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# Not For Me: Older Adults Choosing Not to Participate in a Social Isolation Intervention

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## ABSTRACT

This paper considers what we can learn from the experiences of people who choose not to participate in technology-based social interventions. We conducted ethnographically-informed field studies with socially isolated older adults, who used and evaluated a new iPad application designed to help build new social connections. In this paper we reflect on how the values and assumptions guiding the technological intervention were not always shared by those participating in the evaluation. Drawing on our field notes and interviews with the older adults who chose to discontinue participation, we use personas to illustrate the complexities and tensions involved in individual decisions to *not* participate. This analysis contributes to HCI research calling for a more critical perspective on technological interventions. We provide detailed examples highlighting the complex circumstances of our non-participants' lives, present a framework that outlines the socio-technical context of non-participation, and use our findings to promote reflective practice in HCI research that aims to address complex social issues.

## Author Keywords

Non-participation; oldest old; social isolation; reflective practice; ethics.

## ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous

## INTRODUCTION

What can we learn from the experiences of people who choose not to use technologies that are designed with their interests in mind? In human-computer interaction research, it is rare to find detailed analyses of the decisions people

make to *not* participate in design and evaluation studies. Evaluations tend to focus on the positive impact of the technologies, with decisions to withdraw from the evaluation process typically attributed to a failure in the technology design [17, 19]. In this paper we argue that much can be gained by looking beyond the technology itself, and examining the socio-technical context in which people choose to not participate or discontinue in evaluation studies. This is particularly important when we are designing technologies that aim to support people who might be considered “marginalized” or who typically have limited opportunities to have their voices heard, such as those in the later stages of old age (the “oldest old” [2]).

Technologies designed for (and with) older adults often aim to improve people's lives in some way. Monitoring and assistive devices, for example, can be used to help older adults maintain their independence [22], and there is now a growing interest in the design and use of technologies to improve the social lives of older adults, especially for those considered to be socially isolated ([1, 13], [39]). This brings with it responsibilities for researchers to be sensitive to the diverse needs and experiences of older adults and the possible disruption new social technologies might create for people who are considered vulnerable. When we design technologies to address a social concern such as this, we are effectively intervening in people's lives. As Satchell and Dourish [38] noted, designers and researchers have responsibilities towards the “people in the worlds into which our technologies are introduced [...] responsibilities for taking people – their actions, their statements, and their interpretations – seriously” (p. 15). This means not only “democratizing design” by engaging our intended users in the design process [28, 42], but also listening to, and reflecting on, the experiences of those who choose not to use the designed technologies and who disengage from the evaluation process.

In this paper, we discuss the experiences of older adults who chose to disengage from a project in which they were using and evaluating a specially designed iPad application as part of a social isolation intervention. Our aim is to consider how the experiences of these “non-participants” can help us to better understand our intended users and

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inform our approach to working with older adults. In the following, we position our work by describing the social concern we aimed to address – older adults’ experience of social isolation – and discussing related attempts to understand non-use and critique non-participation. We then describe the socio-technical system we developed and the field studies we conducted, which were informed by ethnographic methods and resulted in the creation of detailed field notes describing each participant’s experiences. Drawing on the field notes about those who chose to disengage from the project, we present three semi-fictional personas to illustrate the factors that were important in influencing their decisions. These factors were related to personal circumstances (such as health issues and personal preferences), social settings (such as the influence of family members), and the technology context (that is, experience and confidence using technology). Together, these factors form a framework for understanding the socio-technical context of non-participation.

This paper builds on, and contributes to, a growing movement within HCI that promotes critical and reflective practices (e.g., [5, 6, 25, 32, 42]). We argue that taking into account the experiences of non-participants, as well as participants, is crucial when designing and evaluating technologies in sensitive settings. Indeed, the lessons we have gained from understanding the experiences of our non-participants are valuable for informing the future ethical design and evaluation of technology-based social isolation interventions for older adults.

### **SOCIAL ISOLATION**

Although not limited to old age, social isolation is often viewed as a negative experience associated with ageing. As we age, we may outlive family and friends and our mobility may become limited due to deteriorations in physical health. People who are socially isolated are those who have few opportunities to meaningfully engage with others. Older adults are often positioned as being at increased risk of social isolation, and although not all older adults are vulnerable to isolation, social isolation in old age is a significant social concern [44]. It is associated with a range of health problems, such as depression, and can lead to people having limited access to support as they get older ([7], [12], [33], [44]).

Many aged care organizations have devised programs and interventions that aim to address social isolation in old age. These programs often involve face-to-face interactions or require older people to participate in local community activities (e.g., [3], [11], [27], [37]), but interest is beginning to grow in using new technologies to address social isolation (e.g., [13]). Technology-based interventions provide opportunities for older people to communicate with others at a distance or to participate in social activities without having to leave the home, making social groups accessible to those with limited mobility. Recognizing these benefits, researchers have explored the design and use of

technologies to enhance older people’s social lives – for example, providing opportunities to maintain intergenerational communication [47], to participate in online forums [10], or build connections within the local community [18]. Innovations include a personal reminder and social management system for isolated older adults [13], a design that leverages television as a “ticket-to-talk” to foster social connections [45], and the use of playful technologies to encourage social interaction in a care home setting [8]. These are valuable innovations, and studies have reported a range of benefits, as well as challenges, arising from the use of social technologies by older adults. These studies tend to report on the experience of those who successfully used the technologies being evaluated. The experiences of people who chose not to use the technologies, or to discontinue participating in an evaluation/intervention study, are generally missing from the conversation.

