

Vicious or Virtuous Cycle? The Privacy Implications of Active Assisted Living Technologies for Older People

Ava Scott

ava.scott.20@ucl.ac.uk

University College London Interaction Centre
London, UK

Jasmin Niess

jasmin.niess@unisg.ch

University of St.Gallen
St. Gallen, Switzerland

Carolin Stellmacher

cstellma@uni-bremen.de

University of Bremen
Bremen, Germany

Yvonne Rogers

y.rogers@ucl.ac.uk

University College London Interaction Centre
London, UK

ABSTRACT

A variety of technologies are being developed to help older people live healthier, more independent, and safer lives, for longer. While many of these technologies are positively impacting the lives of older adults, they also have the potential to dictate specific behaviours or restrict their autonomy rather than empower them. The vulnerability theory of privacy proposes that vulnerable populations are not only more likely to be susceptible to privacy violations, but are also disproportionately affected by said violations. In this position paper, we adapt the vulnerability theory of privacy to the older adult population, and identify a further potential exacerbatory cycle. The risk of a 'slippery slope' of privacy violation occurs when AAL technologies enable an elevated and quantified visibility of (mis)behaviour and irregular activity that could seem to justify the deployment of further AAL technology. We present 'ratchet-wise rehabilitation' as an alternative vision to the 'slippery slope' and identify research and design challenges throughout the paper.

CCS CONCEPTS

• **Security and privacy** → **Social aspects of security and privacy**; **Usability in security and privacy**.

KEYWORDS

active assisted living, privacy, privacy vulnerabilities, older people, ratchet-wise rehabilitation, digital health technologies, digital wellbeing

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1 INTRODUCTION

With populations ageing around the world, enabling older people to live healthier, more social and safer lives for longer is a key challenge facing the global community. Many hope that Active Assisted Living (AAL) technologies will help build medical and social infrastructure to support ageing populations around the world, while preserving their dignity and wellbeing [9, 14]. Such technologies include smart wearables that can monitor hydration levels, blood metrics, temperature, activity, and location, and report these back to the caring community [1, 6, 13], as well as smart access systems which can automatically identify friends, family, and caring professionals and allow them access to an older person's home [3, 19, 21], among many others. However, many AAL technologies, contemporary or speculative, demand extensive access to the private lives of their older users, even restricting their autonomy or imposing new regimes against their will [2, 11]. These technologies will only be acceptable if they actively avoid these risks, and are tangibly aligned with the older person's values, not just the concerns of their caring community.

The short film titled 'Uninvited Guests' [18] demonstrates this tension well. It focuses on an older man, who has been given three Internet of Things (IoT) devices; a smart fork, walking stick, and mattress which monitor his diet, exercise, and sleep patterns, respectively. When he does not follow the pre-programmed guidelines for healthy behaviour, he is barraged by notifications, first by the device itself, and then by concerned family members who are receiving constant reports on his behaviour. Rather than change his behaviour to meet the devices' expectations, our protagonist finds ingenious ways to trick the devices into thinking he is obliging. When faced with intruding devices, older people may craft workarounds and avoidance strategies to continue living on their own terms and with dignity. However, evasive behaviours could lead to morbid health outcomes, and if discovered, even further restrictive or invasive interventions. How can we map the risks and opportunities associated with deploying AAL technologies?

Focusing on the unequal distribution of these costs and benefits, McDonald and Forte [10] present a theory of 'privacy vulnerabilities', arguing that different populations are implicated differently within privacy management and security issues. Firstly, vulnerable populations may be more susceptible to privacy invasions, and secondly, they may also face disproportionate consequences as a result of a violation. We will adapt each of these postulations to the case of

older adults and AAL technologies, while considering the specific complexities that are associated with this demographic. While privacy violations can be unintended or intentionally malicious, in the case of older adults, they are largely well-intentioned and often the product of extensive negotiation between the older adult and their caring community (although not always). Providing appropriate and personalised care services can require the exposure of an older person's current behaviour and care needs. This position paper will focus on AAL technologies that are employed to help the older person and their care, and the subsequent well-meaning privacy invasions. While we recognise that these technologies could be used in a malicious, neglectful or criminal way, this is not the focus of this paper.

