Finnish Journal of eHealth and eWelfare

SCIENTIFIC PAPERS

VERTAISARVIOITU
KOLLEGIALT GRANSKAD
PEER-REVIEWED
www.tsv.fi/tunnus

Informed consent in the age of smart technologies

Jaana Leikas[1], Arja Halkoaho[2], Marinka Lanne[1]

[1] VTT Technical Research Centre of Finland Ltd., Tampere, Finland; [2] Tampere University of Applied Sciences, Tampere, Finland

Jaana Leikas, Ph.D., VTT Technical Research Centre of Finland Ltd., Visiokatu 4, FI-33720 Tampere, FINLAND. Email: jaana.leikas@vtt.fi

Abstract

Technology is increasingly being brought into the home care of older people. Digitalization is seen as an enabler for efficient and resource-saving operations. In the use of technology, informed consent is considered an ethical practice and part of a responsible home care service system. The aim of this article is to describe the problem of informed consent in situations where emerging technologies, such as artificial intelligence (AI) and mass data, are used as part of welfare services and home care for older people. The article discusses principles and ways to better integrate informed consent as an ethical practice into a responsible home care service system.

A qualitative study was carried out to gather the views of experts in the field of elderly care and ethics. A content analysis of a semi-structured focus group was used to explore perceptions of the changing nature of informed consent. According to our findings, the informed consent model requires updating. The key is to embrace the idea that consent is a living process designed to respect people's autonomous choices and protect them from risk. If the nature of the use of the data collected from individuals changes significantly in the future, the consent should also be updated to reflect this change. This aspect is important because new technologies will change the nature of the collection and use of the data. Mass data collection combines multiple databases so that the resulting data can be used even far from the original purpose or context in which it was collected. Therefore, consent should always be tailored to the context, allowing sufficient time for the person seeking and giving consent to clarify the content of the consent. This process highlights the importance of understanding the agency of the consent giver.

Keywords: informed consent, technology, older people, home care services

Introduction

The analysis of registers and electronic health record systems in research, healthcare, and government databases offers countless opportunities to answer important clinical and human well-being research questions. Add to this the possibility of using the vast amounts of data available in commercial databases, social media, and health data from different apps, wearable devices, and connected medical devices, and we are already talking about unprecedented visions of data exploitation [1]. A

new and growing trend is to bring data-collecting technology into the home of the elderly in the form of preventive monitoring, to gather information on the functional capacity and health status of older people [2].

The issue of informed consent and its importance have long been a topic of debate among researchers. Traditionally, informed consent has been requested in writing when the potential participant has been told in writing and orally about the facts related to the study [3]. However, it is notable that there are several ethical issues regarding informed consent in smart technologies, especially home monitoring in older age. These ethical concerns encompass facets such as autonomy, safety assurances, diminished human interaction, and equity [2].

Digital consent and mass data

The GDPR and the Data Protection Act guide treatment-related research. In social and healthcare services, personal data processing follows statutory grounds. Thus, explicit consent under GDPR is not mandatory from the client or patient. However, consent is necessary for implementing technology to preserve individual autonomy, particularly if it impacts privacy or everyday life significantly.

Technological and societal changes in information practices offer new opportunities for innovative implementation of informed consent. In traditional informed consent, consent is signed on a paper form, while digital consent can include electronic data, multimedia, video, and interactive computer interfaces [3]. An alternative way to sign consent can be by clicking on the consent form or by providing an electronic signature. In this context, the researcher's role may also differ from the traditional approach, as the researcher may be temporally or spatially distant from the participant. Consequently, it becomes evident that ensuring freedom of choice is even more challenging with digital consent compared to traditional consent. Nevertheless, it is important to emphasize that Finnish law governing medical research mandates written consent, although electronic signatures are permissible [4].

As the introduction of digital and electronic consent methods using smartphones, computers or wearable technology offers new opportunities for signing informed consent, it also requires reflection and recognition of the challenges. Interactions must be simple, informative about the risks and benefits, and understandable to users. Clicking on the agreement box without reading the information would be like signing a consent form without reading it. In line with De Sutter et al.'s findings [5], electronic informed consent exhibits the potential to augment the informed consent process in research when juxtaposed with conventional paper-based methodologies. It is imperative that ethical, legal, regulatory, and user interface considerations be thoroughly deliberated and integrated into forthcoming deployments of electronic informed consent.

