing marginalized users in the design of technology. As participants discussed the trust they have in their communities and technology, they focused on the value of VFAs beyond what existing care could provide. Participants focused on using this tool to support older adults who are living with a disability, isolated, LGBTQ+, and unsheltered, giving such users reliable support when they are usually dismissed.

Integrating accessibility for older adults with disabilities. Across use cases, participants integrated accessibility features into their prototypes. P13, who was blind, referred to such features as “*lavish*” compared to the accessibility of current technology. For example, P5 designed for disabilities by including braille and eye buttons on her device. More specifically, P8 spoke of the positive benefit talking to the VFAI can have for her as someone with dementia:

Sometimes I can't remember words. I know what I want to say, but it just escapes me. So maybe this thing will help me, because... it gets used to your inflections and everything... Because I just feel like I'm losing my mind and I'm losing my memory. I'm like, who is that person?

P8 wanted the VFAI to record her speech and the way she thinks, helping her remember herself. P8 explained, “*people get frustrated because I repeat things or it goes totally over my head.*” P5 suggested a feature of “*repeat mode*” in response to this, involving the tool repeating information to the user to help them remember it. P13 and P1 similarly incorporated reminders into their prototypes to support older adults with Alzheimer’s in remembering information such as the date and time. In these cases, the VFAI was seen as a direct provider of accessible support, capable of patience that others in their lives do not show them.

Reaching isolated older adults. Many participants discussed the benefits this tool might have for people who are isolated, which P1 said is “*true of the majority of the people*” in the senior center’s community. P2 shared the difficulty in supporting such individuals when they “*push society away.*” P8 shared her personal experience with isolation as someone without family contact. She valued the support this tool could provide by connecting her directly to people she trusts, since the “*person that cares most is my caregiver and my doctor.*” She also shared her difficulty in trusting her landlord to check in on her due to her mental health conditions and history of being unsheltered:

The landlord will say, “Oh, where’d she go? Oh, she hasn’t been in her apartment. Maybe she deserted it. She used to be homeless. She might have just had a psychiatric episode,” because she knows that I have depression.

P8 then shared a story about a friend who used a Fitbit to track a daughter who had overdosed while living alone since “*she didn’t move for a couple of days, and then they found out the reason why was because she had overdosed.*” P2 similarly focused on the possibility of using of this tool for welfare checks, a service in which authorities “*see if the person is alive in the room,*” and discussed a situation he faced in which he requested a welfare check for a friend who refused the help. P2 imagined using the VFAI to conduct digital welfare checks without forcing an isolated older adult to interact with others. These findings illustrate the complicated social relationships that VFAs must exist within, demonstrating both their boundaries and possibilities.

Representing LGBTQ+ older adults' identities. In supporting LGBTQ+ older adults, participants were focused on communicating how others identify in terms of gender identity and sexual orientation. P8, who identified as bisexual through the demographic survey, suggested adding a feature to track pronouns to respect others' gender identities since she sometimes "*forgets what pronoun and it really hurts the person.*" Additionally, she created a telepathy device with a brain-interface that identifies others' sexual orientation automatically (see Prototype 29 in Figure 3), saying that "*people hate that when you have to ask.*" These ideas show potential for VFAIs to facilitate more inclusive social interaction.

Designing for unsheltered older adults. Participants imagined the VFAI providing unsheltered older adults with secure forms of protection, though ideas encroached on unsheltered users' privacy. P6 specified that when designing for unsheltered people, it is important to design with the assumption that things might get lost. He suggested that the tool should be kept physically close through "*their phone... or an implant so that they don't have to keep track of it.*" P6 focused on the levels of maintenance unsheltered users can provide for the tool, creating a necklace that does not require upkeep (see Prototype 17 in Figure 3). P7 saw potential for this tool to provide security for unsheltered older adults and added a video feed of the user's tent to keep watch on a user's belongings. These prototypes show participants' hope in the dependable support VFAIs can provide for people in unstable situations.

