

Policy Brief: Privacy implications of technologies to address social isolation amongst older adults

MobileAge

1. Summary

- Currently we are observing a demographic shift towards older populations and increasing use of digital technologies by these citizens.
- Older adults have different privacy vulnerabilities than the general public.
- Current data protection regulations such as the GDPR do not address the privacy issues of older adults as they focus on the general cases – extensions or revisions may be necessary.
- Special attention should be paid to the implementation of data protection requirements for ICT aimed at older adults.

2. Background

An increasingly ageing population is not only a demographic change, but is also often framed as a challenge for health care systems, pension schemes, the stability of social care systems and so on. Accompanying this rhetoric is the vision that investments in techno-scientific innovations will alleviate the societal consequences of demographic ageing, providing a better life for older people (often by promising that elders will be able to live longer at home), and generating business activity and economic growth. Indeed, older adults are frequent users of ICT for a wide range of purposes.

While early ICT systems aimed at older adults often focused on sensing and actuation for care purposes, current applications are moving focus to data-driven models and AI. For example, projects such as Mobile Age aim to tackle social isolation by building sociotechnical systems for the seniors that make extensive use of profiles created from data collected by users, intermediaries such as carers and IoT devices.

Older adults are well known to have complex attitudes to technology. While people born in the information age are typically more at ease with using technologies, there is a broad diversity in use and perceptions of technology in older adults born outside the information age, ranging from adversaries

and early adopters to laypersons and non-users. This diversity contributes to the fact that older adults can experience privacy vulnerability to different degrees and at different times, depending on their circumstances.

3. Understanding privacy needs of older adults

In academic literature privacy theories typically try to fixate privacy in philosophical categories or abstract dimensions. However, these traditional privacy framings often do not fully account for the privacy issues, needs and perceptions of older adults. Older adults are different in their privacy needs due to a number of factors including a changing set of personal priorities and attitudes to technology, increased reliance on interdependencies in informal care settings, diminished autonomy (i.e. limited capacity for decision-making), and increased overt monitoring and surveillance.

Changing priorities

Studies looking at privacy perceptions of older adults have shown their specific characteristics that need to be taken into account when thinking about designing technologies or data protection. While older adults have very similar concerns about privacy or data sharing as the general public, their prioritisation is influenced by their circumstances and later life:

1. Many older adults “[...] tend to equate ‘private’ information with ‘secret’ information, which is not necessarily useful in protecting informational privacy or managing data in pervasive applications.” [1] In particular, they are quite unfamiliar with concepts of data sharing, aggregation or analysis, hence they tend to underestimate the potential risks of sharing data that they don’t conceptualise as secret.
2. While control and maintaining autonomy become a greater focus in later life [2], many older adults are less concerned about sharing sensitive data (such as health data, financial information, etc.) with family or carers. Hence maintaining autonomy and independence is seen as more important than (often intangible) data protection [3]. Further, due to different perception of time [4], which is less long-term future oriented, they have less interest in learning about abstract data

protection issues [5].

3. While usefulness is one important component in their choice of technology usage [6], social factors play an increasing role in legitimising privacy trade-offs in later life [7]. In particular, maintaining personal contacts and social connections become a deciding element. For example, some older adults reject online banking, not because it is conceptualized as not useful, but to keep social interaction with their local bank branch. Similarly, the rationale to use certain technologies is often motivated by emotional reasons: in order to improve communications with key relationships (e.g. with family members or friends) older adults are often willing to adopt complex technologies [1], [7].

The role of intermediaries

Generational change and the increasing digitalisation of all aspects of life have led to more older adults using technologies and technologies specifically developed for older people. Many older adults rely on a set of trusted intermediaries to help them use such technology. These intermediaries can range from friends, family or community members to informal and formal caregivers. This is problematic from a data protection point of view as the set of stakeholders who handle data or represent older adults widens. In particular, the set of stakeholders handling data is not necessarily legal guardians and it is often hard for data controllers and data processors to verify if consent has really been obtained – leading to the risk of data being illegally processed and privacy violations.