### **NON-USE AND NON-PARTICIPATION**

While it is rare to find research that examines the reasons people choose to not participate in HCI projects, there has been a recent trend in human-computer interaction literature towards studying and understanding “non-use” (e.g., [4], [5], [38]). To date, much of this research has focused on deliberate non-use of social media, such as “leaving” or “refusing” Facebook or “rejecting” the Internet [4], [36], [55]). These studies illustrate that there are various sociocultural forces that both push and pull people towards and away from using apparently ubiquitous technologies and services such as social media. According to this body of work, the distinction between use and non-use can be fluid and is often related to issues beyond the technology itself, such as institutional expectations and cultural rules for established communication practices. In order to understand how people experience and justify their decisions to not use new technologies or applications, then, we need to consider the socio-technical context in which those decisions are made.

Older adults’ non-use of new technologies is commonly attributed to limited digital literacy, or experience using technologies and poor accessibility and usability of consumer technologies (see Selwyn [40, 41] for a critique of this argument). Much of the research into technology non-use by older adults has focused on identifying barriers to the adoption and use of new technologies by older adults, such as high costs, concerns about privacy and trust, and attitudes towards social media (e.g., [21], [26], [39]). These studies identify issues that prevent older adults from making use of social technologies before they have familiarized themselves with the available technologies. They provide valuable insight into the reasons older adults might be disenfranchised or excluded from using new technologies. They do not, however, provide detailed analyses of individual experiences of non-use, nor understanding about what happens when older adults make

decisions to not use technologies developed with their particular needs in mind.

Technologies designed for older adults often aim to support them (or their carers) in some way, and decisions not to use those technologies need to be understood. In some cases – such as emergency alarms – non-use can lead to serious consequences and impair the support the technologies supposedly provide [22]. There has been some discussion in the sociology and gerontology literature about the need to understand why older people choose not to use e-health systems, which can highlight ethical issues associated with telecare and assistive devices [31, 35]. One recent study, which gained detailed insight into the lives of people using (or not using) assistive devices [22] highlighted the unique needs of older adults, which each individual managed by appropriating technologies according to their own circumstances and preferences; this included, in some cases, choosing not to use particular devices.

While researchers are beginning to recognize that individual responses to assistive technologies need to be taken seriously, technologies designed to address social isolation have rarely received the same scrutiny. Instead, there is an underlying assumption that social technologies are “good” for older adults – that they address an important social concern and empower older people to build and maintain strong interpersonal relationships. However, the research on non-use suggests that we need to adopt a critical stance towards the assumptions that underlie the development of new technologies [5]. We need, as Baumer and Silberman [6] have noted, to critically reflect on whether new technologies are, in fact, an appropriate solution for the particular problems we aim to address.

Alongside growing awareness that HCI researchers need to consider technology non-use, as well as use, recent discussions have critiqued notions of participation in HCI [29, 54, 46]. These discussions tend to focus on user participation in the design process, with limited interrogation of issues surrounding how users participate in the evaluation and use of new technologies. Enabling users to participate in the design of new artifacts and technologies is assumed to be an empowering and democratic process. There may, however, be political issues at play – such as the priorities of researchers and funding bodies – that determine who gets to participate and how [54]. Non-participation, therefore, should be included as part of critical reflection in HCI.

Calls for critical reflection in HCI also tend to focus on design, rather than evaluation and use. For instance, Sengers and colleagues [42] highlighted a number of critical approaches in HCI, all of which are approaches to design, such as participatory design, value-sensitive design, and critical design. They did, however, note that use is an important part of design, and that critical reflection can be valuable for users as well as designers. In addition, they argued that HCI researchers need to “be able to identify

when and how a design has failed” (p. 57). One way this can be achieved is by examining non-use and non-participation, thereby broadening our understanding of when and how a technology design or intervention has been successful.

Building on these calls for more reflective practice in HCI, in this paper we go beyond critiques of technology non-use and participation in design (although these are still relevant to our inquiry) to examine non-participation in the context of evaluating and using specially designed technologies. We focus on the experiences of older adults who chose to discontinue participation in a research study in which they were using a new iPad application to trial new forms of communication. The study continued and was successful for the participants who remained in the project, but we believe it is important to interrogate the reasons these non-participants chose to stop using the iPad application. Understanding the decision and its drivers provides us with an opportunity to better understand the lives of the people we are aiming to support – the challenges they encounter on a daily basis and the role technologies can or do play to support them. Just as Greenhalgh and colleagues [22] identified the role individual circumstances play in people’s responses to assistive technologies, we identify how individual preferences and the social contexts in which new technologies are introduced play a role in how people respond to and accept social technologies.