4.3 Workshop evaluation

Our study's outcomes suggest that this workshop method was successful in allowing participants to feel comfortable engaging with the workshop's prompts, discussing sensitive health topics, and prototyping a diverse range of ideas. Given participants' diverse cognitive needs, physical prototypes seemed especially helpful to remind participants of previous conversations over the course of multiple days and serve as a starting point for additional prototype iterations. Participants' qualitative responses to exit surveys showed largely positive impressions of the workshop. The most common words participants used to describe their experiences were "*fun*" (17 instances) and "*informative*" (12 instances). Participants also reported feeling "*inspired,*" "*represented,*" and "*amazed.*" They also shared their engagement with critical conversations of ethical considerations, additionally describing their experiences as "*challenging,*" "*stimulating,*" and "*invigorating.*" Participants' quantitative responses further support participants' positive experiences. The final exit questionnaire showed participants' overall enjoyment of the workshop. On a scale of 1 (poor) to 10 (excellent), participants' rating of the workshop overall had an average of 9.56. Trends in Likert scale responses from daily exit questionnaires showed that participants felt comfortable voicing their opinions every day of the workshop. Their averaged out responses to how much their opinions about ethics in computing had changed shifted from "*changed a little*" after the first session to "*changed a lot*" after the last session. Their confidence in identifying ethical implications of technology products also increased over the course of the workshop. Nine participants listed "*privacy*" as the the most important ethical implication at hand. Overall, participants' self-reported outcomes and reactions to the workshop suggest that this method was not only effective, but also enjoyable and beneficial to participants.

5 Discussion

Participants' ideas and prototypes touched on our three key research questions, which we address in this section. We start by discussing workshop considerations (RQ3), then ethical implications and value tensions (RQ1), and conclude with five design considerations for VFAIs for home health (RQ2). The combination of our senior center partnership and workshop adaptations for older adults

resulted in a comfortable, familiar, and generative environment for our participants. This in turn resulted in rich findings that we will now discuss.

5.1 Workshop considerations

We now discuss how our community-based method with adaptations for older adults allowed participants to have a nuanced discussion on values at tension in the design of VFAs and key ethical implications around taboo topics, such as drug use, sex, and isolation. Then, we discuss the limitations of this workshop in addressing stigma of taboo topics.

5.1.1 *Addressing technosolutionism: creating a space for discussing values in tension.*

The workshop sought to avoid technosolutionism by centering a discussion of value tensions, rather than solutions. By using Toilet Buddy as a hypothetical example, participants felt comfortable voicing their fears around ambient tools, and acknowledged rejection of technology as a viable option. Throughout the workshops, the method enabled them to create prototypes to maintain control over the tools or opt out of them completely, which then created the space for them to bring up further concerns or benefits once their initial concerns were addressed. It was necessary for participants to acknowledge their fear of the technology and create features to protect themselves within the system to be able to more deeply engage with the trade-offs designers regularly have to grapple with. Grounding the stories in their lived experiences enabled participants to explore the conditions in which they would value health technology as well as the concerns in tension with the added values, especially when existing care could not be depended on. Aligned with prior work [34], we found that engaging our participants in navigating the trade-offs while creating a space for rejection of technology brought a more layered discussion to the discussion on ambient technology for older adults.

5.1.2 *Surfacing priority issues beyond care: sexually transmitted disease (STDs) and drug use.*

In creating this space to share diverse narratives, our workshop surfaced priority issues for our participants that are not commonly present in prior work. These were likely due to our workshop being held through and with a senior center in which participants were already comfortable with each other. While research around older adults' health informatics needs often focuses on traditional health metrics [22], participants highlighted pressing concerns beyond these common interests, such as STDs and drug use. Participants imagined using Toilet Buddy to expose STD status and how this might effect determination of their own sexual partners. There was a heightened focus around how drug use data might harm users' employment or insurance benefits. Other participants worried about how the VFAI could be used to fake urine tests for people in drug recovery. In these cases, using ambient AI-tools carried a risk of sensitive information being exposed to stakeholders then subjected to formal or informal judgement. These participant perspectives highlight the need for health technology research to look beyond the hospital and home to consider socially sensitive health implications as well.