First, we will adapt the framework of privacy vulnerabilities to the case of older people, addressing their increased susceptibility to privacy invasion and how they are subject to corresponding disproportionate consequences. Then we identify a 'slippery slope of privacy invasion' as an additional exacerbatory dynamic within this framework, where AAL technologies may justify their own privacy invasion, and those in the future. As an answer to the slippery-slope, we present a vision of 'ratchet-wise rehabilitation', where user and technology work together to achieve a desirable goal. We pose research questions and challenges throughout the paper, and conclude with a discussion on the role technology could have in subverting ageist narratives.

2 PRIVACY VULNERABILITIES IN OLDER PEOPLE USING AAL TECHNOLOGIES

Presented as a concept that moves the focus beyond both the individual and social norms, privacy vulnerabilities address the fact that the privacy norms of some groups are privileged over others, rendering others' thoughts and values concerning privacy invisible [10]. With privacy norms defined by those who can participate freely and non-anonymously, those who suffer from privacy invasion can experience victim-blaming; they are accused of being disengaged and illiterate when it comes to privacy issues, or that they engage in risky behaviours due to their own ill-decision making. This line of argument blames those with greater vulnerabilities for their own disempowerment, redirecting responsibility away from those with influence and power. In the original paper, the authors illustrate privacy vulnerabilities with the case of open collaboration projects, such as Wikipedia and open source software [10]. Those with privacy concerns are less likely to contribute to these public sources of information, due to fears of 'harassment, threats, and reputation loss', and as a result, take steps to self-censor. Older peoples' privacy in the age of AAL technologies is an urgent field of enquiry, and we believe it adapts aptly to the privacy vulnerabilities framework. We discuss how older people may firstly be more susceptible to privacy invasion, and secondly, may face more significant consequences as a result of such invasions.

2.1 Susceptibility

An older person may be more susceptible to well-meant privacy invasions than the average population for many reasons. Firstly, older peoples' needs and desires, in all their diversity, are less likely to be reflected in technology design or privacy practices,

than those of younger people. Critics say this is at least partly due to a 'rhetoric of compassion' that has dominated the research and design of technologies for older people. While well-meaning, this attitude can lead to the prioritisation of designers' (potentially ageist) assumptions and perceptions about the desires of older adults, rather than their actual wishes. The problems with excessive paternalism and outright ignorance of older peoples' views has been discussed extensively [7, 16], and has multi-faceted causes, including high levels of digital illiteracy in older people, ageism in the tech industry, the patronisation of elderly people, and a preoccupation with assistive technologies rather than fun, creative, or challenging technologies. Without older peoples' ideas in the blueprints, technologies are unlikely to align with their values, including those around privacy.

Once a technology has reached the market, older people face further obstacles to asserting their privacy values within their caring community. Intergenerational and cultural differences may cause family, caregivers, or medical professionals to have different motivations, values and privacy norms compared to the older people they care for. These stakeholders often have elevated authority and control over older peoples' lives. Indeed, older people are at risk of being patronised, where caregivers assume that they do not know what is best for them, or have inadequate literacy in technological or privacy issues to make a decision for themselves. In particular, older adults are often not familiar with technical devices or struggle to fully comprehend their functionality. They have not grown up with modern technology; some might have not worked with computers in their previous jobs and others may have never used a smartphone. When they are confronted with the decision of using AAL technology in their home, they lack the knowledge or experience to understand what the system actually does, what kind of sensors or cameras are used and what they can monitor, and the subsequent privacy risks and their consequences. At other times, older people may not even be consulted before a decision is made for them.

Diagnosed or undiagnosed cognitive and physical disabilities can also make it difficult or impossible for older people to give meaningful consent to a system, use a system appropriately, or remember that they have consented in the past [20]. For example, if an older person is asked to wear the smart bracelet discussed in the introduction, they might not understand the number of different metrics it tracks, who it is shared with or when. Even if they can tolerate this ambiguous wearable on their arm at all times, their original consent (if given) may not be meaningfully maintained.