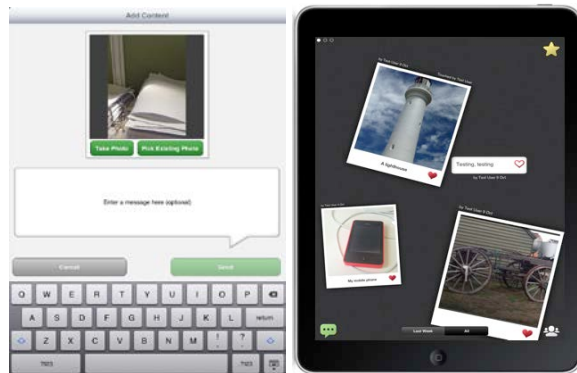
## **EVALUATING A SOCIO-TECHNICAL INTERVENTION**

Our research involved designing and implementing a socio-technical intervention: we designed both the technology (an iPad application used to create and share photographs) and the social setting in which it was used (a closed social network comprising a small group of older adults and their care managers). Previous analyses of the data have demonstrated the value of the system for enhancing older adults’ creative self-expression and augmenting the psychosocial care provided by aged care workers [48, 53]. Here, we focus on the reasons some participants chose to stop using the iPad and to disengage from the project.

### **The iPad Application**

We developed an iPad application, *Enmesh*, drawing on earlier work that examined the communication needs of older adults [34]. *Enmesh* (“engagement through media sharing”) features an interactive display that shows photographs and messages floating down the screen in a semi-random fashion. *Enmesh* can be used to both create and view content. Tapping a “speech bubble” icon brings up a dialog box that enables users to take or select a photograph, write a caption, or write a message on its own, without a photograph (see Figure 1). The content is sent to a server, which is used to populate the shared display. The display features photographs and messages created by people who are connected to each other as “friends” on *Enmesh*. If two or more connected users are viewing the display at the same time, they will see the same

configuration of photographs/messages as they move down the screen. Using the touch-screen interface, users can move objects around the display and reduce or enlarge their size; these interactions are visible to other users viewing the display at the same time (see [53] for more information).



**Figure 1.** Screen shots showing how to create content on Enmesh (left) and the Enmesh display (right)

### Field Studies

The project was conducted in an Australian urban setting, in collaboration with an aged care organization. Participants were clients of the organization who lived independently in their own homes but received home care services. Over the course of the project we conducted three field studies, varying in length from 3 to 12 months. In total, 26 participants agreed to take part in one or more of the field studies. Ten older adults decided to withdraw from the project after using Enmesh for a week or more, leaving 16 participants who remained in the project. Participants were aged in their 70s, 80s, and 90s (mean age 82). All experienced some health or mobility impairments that made them eligible to receive aged care services at home.

### Recruitment and Consent

As part of the aged care service, each participant had an assigned “care manager” who visited them each month to oversee care services such as domestic help, healthcare, and personal care. Care managers knew their clients well and were the first point of contact for recruiting suitable participants. Care managers nominated clients who were actively experiencing or were at risk of experiencing social isolation. When nominating suitable clients, care managers spoke to a member of the research team to provide some background information about the client and to describe their social situation. Following this initial pre-selection, researchers contacted the nominated clients directly and met with them to explain the purposes of the study and to introduce them to the technology. The clients then made an independent, informed, and voluntary decision about whether they wanted to be involved in the project and, if they chose to participate, signed a consent form. The project was approved by the university’s ethics committee.

Although care managers were often present at this initial meeting, their role was limited to facilitating introductions between the researcher and the clients. They did not play a role in obtaining clients’ consent to take part in the project. They did, however, take part as co-participants in the study and used Enmesh to communicate with their clients if clients gave approval to include their care managers in the project. All clients wanted their care managers to be involved. The care manager was someone participants knew and trusted and felt comfortable communicating with; the care managers’ involvement therefore provided participants with a “safe” entry point into a new social network. In most cases, care managers co-participated with a single client; in other cases, care managers had two or three clients participating in the project [48].

### Creating a Social Network

For the purposes of this study, we created closed social networks, comprising small groups of older adults and care managers who were connected to each other via Enmesh. Participants did not know each other prior to the study. It was therefore crucial that we provided scaffolding to support participants’ interactions, as some may have found it difficult to share photographs and messages with strangers. We achieved this by:

- 1) Involving care managers in the project as co-participants. By using Enmesh alongside their clients and sharing their own photographs and messages, care managers provided crucial support for clients [51]. Their contributions to Enmesh included gentle encouragement, playful messages designed to provoke a response, and photographs and messages that aligned with clients’ personal interests [48].
- 2) Adopting a staged process, so that participants gradually expanded their use of Enmesh. In the first stage, participants were only connected to their care managers until they felt comfortable using Enmesh to create and share photographs and messages. As they gained experience using the application and creating and sharing photographs and messages, participants had the opportunity to meet other participating clients at a face-to-face social event. Following this event, participants were connected to each other through the iPad application and could then see each other’s photographs and messages on a shared display.
- 3) Providing opportunities for participants to meet in person. We held regular social events over morning tea, during which participants and care managers met to talk about how they were using the iPad and to ask questions and provide feedback to the research team. These meetings were important for enabling participants to discover common interests and to share experiences, creating a stronger sense of community within the group. However, not all participants were able or wanted to attend the social events.