5.1.3 *Discussing taboo topics: LGBTQ+ identity silence.*

When discussing stigmatized health topics, non-disclosure is a common coping mechanism to avoid judgement [92]. We found this especially true for taboo topics discussed during the workshop, as participants often opted to talk about others' experiences with stigmatized topics rather than their own. While participating in the workshop as a community may have increased openness generally, it may have also limited the comfort attendees felt in sharing sensitive information with others that they have varying levels of closeness with. The workshop structure enabled the participants to address the taboo topics through role playing as others without jeopardizing their own privacy. For example, several participants designed for LGBTQ+ older adults, but no participant shared their firsthand experiences being

LGBTQ+ despite six participants identifying as LGBTQ+ in the demographic survey. Similarly, P8 referenced her friend's daughter who had overdosed and P2 recounted his isolated friend's situation around refusing welfare checks. Participants also omitted personal experiences around being unsheltered, though they hinted at being unsheltered in the past. This speaks to the stigma surrounding these experiences and the sharing of them, as other participatory and co-design methods with marginalized populations have found [37]. As stigma has been shown to worsen health inequities [41], there is an opportunity to destigmatize health topics through workshop design and health tools themselves. Additional workshop scaffolding, such as relationship building with "Non-Design Proposals" [97], to address these identity aspects may have increased comfort.

5.1.4 Designing for marginalized others: challenges with compromising values. While the activities enabled the participants to share taboo subjects in the context of experiences of "marginalized others", we found that the prototypes designed for others often reinforced oppressive patterns, a finding aligned with prior work [99]. When designing for others, participants' prototypes compromised user privacy beyond what they personally deemed comfortable, such as P7's idea around body implants for unsheltered users to ensure they do not lose the tool. Prototypes had invasive features, including tracking individuals at risk of drug overdose, conducting digital welfare checks, and recording unsheltered individuals' tents to track their belongings. These power dynamics between participants and potential users who were not present could reinforce patterns of oppression that participants were initially concerned about. To further navigate conflicts between identified community needs and potentially oppressive ideas, future work could analyze prototypes in context with other impacted individuals, such as through "provotypes" [100]. However, in the absence of other stakeholders, it is an open question of how participants can mindfully design for others while addressing their personal values.

5.2 Ethical implications and value tensions

Throughout the workshop, participants prototyped solutions to address areas of concern while maintaining perceived benefits of their proposed systems. In their process of navigating value tensions, important ethical implications for VFAs in healthcare were surfaced. Below, we discuss how participants navigated trust in broken social systems by designing for connection and protection. Then, we discuss the tension between participants' rejection of technology and their eventual perception of VFAs as a part of their care team.

5.2.1 Navigating trust in broken social systems: providing protection or connection. It is well-known that the success of health technology in community contexts is dependent on the success of the care already being provided [53]. This workshop elicited narratives that further surfaced participants' varying levels of trust in people and services involved with their care. Building on research that emphasizes the importance of contextual factors in health design [10] and informal care networks for older adults [103, 107], this work extends our understanding of users' mental models of differential trust in care teams. Through prototypes, we see how these mental models affect how stakeholders are treated accordingly. In many cases, institutional care services were unsatisfactory, or even put participants in harm's way, leading to participants not trusting such services with their data. On the other hand, participants wanted to further connect and communicate with trustworthy stakeholders. Trust varied with formal versus informal providers of care as well. As health technology seeks to integrate with existing care teams, technology that fails to consider user trust of stakeholders may reinforce harmful systems already in place. Existing distrust in people and services must be evaluated and accounted for in the use of health technology. However, as trust and distrust are deeply personal and difficult to quantify and encode, there is no clear

answer of how to best introduce potentially beneficial technological solutions into existing social structures.

5.2.2 *Perceiving AI as a stakeholder.* While maintaining hesitation around technological dependence and technology itself as discussed in 5.1.1, participants elevated AI-powered tools to stakeholders in their care when tools could provide care beyond human capabilities. These tools took on roles such as scheduler, protector, and therapist. In many of these cases, the tool was a mediator between the user and another stakeholder to provide protection and communication, such as scheduling appointments with doctors, guarding against untrustworthy caregivers, and sharing care preferences with emergency personnel. As participants started creating ideas around depending on the VFAI to deliver judgement-free and context-specific care on-demand, the AI morphed into a direct provider of care, beyond just a mediator between other stakeholders. This concept of AI as a stakeholder grants such technology misleading attributes of agency and empathy when in reality the structure of AI relies on various entities, which do in fact impart harmful judgement, creating potential for deception. When seen as stakeholders in healthcare, AI tools also become subject to the same concerns participants have with existing care services, namely the fears of becoming dependent on care, being taken advantage of, and stigma around using technology to support aging [11]. Alongside the goal of making AI tools trustworthy and reliable to deliver unique forms of care, these findings highlight the need for AI to communicate the boundaries of its capabilities to avoid users' technological dependence and deception.