Researchers and designers have the responsibility to involve and engage hard-to-reach communities in the knowledge creation process. Previous work has demonstrated that with the right methods, older people can master technology quickly, collaborate extensively and discuss their desires and values in a technological context. For example, inventing and playing with the MaKey Makey inventor's toolkit highlighted older peoples' willingness to learn about, conceptualise and share new technologies with others, with a lot of good humour, confidence, and mastery [17]. This approach and attitude could be deployed beyond a research setting, and used to familiarise and educate new users of AAL technologies, before they are installed or activated.

2.2 Research and design challenges

- How can we sample diverse groups of older people and their caring communities to ensure more viewpoints are represented?
- How can we engage older people in the design and evaluation of AAL technologies, and ensure design values are aligned with the user values?
- How can we introduce new AAL technologies to older people in an engaging and informative way?
- How and why do older people resist or withdraw upon the installation of AAL technologies?
- How can we address the over-preoccupation with assistive technologies for older people, to develop more social, creative or challenging technologies?

2.3 Disproportionate consequences

As well as being more susceptible to privacy invasions, older people also face disproportionately critical, and potentially life-changing, consequences due to these invasions. Many older people have to withdraw from their communities and lose parts of their identities due to cultural expectations to retire, discriminatory policies, or developing disabilities. Many have to give up employment, travelling, shopping, volunteering, and their healthcare autonomy, among other activities and responsibilities. This process of narrowing responsibility can result in a very small area of control, often centred around their domestic space. As a result, any change or intervention into their daily life at home represents a proportionally larger invasion or imposition than for someone with broader and more varied zones of autonomy and control. For example, a young family which spends a lot of time outside the home, at work or school, could be face less exposure from a smart speaker with surveillance capabilities than an older person who rarely leaves the house. A similar pattern could be observed with technologies that monitor nutrition, exercise, socialising, any other behaviours, in the home.

As well as having a smaller base of autonomy than younger and middle-aged people, older people are often encouraged to relinquish decision-making to their caring community. While some older people will hand over control to others willingly and may even enjoy reduce responsibility, others may be less enthusiastic. This means that behaviour revealed by a privacy invasion, such as their dietary, medicinal or hygiene practices, could expose the necessity for intervention. This could quickly result in the imposition of significant new restrictions, interventions or surveillance in their life, by the caring community or even by an AI-driven algorithm. This contrasts to the experience of a non-disabled, younger person; if a dietary surveillance system detects poor diet in these users, they do not have to change their ways unless they want to. For an older person, this detection could lead to a new undesired diet, mealtime regime, and further monitoring issued by their caring community. Another example could be found in mood or sleep tracking technologies; most people, if found to be sleeping poorly or showing low mood, may not think to pursue treatment, and hold the right to reject treatment or medication. However, some older people receiving care from others may feel they are unable to refuse treatment; hence, the introduction of sleep or mood tracking

devices could result in significant changes in medication, against the person's will.

2.4 Research and design challenges

- How can we design technologies to extend older peoples' zones of autonomy and mastery?
- How can we help ensure that those implementing technologies respect older peoples' right to refusal of treatment or intervention?

3 A 'SLIPPERY SLOPE' OF PRIVACY INVASION

As demonstrated in the previous section, we believe that McDonald and Forte's [10] 'privacy vulnerabilities' provide a productive framework for understanding privacy issues among AAL technologies for older people. To supplement this work, we have identified a further dynamic that may exacerbate the privacy invasion within older peoples' lives. The 'slippery slope' of privacy violation can be triggered by the introduction of an AAL technology that monitors and reports on multiple elements of a user's behaviour. The elevated visibility and quantification of (mis)behaviour and irregular activity could seem to justify the technology's deployment, but also that of future AAL technologies, which may be even more invasive. This can lead to an exacerbatory positive feedback cycle where an intervention leads to a privacy violation, revealing behaviour which justifies further interventions, and so on.