### *Data Collection*

During each field study we collected data from a variety of sources, including: 1) In-depth interviews with participants at the beginning and end of the study, as well as informal conversations that emerged during the course of the project; 2) Observations of participants using Enmesh and the iPad both in their own homes and at the social events; 3) Data logs showing how participants had used Enmesh; and 4) Interviews with care managers at the start and end of each field study, along with informal conversations with care managers as the opportunity and need arose. The field studies were not traditional ethnographies, but were informed by ethnographic methods [14]. We spent considerable time getting to know each participant, helping them learn how to use the technology, observing their interactions with each other and with care managers, and learning about their social and family circumstances, which was crucial for enabling us to gain a better understanding of their experiences of social isolation. Because our interactions with participants were not confined to formal interviews and included occasional telephone calls, communication via Enmesh, and other informal conversations, we developed extensive field notes about each participant, which complemented the interview transcripts and other data collected. Our field notes form the basis of the analysis presented in this paper.

### **Analyzing Reasons for Non-Participation**

Ten participants initially gave consent to participate in the project, took part in an interview, and began to use Enmesh, but chose to discontinue participation after a short time (this varied in length from a few days to a few weeks). In three cases, the reasons for non-participation were clearly related to deteriorating health. These participants had been admitted to hospital or started treatment for a specific illness and could no longer commit to the project. Two non-participants chose to withdraw from the project for personal reasons, which they did not disclose to us. In the other five cases we gained a detailed understanding of each person's individual circumstances and the reasons they chose to discontinue participation. Two of these non-participants took part in an exit interview, one provided a detailed explanation of her decision via a lengthy message on Enmesh, and two non-participants explained their decision in a telephone conversation. We gained further insights into the reasons for non-participation through informal conversations with care managers and, on one occasion, a family caregiver, who volunteered additional information about their client/family member's situation. The initial interviews, conducted with each (non)participant, provided further insight into their current circumstances, which helped inform our understanding of their non-participation.

We developed five detailed case studies which were used as the basis for team discussions to interrogate the reasons that some participants chose to disengage from the project. These cases were examined, separately and together, in order to identify features that were common in the five

different accounts. However, the core value in the rich data we collected lay in the detailed understanding provided about *individual experiences* of non-participation. While a typical approach to qualitative data analysis would involve identifying common themes across cases, we believed a more fruitful approach was to identify salient factors that led to each individual decision to stop using Enmesh. We did this by reviewing the individual narratives and discussing as a team the salient features of each case. We found that for each case there were highly specific individual circumstances that made it difficult for our non-participants to continue engaging in the project. Sharing these specific details could threaten our non-participants' anonymity and confidentiality. Therefore, we have used the case studies to create three semi-fictional personas, which we describe next.

### **CHOOSING NOT TO PARTICIPATE**

To overcome the challenge of sharing rich data while maintaining confidentiality, we have amalgamated the details about each non-participant to create three semi-fictional personas. Each persona is based on real experiences, but individual experiences have been combined to illustrate three key contextual factors that were important in influencing decisions to not participate: the personal context, social context, and technological context.

#### **Abigail**

*Abigail is in her early 90s. She lives alone and has limited mobility due to painful arthritis, but is keen to retain her independence for as long as possible. Abigail says she has "always been a loner" and likes a quiet life.*

*Abigail has never used computers before. Despite this, she makes few mistakes when setting up her profile on Enmesh. In fact, she initially seems delighted with the iPad and enjoys being able to see her care managers' photographs. In the first few days of using Enmesh she takes photographs of the family portraits in her living room, flowers in a vase, and birthday cards she has received. She is pleased to be able to do this but expresses disinterest in being connected to other participants via Enmesh.*

*The effort Abigail requires for self-care is quite high and this, combined with frequent visits from care workers and the need for regular rest, leaves her with little time or energy for using the iPad. In addition, eye strain causes pain and makes it difficult for Abigail to concentrate. Abigail stops using the iPad after a few weeks and stores it in the "next room" where she can forget about it. She feels guilty about not participating with more enthusiasm and is reluctant to formally withdraw from the project because this means admitting she has found it difficult. Abigail wants to prove to her care manager that she is capable of looking after herself; withdrawing from the project conflicts with the image of independence she is trying to portray.*

### **Martha**

*Martha is in her 80s and is a full-time carer for her husband Graeme who had a stroke five years ago which left him with impaired mobility and cognitive difficulties. Martha finds caring for her husband extremely difficult and isolating but is reluctant to confide in her family because they are busy and she does not want to trouble them.*

*Martha wants to learn to use the iPad because she feels left behind by modern society. She would like to be able to understand and use the technologies that her grandchildren and great-grandchildren use. She uses the iPad to take photographs of her great-grandchild's birthday party but is anxious when the child and his brother want to play games on the iPad. She worries about the damage they will do to the iPad and decides to keep it locked in the cupboard so the children will not see it when they next visit.*