5.3 Design considerations

We now present five key design considerations for VFAI in healthcare for older adults. While these considerations are intended to address the needs surfaced in our study, it is important to note that an increased trust in the system may lead to overtrust and dual-use, meaning it could have the potential to be used for bad as well as good purposes [68]. Mitigation strategies for bad purposes of use must be developed as these technologies mature.

5.3.1 *Address varying levels of trust in different stakeholders.* As we discuss in Section 5.2.1, older adults have mistrust with stakeholders in their care and sometimes expressed a need for protection from them, though it remains unclear how to evaluate and respond to such mistrust. As participants were focused on differentiating between stakeholders in their data communication, VFAs should avoid generalizations of trustworthiness by role. VFAs can proactively query user trust in stakeholders conversationally, such as by asking users about situations in which they find stakeholders' support most valuable or harmful. Current communication preferences often allow full connection or block communication completely; instead, VFAs can develop a more layered understanding of participants' preferences and respond accordingly.

This trust must also be considered in the interaction modalities of a VFAI system. For example, a user might be able to signal whether they are alone, in the presence of someone they trust, or in the presence of someone they do not trust. Communication of this information should be discreet, such as through a screen-based interface, switch, push buttons, or a key phrase. The system can respond to this input accordingly. When the user is alone, the VFAI might be fully functional. When the user is with someone they trust, the VFAI might limit direct care such as therapy support. When the user is with someone they do not trust, the VFAI might activate additional security features such as requesting double verification when asking about sensitive information. Functionality possible in different situations can have a common default, such as described above, and give the user the ability to modify it. By adjusting VFAI functionality to different situations, trust can be accounted for in real-time. Additional work is needed to explore how existing trust can be encoded and how different levels of trust should be reflected in the functionality of VFAs.

5.3.2 Design for continuous agency. As described in Section 4.2.1, our participants saw user agency as a pre-condition to opting into the system. This includes exercising control over participation in the system, the collection of user data, and the sharing of user data. To maintain agency, participants also need a distinct layer of protection from the system itself as they start to see VFAI as a stakeholder, as discussed in Section 5.2.2. For example, users might be able to see and define the area that the VFAI operates within. If VFAI is installed in a home, a participant might want to only operate while they are in a private space such as a bathroom, but not in a more public space like the living room. Similarly, there could be accessories, that the participant could wear to opt out of the system, filling in the function of the invisibility cloaks or physical walls created by participants. Moreover, data collected by the system should be easily controllable, reviewable, and correctable by the user, with options to restrict the type of data being collected in the first place. By increasing users' control points, a VFAI can provide more user agency and trust in the system, though further research is necessary to understand ideal contexts of use and how users would like to control ambient interfaces, especially since multiple users may be impacted by one VFAI and their preferences may conflict.

5.3.3 Communicate broader privacy considerations to direct and indirect stakeholders. When presented with VFAI that has expansive capabilities, users might choose to use the tool in ways that enforce oppression, such as participants' prototypes that surveil isolated older adults or caregivers they do not trust, as discussed in Section 5.1.4. Building on work that recognizes how voice assistants may prioritize a user's needs while breaching the privacy of others' [99], we see an opportunity for VFAI to help users navigate value tensions by directly communicating broader privacy considerations around how others are affected by the system as well. Relatedly, patients have begun to record their health interactions with clinicians [84], signaling that this design consideration carries legal implications around recording conversations without participants' knowledge or consent, especially with some states requiring the consent of all recorded parties [66]. How VFAs could inform multiple direct and indirect stakeholders of their privacy implications is an open question. Future work can investigate using multiple modalities and cross-device interactions to provide appropriate information to different stakeholders. Similarly, implication design [34, 98] can be used to provide physical indications of what data ambient technology may be capturing.