We can illustrate this cycle with an AAL technology that tracks and monitors a wide variety of behaviours. For example, an older person may be given a smart bracelet, initially intended to track their exercise levels. However, if the bracelet also tracks and reports on additional behavioural and bodily metrics, such as sleep duration and quality, blood sugar, blood pressure, hydration, visitors and location, all of these metrics may suddenly become subject to monitoring by the caring community. Any abnormality or deviance from a pattern can become a cause for concern. Even if the technology was only meant to be used for a pre-defined period of time, it may be left in place out of convenience, or because it provides reassurance to the caring community that they are being vigilant and thorough in their care. While this may lead to identification of previously unforeseen issues, it also presents risk of 'false positives', where a metric highlights an apparent issue which may not necessarily require attention. Importantly, these metrics aren't always accurately tracked, with the quality of the signal and its interpretation differing by product. Nonetheless, the older person may face new interference with their lifestyle, such as medications for sleep, hydration, blood pressure, or restrictions on visitors and travelling, which would have otherwise remained unaffected. If critical medical and care decisions are going to be made using the data collected by AAL technologies, it is critical that the sensors and tracking algorithms are accurate, but also that the tracked metrics are chosen carefully and precisely, potentially starting with opt-in, rather than opt-out, settings.

While the short film, 'Uninvited Guests', described earlier, ends without exploring the consequences of the main character's technology evasion, we can imagine these avoidance strategies could come with significant costs to data quality and care strategy. This could potentially lead to real negative consequences in users' health.

For example, if a user manages to trick a hydration reminder system so they do not drink fluids throughout the day, they could become dehydrated, and their care community may remain unaware as they are misled by the system's inaccurate reporting. If the avoidance strategies are eventually exposed, a persistent, but well-meaning, caregiving community could implement further AAL interventions which are more difficult to ruse, resulting in further privacy invasion. Eventually tiring of rebellion, the older person may withdraw and become disengaged from the decision making process, believing (perhaps rightly) that their wishes and requirements are not being taken into account. This could lead their already marginalised voice within privacy negotiations to become invisible, through self-censorship and disengagement.

This exacerbatory loop is implicit in the design fiction crafted by Noortman et al [12]. HawkEye, a fictional design probe, allowed participants (acting as distant carers) to increase the automation of care in the smart home of a fictional older person called Annie from afar. The carers could choose among four levels of automation, where level 1 meant no assistance, and level 4 meant the smart home would take complete control over the tasks for the resident. However, with each incremental level of automation, more information was collected and acted upon. For example, while the second level for the Nutrition care module could track what Annie had eaten and influence her grocery shopping, if the carer chose the fourth level, the smart home could choose and prepare all meals for Annie, therefore intrude further on her dietary freedom and privacy, by determining everything she consumes.

3.1 Fostering dependence

As well as extensively quantifying and highlighting (mis)behaviour, an AAL technology may unfairly justify its own use by encouraging the constant 'offloading' of a task to the technology [15]. This process could lead to over-dependence on the technology and potentially the deterioration of physical or cognitive skills.

AAL technologies are often implemented to help older people avoid risky situations or incidents, such as getting lost or falling over. Avoiding these dangerous incidents is clearly critical to extending the period of independence, as injury can be difficult to bounce back from, and AAL technologies may be able to reduce this risk to almost zero. However, this risk reduction may come at the cost of more rapid skill deterioration, and hence realising and reifying the risk first identified. Using the nutrition example above, our fictional older person, Annie, was originally able to prepare her own meals to a certain degree. However, with a dedicated and insistent robo-chef, this ability may deteriorate, making her less autonomous and independent than before.

This process could undermine both physical and cognitive skills. When an older person engages in 'unwarranted wandering' around their local area, they may appear to be at risk of getting lost or hurt, causing anxiety among family members and neighbours. To resolve this, a smart access system may be deployed, preventing the older person from leaving the house at certain times or when unaccompanied. This is an imposition on their personal freedom and privacy, but could also lead to a reduction in exploration and navigation. As a result, their mobility may decline, and their mental map of the surrounding area may also deteriorate, leading to even

further navigation issues when they are allowed to leave the house. This may reassure caregivers that the smart access system was a necessary precaution, but in fact, it may have contributed to its own apparent necessity. It has been identified that the fear of becoming dependent and the associated loss of dignity is a key contributor to resistance to care among older people [2, 4, 5, 8]. Addressing this fear in the design of AAL technologies could increase their acceptability among older adults.