Home monitoring of older people

Technology plays an increasingly important role in home care as a new operating logic to support older people’s independence [6]. One promising scenario is to use sensor technology in older people's homes, creating an intelligent environment that gathers data about changes in older person’s functional capacity much more accurately and reliably than short-term or random observations by individuals such as nearest ones, or home care professionals [7] (Figure 1). This data, along with a range of other devices that collect well-being data (such as smart mattresses and well-being wristbands), can be used to detect and visualize fluctuations in the resident's activity level. It complements traditional health

data and provides a holistic view of a person's daily performance. Together they can provide a comprehensive picture of a person's functional capacity and reveal acute or gradual changes. In Finnish care for the elderly, when using technology, careful consideration must be given to the distinction between primary and secondary uses of data. Data collected in the context of care provision may be repurposed, for instance, in research endeavors. Data gathered for care purposes, termed primary use, typically aligns with initial consent, while secondary use, such as for research, entails employing data for new objectives, often necessitating further consent or robust legislative measures.

In order to identify changes, algorithms are needed to draw a wide range of conclusions about a person's functional capacity based on the data collected by sensors. The analyses will result in suggestions for the person, their loved ones or health professionals to initiate the necessary treatment and rehabilitation. At best, such applications bring significant improvements in the sense of security and overall quality of life. On the other hand, they reduce the elderly person's control and prevent them from being constantly aware of the technology's performance.

The service scenario described above usually involves formal (and often informal) care and multiple stakeholders, raising questions of integrity, autonomy, and privacy. A variety of actors may be involved: home care staff, employees of a technology company, researchers, and representatives of the service organization. All should have a view on ethical issues and their solutions.

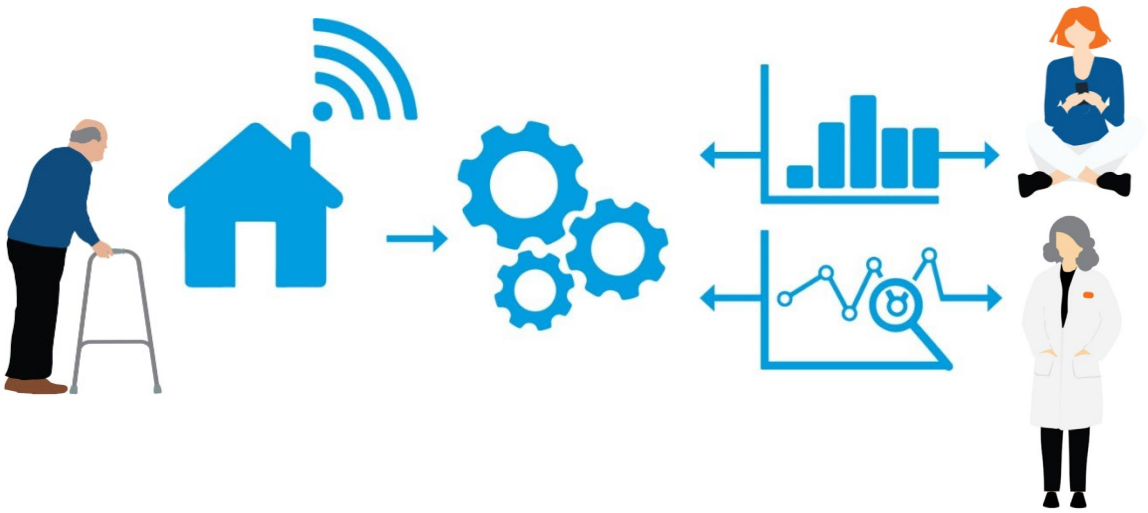

Figure 1. Home monitoring of older people.

The principle of autonomy

The principle of autonomy asserts individuals' right to make decisions for themselves, encompassing their capacity to plan and act towards their own goals [8]. It is a fundamental human rights consideration in technology design for older adults, emphasizing respect for their will and choices, even when conflicting with perceived best interests. Under this principle, technological interventions are justified only if older adults are provided with meaningful choices and comprehensive information about their options and consequences. This approach prohibits installing technology against an individual's will [3].