*Martha regularly takes her husband to medical appointments, hydrotherapy classes, and to the local shopping centre. Graeme does not like Martha to be too far away. When they are home and she is in the garden he rings a bell to let her know that he wants something. Martha finds that she has little time or energy left in her day to do anything for herself, let alone to learn something new. Eventually she decides to return the iPad because she feels it is creating an extra burden that she does not have time for at the moment. She believes she has failed in this project and that she has left it too late to learn how to use the technologies that younger people use.*

### **Victor**

*A widower in his late 80s, Victor has been lonely since losing his wife to illness two years ago. Victor was once a professional photographer and owned a camera shop. He sees himself as knowledgeable and experienced at using new technologies. However, Victor retired thirty years ago and since then has found it difficult to maintain his digital literacy, although he uses email and skype on a desktop computer to keep in touch with his children who all live some distance away. Victor's eye sight is deteriorating and he has started to experience some cognitive difficulties which can make it challenging to learn new things. Because of this, Victor has been unable to continue his hobby as a photographer, an activity he misses greatly.*

*Victor is keen to learn how to use the iPad. Although he uses a desktop computer, he has never used a tablet device and does not have a mobile (cell) phone, so he feels the need to update his technical skills. He enrolls in a local "iPad for Seniors" course soon after joining the project. However, Victor finds the course to be less than satisfying. Most of the other attendees are recent retirees who are younger than him and have a more up-to-date knowledge of modern technology. Victor is confused by the questions other attendees ask about "apps". He does not fully understand what apps are and what they are used for. He is also confused by the conversation about how to connect the iPad to a wireless internet (his son had set up the internet*

*for him at home). After attending a few classes, Victor realizes he is struggling to keep up and begins to lose enthusiasm for learning to use the iPad.*

*Victor initially shares photographs of his garden on Enmesh. He is happy to have the opportunity to take photographs and hopes to be able share his skills and knowledge with the rest of the group. However, Victor is frustrated at not being able to take photographs in the same way that he used to (e.g., changing the shutter speed and aperture in response to the light levels); he does not think automatic digital cameras are as good as traditional photography and is concerned about the quality of the images captured on the iPad. In the end, Victor finds taking photographs on the iPad to be a frustrating, rather than enjoyable, experience. Despite being relatively tech-savvy, he struggles to learn how to use the iPad because he is not familiar with Apple products or touch-screens and has to learn new ways of interacting with technology. He worries that deterioration in his cognitive abilities have made it difficult for him to learn new things. In the end, family members advise Victor to stop using the iPad because it is having a negative impact on his self-esteem.*

The three personas of Abigail, Martha, and Victor encapsulate the key circumstances that led our non-participants to disengage from the project. Drawing on these examples, we present a framework that illustrates the socio-technical context of non-participation.

### **SOCIO-TECHNICAL CONTEXT OF NON-PARTICIPATION**

We now return to the question posed at the start of this paper: *What can we learn from the experiences of people who choose not to use technologies that are designed with their interests in mind?* From an analysis of the detailed narratives elicited about our five non-participants, we identified a number of individual circumstances that led these older adults to choose to stop using Enmesh and to disengage from the project. We broadly categorized these into three dimensions that together describe the socio-technical context in which participants chose to disengage from the project: 1) the personal context, including individual circumstances such as health and personal preferences, 2) the social context, such as the influence of family members and others, and 3) the technological context, including prior experiences of technology and digital exclusion. Together, these comprise a contextual framework for understanding the circumstances of older adults' non-participation in technology design and evaluation research.

#### **Personal Context**

At the time of the study each non-participant was experiencing difficult personal circumstances, such as those described in the profile of Abigail, which prevented their active engagement in the project. Given that we were specifically targeting people in the later stages of old age, it is not surprising that these personal circumstances often included health problems. Abigail, who represents the

frailer non-participants, was unable to hold the iPad and suffered eye strain that made it difficult to look at the screen for any length of time.

Difficulty concentrating and learning new things was a common challenge for both our participants and non-participants. Learning to use the iPad sometimes raised feelings of failure and inadequacy, particularly for those like Abigail who had to disengage because of the challenges they faced. In addition to being anxious about frailty, Abigail was disinterested in using Enmesh to communicate with others, challenging the assumptions embedded in the intervention. Like Abigail, some of our non-participants wanted to disengage socially and were content to be disconnected from society. In fact, when we asked if she ever felt disconnected from society, one non-participant replied “yes, but that is a good thing”.

This finding challenges our assumption that designing and introducing a social isolation intervention is the “right” thing to do for all older adults who are socially isolated. Some people experiencing social isolation gained great benefit from this intervention, but it was clearly not right for everybody. This is a reminder that we can’t always predict how people will respond to new technologies, nor what impact the technologies might have. In some cases, our non-participants experienced unexpected strong and negative emotions when taking part in the project. They encountered a range of health problems and personal circumstances that prevented their full participation – problems that were sometimes amplified by the intervention. Notably, other participants who continued in the project encountered similar difficulties. For the very old, daily life is often plagued with health problems and personal challenges. For those who continued in the project these problems were not insurmountable and did not become the barriers to participation that the non-participants faced. Why did difficult personal circumstances prevent some people but not others from fully engaging in the project? To answer this question we broaden our lens to consider the social and technological contexts in which non-participation took place.