3.2 Ratchet-wise rehabilitation

When implementing AAL technology, the risk of skill deterioration must be balanced with the risk of incidents and injuries, which may be even more damaging to an individual's capacity. Assessing the existence of a skills deterioration process, and designing technology that can balance these two risks, can help us design more acceptable and useful AAL technologies. We propose a model of 'ratchet-wise rehabilitation', which could help invert the slippery slope by leveraging technology's ability and older peoples' determination to cultivate skills, maintain dignity, and regain autonomy. A ratchet is a mechanical device that facilitates continuous movement in a single direction, while obstructing the reverse action or motion; the metaphor of a ratchet nicely invokes a vision of technology and users working together to achieve a desirable goal, while preventing regression. There is potential to design AAL technologies that actually increase physical and cognitive capacity. For example, a VR environment could be used to simulate a local walk or shopping trip, facilitating safe practice of the journey at home. When attempting navigation in real life, AR glasses could provide live support to users as they walk. Part of our future research programme will be to assess how a vision of ratchet-wise rehabilitation in AAL technologies can empower older people by building autonomy and independence, rather than fostering reliance and dependence.

A 'slippery slope' of privacy invasion and life intrusion is implicitly assumed as justified and normal in many peoples' understanding of care for the older. Simply put, the older are often expected to hand over their privacy and their autonomy to their caregiving community, with increasing indiscretion as they age. Challenging this norm, and ensuring privacy is surrendered only when absolutely necessary, and always precisely, sensitively and transparently, is key to designing and implementing privacy aware technology solutions for AAL. Further, we should be thinking about how to build interventions that do not result in permanent privacy invasion, but can facilitate skills acquisition and be withdrawn over time.

3.3 Research and design challenges

- How can we ensure that AAL metrics are appropriately bench-marked and interpreted by older people and the care community?
- Do AAL technologies actually encourage a slippery slope of privacy invasion in-the-wild? If so, which ones and how?
- How can we ensure that AAL technologies are deployed precisely, without larger remit than necessarily?
- Can we avoid the 'slippery slope', and build AAL technologies with surveillance and other invasive features that can be incrementally or completely withdrawn?

- Do AAL technologies promote over-reliance and skills deterioration in-the-wild? If so, which ones and how? How can this be balanced with the risk of accidents and incidents?
- How can the risk of incidents be balanced with the risk of skill deterioration and over-reliance?
- Can we promote ‘ratchet-wise rehabilitation’ and design technologies that incrementally improve skills and capabilities in body and cognition?

4 CONCLUSION

With our goal to extend the period of time in which older people can continue living happily and healthily in their own home, while respecting and supporting their right to privacy, it is critical to explore how assistive technologies may betray or undermine older peoples’ capacity, ability and autonomy. This may be exacerbated by a slippery slope of privacy invasion and dependence, enabled by AAL technologies. With this knowledge, we can design AAL technologies that avoid this trap, and actually enhance or train older peoples’ capacity to extend their period of healthy, independent living.

A key assumption we are challenging is that age and privacy violation must be linearly positively correlated, and that as someone gets older, they must hand over more of their private information and autonomy to other people or AAL technologies. While this may be unavoidable for those with fast-progressing, degenerative conditions, in many cases AAL technologies should be precisely and strategically deployed, and ideally, should encourage the maintenance of the skills they support or replace. AAL technologies could be designed in a way that encourages a reevaluation of their installation, and makes any privacy intrusion revocable. This would involve reconceptualising AAL technologies as short-to-medium term interventions that could help or train an older person to relearn a particular skill, rather than permanent surveillance systems. Indeed, this is a radical vision, as it insists that older people not only can learn new things, but may enjoy this challenge, and that they deserve a stake in determining their future as much as their caring community. With a clear, positive end-goal in sight, this format could increase both the acceptability and usability of AAL technologies.

Finally, it is important to recognise that the global population of older adults is diverse, and harbour many intersections with gender, race, class, wealth, education, amongst many other variables. These intersections, as well as individual personal history, will shape an individual’s perception of privacy and their privacy vulnerabilities. This multitude of factors should be considered in any research programme, and recommendations should be qualified by the location and context of the research.

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