Respecting a person's autonomy entails refraining from overriding their will through coercion, threats, or restrictions on their freedom. In technology design for the elderly, this means ensuring that they are adequately informed to make decisions about adopting and using technology. Rauhala-Hayes suggests that this requires the elderly person to be competent, possessing cognitive skills such as receiving and understanding information, reflecting on issues based on this information, justifying decisions, and implementing them. Autonomy can be seen as the freedom to act according to one's wishes without interference from others [9]. Respect for human autonomy is a central ethical principle in European Union directives on emerging intelligent technologies. It emphasizes the moral imperative to honor individuals' autonomy and treat users as valued members of society in technology design [10].

Privacy encompasses four key dimensions: physical, social, psychological, and informational. Physical privacy, related to personal space and territory, is particularly significant in contexts like elderly home care. Social privacy involves managing social interactions, posing challenges in settings like nursing homes or technology-driven monitoring. Psychological privacy concerns individuals' control over cognitive and emotional behavior, values, and disclosure of intimate information. Informational privacy pertains to the confidentiality of personal data, with challenges including data anonymization and navigating complex regulatory frameworks. [11,12]. Confidentiality is rigorously regulated both at the national and European Union levels. Challenges in maintaining confidentiality include data anonymization, collaboration among stakeholders, complex regulatory frameworks, and the delicate balance between social benefits and privacy concerns [13].

The principle of Informed consent

Technology should be integrated into societal services and activities to enhance quality of life while minimizing harm. The approach to implementing home care technology varies depending on the society's adopted theory of justice, which may emphasize principles of social justice (such as equality and solidarity) or autonomy (focusing on individual freedom and choice). Rauhala-Heyes [9] explores technology adoption based on needs, advocating that introducing technology into an elderly person's daily life is justified if it helps fulfill fundamental rights-based needs.

Informed consent is essential for implementing and adopting any technology, especially concerning vulnerable older individuals. It affirms people's right to consent to the introduction and use of technology in their lives. This concept involves three key components: providing information about options and consequences, ensuring voluntary and uncoerced consent, and confirming the person's ability to reason the options [14,15]. To give consent, individuals must receive necessary information and understand the role and consequences of technology. The principle of informed consent also extends to

research and experimental use of assistive technology, where participants are presented with detailed information and asked to provide consent for new interventions, ensuring they understand the implications and risks involved [16].

Research objective and research questions

Our aim was to discuss the problem of informed consent and the use of consent in situations where emerging technologies, such as artificial intelligence (AI) and mass data, are used as part of welfare services and home care for older people. We wanted to address the following questions:

RQ1. What is the purpose of informed consent?

RQ2. What is its role in healthcare?

RQ3. Should the practice be embedded not only in medical research but also in data collection situations for AI-based applications, such as home care for the elderly, where various monitoring and data collection technologies are becoming more common?

As there are already significant challenges in applying informed consent and putting it into practice, even in traditional research, let alone in implanting consent into the technology needs of home care, it is important to consider the situations in which consent is appropriate.

RQ4. Where should it be embedded?

RQ5. How should consent be implemented in an ethically sustainable way?

Research methods

A qualitative study was carried out in Finland to gather the views of experts in the field of elderly care and ethics. Our methodological approach can be characterized as documentary and discourse research [17,18]. We explored the key conceptions of informed consent in the research literature [19] and used discourse to consider the key paradigmatic case of home care for older people.

A semi-structured focus group method [20] was used to explore perceptions of the changing nature of informed consent. This qualitative co-design method is based on a semi-structured group interview technique that facilitates direct interaction, generates new insights, and encourages participants to compare different perspectives [21]. The method was chosen to gain insight into the collective views of the experts about the changing context of informed consent, as well as the experiences of the participants. The pre-set questions addressed in the focus group were:

What ethical challenges are identified in the consent process?

How could these challenges be approached?

What values need to be protected and how are these values decided?

How can ethical reflection be put into practice?

What solutions are proposed?

We invited a group of academics, 6 women and 3 men, working on ethics, regulation and aging research to join the discussion. The group consisted of researchers (research director, associate professors, senior researchers, post-doctoral researchers, doctoral students, project manager) from six research organizations, with different backgrounds, including social sciences, aging, ethics, regulation, and technology for older people. Consent was sought and obtained from the participants to use the material collected for publication purposes, and permission was also recorded.