Diminished agency

In theory, older adults should consent to their data being collected, used or shared. Major issues arise when the ability to give consent is fading or reduced due to cognitive decline. For example, individuals with a light form of dementia might be perfectly able to give consent on one day, while their ability to give consent might be indistinct on other days. While there are well established legal frameworks for dealing with cognitive impairment such approaches are often heavyweight in nature. The gradual and changing nature of cognitive decline means that more lightweight mechanisms may be required when considering consent for these older adults. For developers, we note that the requirement for privacy notification and privacy information to be easily comprehensible is challenging as such notifications may cause distress for elders who don't feel com-

petent enough to judge the risks and consequently might keep them from using (particular features of) digital technologies.

Increased monitoring

Nevertheless, even with the ability to consent older people often find themselves in settings where other stakeholders (e.g. family or community members), might use systems on their behalf in good intention, but without (legal) consent. Especially in the context of care, either at home or in care home, privacy issues are multi-fold. In many care settings, older people are already more vulnerable to the invasion of their privacy, which often comes along with diminishing their agency and autonomy following the ideal of successful ageing and health interventions. This is also rooted in an increased biomedicalization of later life, which is characterised by: 1. increasing privatization of medical care, with for-profit companies and hospitals becoming increasingly important actors; 2. widespread expansion of illness categories into everyday life. This impacts elders especially as more and more healthy conditions are being labelled as disease or risky, which leads to elders will be increasingly managed and subjected to surveillance by professional and informal carers, tests, and clinical processes; 3. exposure to surveillance practices that are accelerated with the use of technologies, in particular IoT devices that allow for very fine-grained surveillance [8]–[10].

In summary, these specific privacy needs and motivations put older adults in a vulnerable situation, in which they are often not able to exercise their data subject rights and that dictate special care is taken when considering this group.

4. GDPR and the privacy of older adults

The GDPR largely aimed at giving data subjects and regulatory bodies more control over data, primarily in order to stop data brokers illegally selling data without people's knowledge. Article 5(1) created a set of principles when processing personal data: lawful; fair and transparent processing; purpose limitation; data minimisation; accuracy; storage limitation; and integrity and confidentiality. In order to process data, data controllers and data processors have to comply to these principles. One lawful basis of data processing is consent. However, as described above, older adults might not be fully able to or not be the ones giving consent. In addition to the obvious risks of processing data when consent is not clear, there is an additional danger that stakeholders retreat to other lawful reasons of data processing as defined

in Article 6(1). For example, in the situation of care settings, the need for help might be exploited to circumvent consent. In particular, research-based projects might argue for 'public interest' of the research results while commercial care providers might try to legitimise surveillance regimes with either their 'legal obligation' to provide care or the 'vital interest' of the data subject. Further, the effect of biomedicalization might easily subvert data protection principles like purpose limitation or data minimalization as any kind of data collection might be labelled as important to improve health or the quality of life of elders, leaving older adults with little or no control over their data or the surveillance regimes they are exposed to, stripping them of their rights for self-determination.

As we have argued above, older adults might be specifically vulnerable to privacy invasion and data protection issues. However, this is not reflected in the GDPR. The only mentioning of vulnerable persons is in Recital 75, where it identifies some risks to vulnerable individuals that data controllers and processors need to take into account, but without clear guidance or practical implementation of data protection regulations. One group is exempt from this, which are children. They have a special protective status in the GDPR and data collection and processing is limited. The provisions for children cannot be easily transferred to other vulnerable persons without undermining agency, rights and freedoms (such as self-determination). However, consideration should be given to adding provisions for vulnerable persons which balance paternalistic protection and self-determination.

5. Approach and Methods Used

We conducted a literature review comprising of privacy theory, articles on the special privacy issues of older adults and the socio-material conditions of later life. Paired with insights gained from the results of our own qualitative research as part of the Mobile Age project we analysed the GDPR and its recitals with respect to their support for the special requirements of older adults.