5.3.4 Distinguish between various stakeholders. Towards increasing transparency and user agency, VFAs should consider how various stakeholders in the care ecosystem are represented by the system. As discussed in Section 5.2.1, one of the main use cases of VFAI is connecting users to stakeholders in their care, calling for an opportunity for VFAI to represent these relationships. Prior research found that users recognize different voices coming from the same device as different social actors [73]. If a VFAI is placed in a third place location [77], such as a senior center, then different voices to represent digital services provided by different entities could give important cues regarding the trustworthiness of these entities. For example, one voice could represent senior center announcements, and a separate voice could represent health or wellbeing recommendations from a nearby hospital. If a different or an unknown voice appears, the users may know that it is not coming from the same entity they may have already developed trust with. By mimicking talking with different people over the phone, an interaction pattern users are already familiar with, VFAs can increase transparency. Additionally, they can give users agency to ignore or block entities they do not trust. However, as these different voices introduce additional information, this design consideration also calls for research around how to improve clarity of verbal information while maintaining or reducing users' cognitive load.

5.3.5 Reduce stigma regarding taboo topics. Participants highlighted taboo topics that were difficult to talk about but important to prototype for, such as the implications of Toilet Buddy's waste analysis on the recognition of past drug use or STDs. VFAIs present an opportunity to reduce stigma, as it exists outside of care resources that may be the source of social stigma. However, accounting for stigmatized topics may perpetuate stigma as well. Research shows that imposed labels around stigmatized conditions deters people from seeking care [17]. Similarly, older adults may react negatively to technology labels related to stigmatized aspects of aging [11]. Accordingly, VFAIs should not aim to identify or label users who experience stigma, but instead build foundations for social support without shaming the user and create a welcoming environment for voluntary disclosure. For example, the VFAI can ask general questions about wellbeing, such as whether a user has eaten for the day, and direct users to community resources if they have not. This addresses an aspect of a stigmatized topic like isolation or housing instability that does not depend on users' disclosure of their condition. The VFAI can provide praise when a user's health is "improving" and empathy when they face barriers in their care. However, such ideas present challenges in defining what "improvement" looks like and who should define that. In the event of disclosure, VFAIs should ask participants for their preferences around care, as some users may desire different levels of accountability and support. If a user would like additional support, the VFAI could provide antistigma interventions that have shown to decrease internalized stigma [61]. Through this, VFAI can serve as a safe space for support and disclosure. To most effectively address older adults' needs around taboo topics and stigma, designers should collaborate with mental health professionals to incorporate sustainable, scalable, and responsible support.

6 Limitations

We conducted a qualitative design study with a small participant group in one senior center in San Francisco's Tenderloin neighborhood. Our participants' perspectives do not represent those of their entire community, or older adults in general. The group nature of our workshop may have affected the comfort some participants felt disclosing health experiences around taboo topics. Unlike in the method introduced by Haghighi & Jörke et al. [34], our workshop required a large amount of facilitator involvement, which may have affected in-group power dynamics. Moreover, we did not have any older adults researchers in our on-the-ground facilitation team, something that may have created a separation between us and our participants. To address these limitations, we see room for future improved iterations of the workshop as done in [34]. These iterations might include conducting follow-up interviews to create more comfortable spaces to discuss sensitive personal experiences, involving community members as facilitators, and making workshop materials clearer to minimize external researcher involvement. Additionally, as our workshop focuses on VFAIs for home health, our findings are limited to this technology choice and it is unclear how they might generalize to other technologies. Finally, we do not yet know how effective the design considerations from this work will be in shaping the direction of future work towards more ethical projects. Evaluation of future workshops might benefit from more robust assessments of effectiveness, such as quantitative analysis of Likert scale responses from a larger number of participants. More work is needed to understand how highly structured and technical workshops, such as this one, could be enacted at larger scales with people of diverse ages and backgrounds, and how to ensure that their outcomes result in real-world positive impact.