### **Social Context**

The social context into which the technology was introduced played a crucial role in driving the decision to disengage from the project. This context included the physical space, family circumstances, and established norms for social activity. Each non-participant did initially choose to use Enmesh but it did not become integrated into their lives. Some non-participants (such as those represented by Abigail and Martha) chose to keep the iPad hidden from view, which limited their opportunities to engage with the iPad. The physical location of technology in people’s homes plays a role in how it is used and how it becomes embedded in people’s daily activities. The decision to keep the iPad locked away or hidden in the spare room could be seen as both contributing to the

decision to disengage from the project, and as emerging from that decision.

The domestic environment includes the presence (or absence) of family members. The burden of caring responsibilities made it difficult for some, such as Martha, to fully engage in the project. For others, the absence of family members was keenly felt and may have contributed to the difficulties they experienced learning how to use the iPad (as illustrated by Victor’s reliance on his son to set up the technical infrastructure in his home, leaving him feeling ignorant about what was required). In addition, family members sometimes advised participants to disengage from the project; this may have been because they were concerned about their loved one (as seen in the persona of Victor, whose family members believed the iPad was negatively affecting his self-esteem), or because family members misunderstood the project.

Family could be a source of tension that affected people’s attitudes towards the iPad and the project. Being a full-time carer meant that Martha came to see the project as another burden competing for her time. Meanwhile, the attitude of her great-grandchildren, who saw the iPad as a “toy” left her feeling anxious and worried about protecting the iPad from their intrusion. This concern was echoed by others who remained in the project. Participants noted they had trouble understanding the attitudes that young people had towards new technology because it conflicted with their own upbringing. As children they had been taught to revere expensive technology and equipment; they were told “Don’t touch! You’ll break it”. Understandably the more hands-on and playful approach exhibited by their grandchildren and great-grandchildren provoked some anxiety, although participants were still eager to have a go at using the iPad themselves. In other words, this anxiety was not about participants’ own fear of using the iPad, but their concern about how visiting children might use it. As we saw in the example of Martha, worrying about how children used the iPad could potentially interfere with participants’ own experience of the iPad. This occurred despite our reassurances that the iPad was a robust tool and it was unlikely to be broken. In addition, those who worried about children’s use of the iPad may have missed a valuable opportunity for enriched intergenerational play.

### **Technological Context**

A simplistic response to understanding non-participation in this setting would be to identify limitations relating to old age that prevented participants from successfully using the technology. While these limitations did exist, such as limited eyesight, frailty, and difficulty holding or touching the iPad, participants were initially positive about using the iPad. All were willing to “give it a go,” challenging established understandings of older adults as unwilling to use new technologies. The fact that our application was designed for use on a popular consumer device is important. The iPad can be seen as a status symbol, particularly when

contrasted with other technologies designed for older adults, such as monitoring and assisted living devices [22]. Our participants were all eager to learn how to use the iPad, beyond the Enmesh application, because they wanted to gain new skills and to improve their digital literacy so they could feel as though they were a part of the 21<sup>st</sup> century.

The Enmesh application, with a simple interface and limited functionality, was generally easy for our participants to learn to use, although they did express some uncertainty about the way objects appeared on the display in a semi-random fashion. In addition to learning the basic features of Enmesh, participants needed to learn how to use the onscreen keyboard, the camera, and to understand general features of the iPad, such as the home screen (which was filled with apps), the on/off button (hidden from view), and how the screen orientation could be changed.

The personas we have presented here all had some difficulty learning to use the iPad, which created anxiety and a fear of failure. In Victor's case, family members were concerned about the impact this may have had on his self-esteem. The difficulty he experienced conflicted with his identify as a competent and experienced technology user. Although he had used computers and cameras before, this experience hindered, rather than helped, his ability to learn to use the iPad. This challenges the common view that older adults with limited past experience of using technologies will find it harder to learn to use a new device or application. In contrast, some of the other participants, who continued in the project, had never used computers before but learned to use Enmesh and the iPad quite easily.

For our non-participants, the iPad came to embody their experience of digital exclusion. Disenfranchisement encompasses more than having limited access to new technologies; cultural knowledge is embedded in the technologies that are now a ubiquitous part of our landscape [15] and lacking this cultural knowledge can lead to disenfranchisement. Digital literacy involves more than learning how to *use* technology; it also involves understanding the *language of use* as illustrated by Victor's confusion when attending the "iPad for Seniors" course. This was based on a real experience; one of our non-participants attended a similar course but found it accentuated, rather than ameliorated, a growing sense of digital exclusion. This example suggests that targeted programs for seniors will not solve the problems of digital literacy unless they address the sociocultural knowledge required to actively engage in our sociotechnical world.

### **LESSONS FOR THE HCI COMMUNITY**

Our contextual framework for understanding older adults' non-participation is necessarily broad, as it aims to capture the range of individual circumstances that led our non-participants to disengage from the project. Our aim in developing this framework is not to provide generalizable understandings of non-use and non-participation, but rather to promote consideration of non-participation as a

legitimate issue of concern for the HCI community. Here we consider the lessons learned for the HCI community in terms of: a) promoting reflective practice, b) questioning the values embedded in the technologies we design, and c) fostering an awareness of situated ethics. We discuss each of these in turn, focusing on how these practices can inform a sensitive and ethical approach when designing and evaluating technologies with the "oldest old".