The discussion session took 2 hours and 30 minutes. The moderator encouraged the group to produce forward-looking ethical debates. Through dialogue, we raised issues of consent and articulated them. In addition, the group explored the potential positive ethical implications for the development of ethically and socially sustainable technology services and the associated model of informed consent. We wanted to discuss how the principle of informed consent could be applied in cases involving new technologies combining AI and Big Data. Is the traditional written informed consent process at all appropriate for these research paradigms? We also wanted to consider the role of informed consent in situations where technology is left permanently at the individual's home. As noted, such use situations include sensor technology installed in the home as a home care service to monitor an older person's functional capacity.

The focus group discussion was recorded and transcribed. This was followed by a qualitative content analysis which allowed the raw data collected to be summarized into themes based on valid reasoning and interpretation. The process uses inductive reasoning, which allows themes and categories to emerge from the data through careful examination by the researchers. By examining themes and meanings, researchers can understand social reality in a subjective but scientific way [22]. The researchers first went through the gathered material individually and drew conclusions about the research questions, and finally unpacked and summarized the results together.

Results

In the following, we present the main topics and respective findings based on a qualitative content analysis of the focus group discussion. The unedited quotes from the group discussion are shown in italics in the indented paragraphs.

Consent is about realizing the right to self-determination (RQ1-2)

Consent has traditionally been understood as an important part of the regulatory framework that limits data collection and ensures respect for individual autonomy and freedom. The focus group discussed that consent requires that the individual is informed of his or her options and the consequences of each option, that consent is voluntary and not coerced, and that the individual has the power to decide on the options. The person must therefore have the necessary information to give consent. In health research in particular, the assumption has been made that consent is based on an understanding of the risks associated with the research. The same applies to technology: for example, a person must be able to understand the significance of the technology to be installed in the home and the consequences of their decision.

> *Consent is based on a voluntary choice and decision by the individual. What does voluntary mean? How can the person giving the information ensure that the consent is valid and that the person giving the consent does not have 'diminished capacity of self-determination'?*

Consent is a form signed by the person. By signing the form, the person gives his or her specific consent to the collection and use of the data or research material, and indicates that he or she understands what he or she is participating in. Consent underlines the right of the individual to refuse, for example, to participate in the research, and the right to withdraw from the research.

The consent form should indicate the purpose of the data collection, and how it will proceed, as well

as any risks to the individual and the opportunity to ask questions. The information in the consent form should be discussed with the person or otherwise made sure that the person understands what is stated in the form.

It is important that consent is signed voluntarily, without any sense of coercion or pressure. Therefore, for example, the data collector or the researcher should not be in a position of authority over the person. For example, the keeping of a register is usually required by law and the authority cannot base the processing of data on the consent of the data subject.

> *This is interesting and somewhat confusing. In other words, consent is not voluntary if the data are collected for the purposes of the controller and by a public authority. In what circumstances, then, should the person giving consent be able to withdraw it?*

Case home care (RQ3-4)

Informed consent must be obtained in a way that respects the individual's right to self-determination. No one should be unnecessarily persuaded or coerced into using a device, for example by threatening institutionalization. The advantages and disadvantages of the use of devices must be considered together, but ultimately older people should have the right to decide for themselves where technology is used and whether it is used at all. They have the right to decide how personal information about themselves is used and to protect their physical, psychological, and social intimacy.

Freedom and autonomy are closely linked to the right to self-determination. There is often a certain stigma attached to aging, a suspicion that a person is unable to weigh up options and make choices for themselves, with relatives or care givers trying to make decisions on their behalf. For people with memory problems, the quest for autonomy is often linked to issues of security and privacy.

A person needs to have sufficient knowledge and understanding of the meaning and use of the devices installed in their home to support their own judgment and decision making. The installation of a device must be based on consultation of the person's needs. This, together with the use, maintenance, and cost of the equipment, must be explained in sufficient detail to enable the person to understand the information.

Older adults, like all citizens, should have the right to choose the technology they accept in their daily lives. These choices may relate to the quality, quantity, and purpose of the technology. However, for older people, the issue of combining autonomy and care is an ethical question that often arises. These problems are most evident in the case of people with memory problems. For example, everyone has a right to privacy, but when a person's memory is impaired, it can be difficult to discern what is best for him or her.