6. Concluding remarks

Older adults are increasingly reliant on digital technology. The privacy needs and data protection vulnerabilities of this demographic are different to the general public. We believe that these special needs of older adults or (other) vulnerable persons are not sufficiently recognised in the GDPR and that work is required to address this shortcoming. Our specific

recommendations are:

1. The GDPR should be reviewed in detail to determine what extensions are needed to meet the requirements of older adults.
2. The issue of consent should be explored in detail to develop an understanding of how to address the specific issues of the use of intermediaries and cognitive decline.
3. Guidelines should be established to help developers that are tackling data protection issues of older adults.
4. Systems processing sensitive data (e.g. health apps) should explore the possible use of tools to assess the ability to give consent.
5. In the case where consent is not the legal basis, privacy guidelines need to be developed and increased oversight is needed to protect the privacy of older adults.

In the meantime, ICT developers must take care to recognize the unique characteristics of senior citizens when creating solutions for this user group.

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This work was supported by Mobile Age and Connected Health Cities.

References

- [1] L. Lorenzen-Huber, M. Boutain, L. J. Camp, K. Shankar, and K. H. Connelly, 'Privacy, Technology, and Aging: A Proposed Framework', *Ageing Int.*, vol. 36, no. 2, pp. 232–252, Jun. 2011.
- [2] D. López Gómez, 'Little Arrangements that Matter. Rethinking Autonomy-enabling Innovations for Later Life', *Technol. Forecast. Soc. Change*, vol. 93, pp. 91–101, Apr. 2015.
- [3] K. Shankar, 'Pervasive Computing and an Aging Populace: Methodological Challenges for Understanding Privacy Implications', *J. Inf. Commun. Ethics Soc.*, vol. 8, no. 3, pp. 236–248, Aug. 2010.
- [4] L. L. Carstensen, D. M. Isaacowitz, and S. T. Charles, 'Taking Time Seriously: A Theory of Socioemotional Selectivity', *Am. Psychol.*, vol. 54, no. 3, pp. 165–181, 1999.
- [5] K. Shankar, L. J. Camp, K. Connelly, and L. Huber, 'Aging, Privacy, and Home-Based Computing: Developing a Design Framework', *IEEE Pervasive Comput.*, vol. 11, no. 4, pp. 46–54, Oct. 2012.
- [6] B. Knowles and V. L. Hanson, 'The Wisdom of Older Technology (Non)Users', *Commun ACM*, vol. 61, no. 3, pp. 72–77, Feb. 2018.
- [7] M. Kwasny, K. Caine, W. A. Rogers, and A. D. Fisk, 'Privacy and Technology: Folk Definitions and Perspectives', in CHI '08 Extended Abstracts on Human Factors in Computing Systems, New York, NY, USA, pp. 3291–3296, Apr. 2018.
- [8] K. Joyce and M. Loe, 'A Sociological Approach to Ageing, Technology and Health', *Sociol. Health Illn.*, vol. 32, no. 2, pp. 171–180, Feb. 2010.
- [9] A. Peine, A. Faulkner, B. Jæger, and E. Moors, 'Science, Technology and the "Grand Challenge" of Ageing—Understanding the Socio-Material Constitution of Later Life', *Technol. Forecast. Soc. Change*, vol. 93, pp. 1–9, Apr. 2015.
- [10] W. B. Mortenson, A. Sixsmith, and R. Woolrych, 'The Power(s) of Observation: Theoretical Perspectives on Surveillance Technologies and Older People', *Ageing Soc.*, vol. 35, no. 3, pp. 512–530, Mar. 2015.

Title: Mobile Age

Call identifier: H2020-INSO-2015: CNECT

Topic: INSO-1-2015: ICT-enabled open government

Total Budget: €2,923,993.75

Project duration: 36 months

Start Date: February 1st, 2016

Project Coordinator: LANCASTER UNIVERSITY (ULANC)

Consortium: TINGTUN AS (TT), AGE PLATFORM EUROPE AISBL (AGE), EVANGELISCHE STIFTUNG VOLMARSTEIN (FTB), GOVERNMENT TO YOU (GOV2U), INSTITUT FUR INFORMATIONSMANAGEMENT BREMEN GMBH (ifib), ARISTOTELIO PANEPISTIMIO THESSALONIKIS (AUTH), UNIVERSIDAD POLITECNICA DE MADRID (UPM), AYUNTAMIENTO DE ZARAGOZA (ZGZ), REGION OF CENTRAL MACEDONIA (RCM)