### **Reflective Practice**

Five years ago Baumer and Silberman [6] noted that, within the HCI literature, there had been "relatively little reflection about where and when not to apply technology, and arguments that technological interventions might not be appropriate for every situation [were] quite rare" (p. 2271). This appears to still be the case. Although several HCI researchers have called for more reflective practice in HCI (e.g., [32], [42], [52]), detailed reflections about negative experiences with technical interventions remain rare. Baumer and Silberman argued that, sometimes, designing and introducing new technologies might not be the best way to address a particular problem. They cited the example of technology interventions that aimed to promote environmental sustainability where there is clearly a mismatch between the goals of the intervention and the fact that new technologies actually create environmental damage themselves. The answer, Baumer and Silberman argued, is not to stop designing technologies, but to "engage in a critical, reflective dialog about how and why these things are built" (p. 2274). In this paper we have opened up critical dialog about designing and using social technologies with the "oldest old".

Our findings demonstrate the importance of engaging in critical reflective practice. Sengers and colleagues [42] defined critical reflection in HCI as deliberate "reflection on unconscious values embedded in computing and the practices it supports" (p. 49). Reflective practice also means constantly questioning the *value* of the technologies we develop, and our methods of design and evaluation [52]. This means paying attention to the experiences of those who use our interventions, as well as those who do not. By interrogating the reasons that people choose not to use the technologies that are designed with their needs in mind, we can better understand the circumstances of their everyday lives and the social context into which new technologies are introduced. This is particularly important when working in sensitive settings with people who might be considered vulnerable. In these settings, it is crucial to constantly ask: Is taking part in the research a positive experience for the participants or does it cause them anxiety? Is the new technology embraced by participants, or does it cause unwelcome disruption? When the answer to these questions is less positive than we would hope, we need to modify our approach and reflect on the reasons that the experience has been less than positive for our participants.

It is valuable to be reflective when reporting the outcomes of the research, too. Rather than reporting only positive findings, we suggest that researchers working in difficult settings should embrace and acknowledge the challenges involved [52]. As a research community we can benefit from ongoing dialog about how to improve practices. Promisingly, some HCI researchers working with older adults are beginning to embrace this shift towards acknowledging both positive and less than positive experiences with technology (e.g., [2] [20]). At the last CHI conference, Gerling and colleagues [20] highlighted some of the social challenges faced by residents of an aged care facility when they participated in a console games activity. Some participants found it difficult to learn how to play the games and felt uncomfortable doing this in front of other residents. Others were frustrated at having to wait for a turn to play, which created tensions within the group. While the paper also reported positive outcomes, it is useful to reflect on the particular challenges that these participants faced so as to highlight the need for researchers/practitioners to pay careful attention to social structures when implementing similar interventions in the future.

### Questioning Values

There is a strong assumption in HCI research that once we have identified common characteristics of specific user groups the process of matching technology design to these characteristics will result in a usable and useful technology [23]. However, the analysis presented in this paper demonstrates that the reality is more complex. Technologies are “not neutral objects but embodiments of our selves and our cultural values” [22, p. 88]. Despite careful user-centered design practices, sometimes the values that technologies embody do not align with the values of the people who come to use them. The term “values” in this sense does not mean how valuable or effective a particular technology is, but refers to “what a person or a group of people consider important in life” ([16], p. 349).

A movement within HCI that can help address these issues is value sensitive design (see [9], [16]). Value sensitive design promotes careful consideration of users’ values during the design process, beginning with a conceptual investigation that involves identifying the stakeholders (both direct and indirect), considering how they are or will be affected by the design, noting what values are important, and questioning whether certain values (e.g., moral values) should have more weight than others. This is followed by empirical investigations of the social setting in which the technology is to be used, and technical investigations, which can involve investigating existing technologies or designing systems that aim to support particular values [16]. While this is a useful method for highlighting the importance of values in design, it does have limitations [9] and, like other critical approaches, its focus is on design, rather than evaluation and use.

The challenges discussed in this paper transcend design issues. In some ways, it would not have mattered what the design was, and the tensions around mismatched values did not become apparent until after implementation and use. Our analysis demonstrates that the values embedded in design need to be critiqued by researchers throughout evaluation and use, not only during the design process.

Recognizing mismatched values provides a valuable opportunity to learn more about our intended users. Our design of Enmesh and the broader socio-technical intervention promoted the value of social connectivity. This value and the expectation that older adults would *want* to build new friendships clearly conflicted with some of our participants’ personal preferences and their desire to *disengage* from society. By realizing this conflict, we experienced a valuable lesson; it helped us to see more clearly that the lives of the oldest old are complex, and older adults, like many other groups, are heterogeneous and cannot be easily defined by their age alone.

