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# Vulnerability: Participatory Design, Older People and Researchers

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**Abstract**

Participatory design research is often used in work involving older people who are using digital technology. This type of research typically opens up both the researcher and the participant to vulnerabilities in the process.

We discuss these issues of vulnerability as it relates to our current study using a local running group as platform for supporting older people in gaining confidence in integrating digital technologies in their everyday life. We discuss the over arching issue of older people, digital technology usage and participatory design. This provides the background for addressing points of awareness regarding empowerment, expectations, boundaries and loss for both the participants and the researcher.

**Author Keywords**

Design; vulnerable individuals; methods; ethics.

**ACM Classification Keywords**

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

**General Terms**

Human Factors

## **Introduction**

A 2009 United Nations report states that by 2050 there will be more people over 60 than under 15 years of age in developed countries [18]. Despite the increase of older people in the population, they are still overlooked in the development of digital technologies.

While the growing older population is diverse and can no longer be divided into 'silver surfers' [3] or 'digitally disenfranchised' [17], studies have shown that on the average the 'grey generation' are a small portion of digital users [12]. On average, older people have ambivalent attitudes toward new technologies due to limited experience of the technology's usefulness in their everyday life [15].

The central theme of our research project is to empower older people by fostering the confidence to engage with digital technologies through a meaningful integration into their lives. We are working with a local London, UK running club whose members regularly visit isolated older people in their neighborhoods: checking on their well-being, encouraging social interaction, delivering newspapers and doing odd jobs. Our research work supports the relationship between the runners and the older people they visit.

Our research takes us into the lives and homes of the participants. This interaction demands that we are sensitive to the ethical considerations when engaging with the participants as well as with the organization [11]. The foremost considerations are: managed expectations, empowerment, and benefits to the wider community. As researchers, we have to manage boundaries of the relationship and the occasional loss of an older person during the life of the project.

## **Background**

There is a body of research that points toward the potential benefits of integrating non-medical digital technology into the lives of older people [1][3][10]. Despite the potential of these digital technologies in supporting health and social engagement, it has been found that older people are not likely to adopt new technologies [7]. Older people's lack of adoption has been attributed to the perceived barriers of the complexity of digital devices (mobiles and laptops), previous 'bad' experiences and lack of motivation [6].

The developed world is increasingly operating online. This has a growing impact on older people's ability to operate on a day-to-day basis [12]. The retail industry has transitioned from checks and cash to debit cards [19], and customer care favors online chats and email while often charging for phone support [13]. For older people, the technology they are familiar with is being phased out. This cycle of transitioning technology is not new, it has repeated itself over the centuries from the Bronze Age to the Industrial Revolution [4]. What makes the digital age different is the pace of the change. In the digital life, the evolution from relevant to obsolete is marked by months not years [2].

Typically the government and organizations provide digital literacy support [9] for older people predominately through technology classes at local libraries or day centers which has at best limited reach in the community [16]. While these initiatives are based on good intentions, they are short sighted since the scheme does not consider barriers of mobility, motivation and perceived usefulness.

Selwyn proposes that successful digital literacy support

of older people will be through trusted sources that are deeply involved in the local community [15]. Our project tests Selwyn's theory through a real world implementation by engaging a local running club in East London, UK as the platform for integrating digital technology in the community.

### **GoodGym and Older people**

GoodGym is a non-profit organization that has 150 runners in East London who regularly visit older people, who are unable to leave their residents on a regular basis, in their neighborhoods. The work is having significant impact at its small scale. The cornerstone of GoodGym is the mutually beneficial pairing of runners, who need to be motivated to exercise, with older people (coaches), who benefit from a weekly visit.

We chose GoodGym for our research as a community organization whose goal is not explicitly aimed at teaching older people how to use computers. Their scheme supports an intergenerational relationship that is not family based. Runners are 22 – 35 years of age and Coaches are 70+. The relationship revolves around weekly visits that require scheduling and checking in if one of the parties is going to be late or not present. These factors made this community an attractive place to explore Swelny's theory of bottom up digital literacy.

The participatory design research approach [14] is being used in our work with GoodGym. We conducted two exploratory studies. One focused on understanding GoodGym's administrative operations. The other was to gain an understanding the various coach and runner relationships. In this process, we are being invited into the both the home and lives of the community members and the organization itself. This type of

access requires the researcher to be sensitive to both parties [6].

### **Vulnerabilities in Participatory Research**

The intent of practices that work with communities and implementing a participatory approach is to conduct research that empowers participants and impacts on the community [14]. These are good intentions but researchers need to be aware of the ethical considerations, particularity when working within a close community organization.

#### *Empowerment*

When working through an organization such as GoodGym the participants need understand that the research is separate from GoodGym services. It is important that the potential participant feels empowered to say 'no' to participation at any stage in the process. We have to be clear that participating in the study is not a requirement to remain a part of the GoodGym scheme.

#### *Expectations*

The hope is that the intervention used in the research project will be beneficial to the participants. The long-term issue is what happens at the end of the study. Is the device left with the user for their continual use? If so, how is it supported? Is the device removed? If so, how are these expectations managed? How are the participants supported in the transition of the loss of the device? The ideal is that the participant can keep the device and the organization supports it. In practice, the intervention is often temporary. While the standard recommendation is to tell participants up front that intervention is only temporary [14], this does not account for emotional connections that develop. In

particular for older people, as we referenced earlier, often experience the loss of a service they had been dependent on. We are hoping to find better transitional methods, when a device isn't supported after the study.

#### *Boundaries*

When working with people, there is always the concern of privacy of the participants and protecting the data that has been gathered. There is also the concern that interventions in the home are not invasive nor compromise their privacy [11]. However, the researcher also needs to consider how accessible they are making themselves to the participants. Contact information is exchanged leaving a lasting connection. As a researcher, one has to manage the boundary of the connection to their participants. There can be risk of participants interacting beyond the frame of the research project. How does one handle these situations, when the researcher may have their privacy invaded or boundaries crossed by the participant?

#### *Loss*

In research we often worry about data loss or participants leaving a study. While the loss of data can be devastating to the research, in our current project we are concerned with the death of participants. When working with older people this is real possibility that we have already experienced. In our time with GoodGym, we have had four coaches pass away. It is part of the GoodGym scheme that there is support available to the runner in the loss of their coach. However, had we been working at a different organization there might not be an inbuilt system of bereavement support that the researcher can access. It is recommend that formal counseling, debriefing and peer support be offered to researchers [8]. As a researcher, we do make a

connection with our participants. The connection does not have to be deep for one to be affected by the death of a fellow human being. When working with older people, researchers need to consider how they will handle the emotional impact of the death of participant. This is also a consideration for work with people with disabilities, as some disabilities contribute to a shorter lifespan. We are interested in developing methods for researchers when dealing with the death of participant.

#### **Conclusion**

In research language, older people are defined as vulnerable. As such, the researcher is trained to operate as transparent and ethically as possible. The focus is on protecting the older person as a participant in the study. However, the researcher must also consider how they could become vulnerable in the process. Particular consideration should be given to emotional areas such as invasion of privacy and loss of life.

We have raised questions and concerns here on which we are trying to find more satisfactory answers. It is our aim to open up and broaden the discussion around vulnerabilities we face as researchers when engaging in participatory research with older people. We hope to be able to learn and share strategies for both the researchers and participants in these vulnerable situations.

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