7 Conclusion

In this work, we explored a participatory method to increase the agency of older adults in the design processes of health technology. We adapted and conducted a participatory design workshop to focus on ambient interfaces for home health with 13 diverse older adults in an area with high

rates of poverty, crime, sex work, and drug use. Using the prototypes they made as discussion catalyzers, participants shared diverse perspectives entailing stigmatized topics that can be difficult to discuss, such as drug use, sex, isolation, and dementia. Our method's focus on value tensions supported participants' deliberation on the negative implications of VFAs, such as a justified concern for surveillance, in conjunction with their positive implications, such as receiving always-available "non-judgmental" support. Similarly, the risk of leaking drug use data to employers and insurance companies was considered alongside the benefits of sharing important medical information with clinicians. By avoiding technosolutionism, our method allowed participants to share their rejection of health tools based on desires for safety and independence, which they maintained as they considered the value such tools may provide. We synthesized our findings into design considerations, such as addressing varying levels of trust in different stakeholders, providing continuous user agency, and reducing stigma around topics that might hinder users from fully benefiting from a technology. We contribute crucial ethical implications of VFAs for older adults' health and wellbeing needs, as well as design considerations that reflect them as we look to create equitable health technology.

Acknowledgments

We are grateful to our community partners at the Curry Senior Center for their willingness to collaborate with us, their support in tailoring the research to the older adults they serve, and providing the space in which the study took place. We especially thank our participants for their openness in sharing their time, stories, and ideas with us. We also thank our colleagues at the Hybrid Physical-Digital Spaces group at Stanford University for their community and feedback. Finally, we thank Ivania Tausche who kindly volunteered to act for the video we presented in the workshop, and Isabelle Hung who edited the footage into a cohesive story of the technology we presented. This work was principally supported by Stanford Institute for Human-Centered Artificial Intelligence (HAI). We additionally received support from a Memorial Sloan Kettering Cancer Center Support Grant (No. P30 CA008748) through funding from the National Cancer Institute, and through the Gordon and Betty Moore Foundation, Grant GBMF9048 to Dr. Fessele.

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A Appendix

A.1 Toilet Buddy prototypes

Screen-readable list of all 12 prototypes shown in Figure 2.

- (1) Outhouse with reading materials, P3
- (2) Remote to control data travel, P4
- (3) Privacy walls, P5
- (4) Toilet seat for outhouse, P5
- (5) Crabs, P6
- (6) Data filter, P7
- (7) Representation of user, P8
- (8) Luxury toilet, P8
- (9) Wand that expels “Purple Haze”, P9
- (10) Feature to hide drug use from tool, P10
- (11) Sledgehammer, P11
- (12) Evidence-removing magic wand, P12

A.2 VFAI prototypes

Screen-readable list of all 45 prototypes shown in Figure 3.

- (1) Wrist cuffs with authentication, P1
- (2) Way to unravel data on screen, P1
- (3) Data filter, P1
- (4) Privacy tie, P2
- (5) Button for data explanation, P2
- (6) Privacy buttons, P2
- (7) Content filter, P3
- (8) Emotional support anti-hacking necklace, P3
- (9) Biometric necklace keyed to thumbprint, P3
- (10) Dynamically generated resources, P4
- (11) Handheld video call device, P4
- (12) Voice-activated ring to protect data, P4
- (13) Anti-hacking helmet, P5
- (14) Affordable device with activities, P5
- (15) Inclusive device, P5
- (16) Buttons with activities and alerts, P5
- (17) Implant for and necklace for unsheltered, P6
- (18) Disability-adaptive screen, P6
- (19) Invisibility mustache, P6
- (20) Hacking pipeline, P6
- (21) Storage tent, P7
- (22) Indicator of caregiver stealing, P7
- (23) Glasses with camera and brain implant, P7
- (24) Reminder of available services, P8
- (25) Reminder of available discounts, P8
- (26) Dashboard of community services, P8
- (27) Camera to track caregivers stealing, P8
- (28) Brain linked to the bionic hand, P8
- (29) Bionic hand connected to the brain, P8

- (30) Privacy screen, P9
- (31) Hack-proof credit card chip, P9
- (32) Hack-proof key, P9
- (33) Indicates dead-ends in cruise ship, P9
- (34) "Buddy" blocking negative information, P10
- (35) Earpiece that stops the technology, P10
- (36) Earbud and mic to call protector, P11
- (37) Ship dashboard, P11
- (38) Anti-theft purse charm, P11
- (39) Beeps indicating computer crash, P11
- (40) Fingerprint lock, P11
- (41) Glasses that grant the power of invisibility, P13
- (42) Laughter indicator to find fun, P13
- (43) Verbal indication of computer crash, P13
- (44) Scan-proof wallet, P13
- (45) Scrambled screen to prevent identity theft, P13

Received January 2024; revised April 2024; accepted May 2024