Our technology intervention also, inevitably, communicated that digital literacy and broader societal engagement through the use of new technologies is important. While this value was shared by our participants and non-participants, it created challenges for those who struggled to use the iPad and were unable incorporate it into their lives. We can see this in the tensions that our non-participants experienced: apparent enthusiasm for learning to use the iPad, followed by hesitation and disengagement. The conflict that non-participants felt about using the iPad and Enmesh was not just about the technology but also what it represented: the opportunity (or obligation) to learn to use a new technology, as well as the opportunity (or burden) of communicating with others. For some, it meant coming face-to-face with their deteriorating health and acknowledging a fading ability to learn new things. The iPad came to embody cultural values, including participants’ feelings and beliefs about old age. This was quite confronting and presents us with a significant ethical challenge. How do we ensure that those who can benefit from using new technologies are given opportunities and support, while also ensuring that those for whom new technologies cause anxiety are not made to feel burdened by a technological intervention? This is not simply a matter of choosing not to design or not to introduce new technologies. Our research had positive outcomes for the participants who continued to use Enmesh and fully engaged in the project. However, because of the complexities of our participants’ lives, we could not predict who among our participants would have a positive experience and who would have a negative experience when using the technology. Therefore, rather than advocating against designing technologies to address social isolation, we believe the appropriate response is for HCI researchers working in sensitive settings to be reflective and to constantly question whether the values embedded in the technology match the values of the people learning to use it.

### **Situated Ethics**

Finally, our analysis of non-participation suggests a need to pay attention to ethical issues, not only when planning and implementing a design or evaluation study, but throughout the project. Recent discussions and presentations at the CHI conference have demonstrated that the ethical issues encountered during “non-traditional” HCI research can be highly complex, emergent, and contingent on the particular contexts in which the research takes place (e.g., [30, 32, 49]). Munteanu et al [32] called these issues “situated ethics”; others have used the term “ethics in practice” [24]. These terms suggest that the ethical challenges researchers face, particularly when working in sensitive settings cannot always be predicted or planned for.

Certainly, in our research it was difficult to fully predict the variety of challenges our participants and non-participants faced. We had to be alert to these challenges and to adapt our methods accordingly. Of course we ensured participants were aware that they could voluntarily withdraw from the project at any time but this was a more complex and sensitive issue than we had expected. As illustrated by the story of our three personas, choosing to not participate could sometimes evoke feelings of failure and inadequacy. If participants did not enjoy using the technology and we (or others) felt their participation was doing more harm than good, this had to be handled very sensitively.

Our experiences highlight a need for flexible practice in response to emergent ethical challenges [52]. Researchers in other disciplines, such as anthropology and sociology, have long acknowledged the need for researchers to respond and adapt to ethical issues as they arise [24]. This is particularly crucial for HCI research conducted in sensitive settings: our research involves not only entering people’s lives, but also *intervening* in their lives. Designing technologies that aim to address particular social problems involves “an intervention in a complex situation” ([6], p. 2272). Further, technologies can be “disabling as well as enabling, disempowering as well as empowering” ([22], p. 88). This paper has demonstrated that while social technologies may provide significant benefit for some isolated older adults, they can also be confronting and raise fears of failure for others. There is an ethical obligation for researchers to recognize and respond to these issues. This is difficult; an ethical approach also means not denying people the opportunities and benefits they may gain from taking part in a technology-based intervention. Some of the “oldest old” who took part in our project successfully used Enmesh to build new social connections and to engage in self-expression by sharing creative and personally meaningful captioned photographs [53]. Meanwhile, learning to use the iPad was a positive experience that gave them new skills, a renewed sense of connection to the world, and enhanced confidence. When designing and implementing technologies with this population, then, we need to incorporate flexible methodologies that allow researchers to respond to individual needs. We need to provide

considerable time for participants to become familiar with the technology and ensure they feel confident about deciding whether or not they want to use it [50].

### **CONCLUSION**

Why did our non-participants choose to disengage from this social isolation intervention? Our analysis suggests the reasons were highly specific, but together paint a complex picture of the socio-technical context into which new technologies must be integrated. In this paper we have presented a contextual framework that highlights how *personal circumstances* and preferences, *social contexts*, and *technological contexts* inform experiences of non-participation in a socio-technical intervention.

This paper responds to and builds on earlier calls for HCI researchers to engage in considered reflection about the benefits and potential disruption that new technologies can bring. We add to this conversation, by calling for HCI researchers to pay attention to the experiences of those who choose not to participate in design and evaluation studies, as well as those who do, which we believe is especially important when working in sensitive settings. Our experiences highlight the need for researchers to engage in reflective practice, to constantly question the values embedded in the technologies we design and introduce, and to recognize and respond to ethical issues as they arise in the course of the research.

While we acknowledge that the arguments in this paper are based on the experiences of a small group of people, we believe there is great value in undertaking in-depth explorations of individual experiences. The paper’s contribution lies in the detailed discussion of the complex circumstances of our non-participants’ lives. We argue that design and evaluation in sensitive settings can be improved by taking into account the experiences of non-participants. This perspective has not been fully explored in existing literature, and detailed reflections on the particular challenges faced in these settings remain rare. The examples presented in this paper serve as a valuable reminder of the need to adopt a respectful and sensitive approach when developing and evaluating technologies with the “oldest old”. This means respecting the needs, desires, and preferences of the people we design for [38, 50]. In our research, this meant understanding older adults’ wishes to disengage from society and honoring their active and considered choice to *not* participate in social isolation interventions.

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