It can be difficult to obtain informed consent for people with memory problems, even if the person has been adequately informed. Also, the consent can be difficult to interpret correctly. The memory disease may have progressed to the point where the person is no longer able to understand the function of the equipment. He or she may indicate consent to the devices but may mean something else. Therefore, instead of informed consent, it may be worth considering some other way of ensuring the person's consent to the use of the technology. In such a situation, a possible approach could be, for example, to refer to the person's life history and, from this perspective, to consider what the person would have chosen to do in that situation, before becoming ill [16].

Alongside memory loss, the question of the principle of protection of the individual, which can be seen as a counterpart to respect for the right to self-determination, may arise in the care of the elderly. In line with the principle of protection, it can be assumed that caregivers, for example in home care for the elderly, have a duty to protect the fundamental rights of the elderly person. This protection can be applied from the perspective of the individual's personal interest and freedom and can be seen as a right to protection against violations of their rights by third parties or by the elderly themselves. In this case, decisions relating to technology should be made in the individual's best interests [23].

At some point the responsibility for making decisions about the introduction and use of technological devices will shift from the elderly to informal or formal caregivers. In this case, it is important to clarify who will decide when this point is reached.

> *It is a relief to remember that the authority is always acting under its official responsibility, and that the action must be organized in accordance with the law.*
>
> *The public authority is not necessarily the only one processing and using the information. Increasingly, the data processor is a private company, and the role of the public authority is to act as a subscriber to the data processed. If the authority discloses information to private actors, are these actors also subject to the same liability?*

Obtaining or even asking for informed consent may not always be straightforward. The home care process should therefore take time to discuss the risks and benefits of technology and the importance of informed consent with the client. The uncertainty of obtaining consent and making a voluntary decision based on it has been seen as problematic, particularly for people with memory problems.

> *It is not always easy to ensure that a person has understood what they have been told. If they have not, the decision can be taken jointly by all stakeholders - the older person, their loved ones and care staff. What if the person has no relatives or friends? Is this where the guardian comes in?*

Because the consent process emphasizes cognitive abilities, it often excludes people with memory problems from studies. A key question here is what an alternative condition for a signed consent form could be to collect data in the most ethical way possible.

Mass Data - How do you know what you agree to? (RQ5)

The increasing collection and analysis of mass data in preventive health care and home care brings new perspectives to the concept of informed consent. The essential question is whether true informed consent is even possible in the era of Big Data and artificial intelligence, where vast amounts of data are collected [24]. Traditionally, consent is given for one specific research or technological use, not for several different uses of data. Mass data collection and aggregation, on the other hand, aims to combine numerous databases so that the resulting data can be used even far from the original purpose or context in which it was collected [25]. In this case, the individual cannot know to which use of the data he or she gives his or her consent. "Informed" consent is therefore impossible because even the data collector may not know in advance all the purposes for which the data will be used.

> *The new wellbeing services counties should find out where all the health data collected*

from people will be disseminated and who will use it. Will the data be collected to promote public health or individual well-being?

From a privacy perspective, the situation may also change when databases are merged. Current methods of data anonymization may not be sufficient to ensure that health data shared by individuals remain anonymous in the future. When databases are merged, data de-anonymization methods may make it possible to re-identify individuals based on the information shared.

If a person changes their mind, and even if they are promised that they can withdraw their consent later if they wish, the consent data may already have been entered into the systems in an anonymized form. Once anonymized, the individual cannot withdraw consent or request the deletion of their data. This must be explained in the information notice to data subjects. This is standard practice in research.

Secondary use of health data is increasing, and information is flowing to many parties. More and more data are collected on healthcare customers proactively, for preventive healthcare. The reason for the length of research communications is that they must tell the subject everything that is relevant to the research. But is this always possible? So perhaps informed consent in healthcare is not such a good way to collect data, and this is a much-debated issue in the use of health data. At least that consent should only be sought for a specific purpose or purposes.

The world is constantly changing with the development of artificial intelligence and technology. Values change over time and in society. How do they evolve and how does our thinking about values evolve? What does human autonomy mean, which has a huge number of different dimensions as a physical and mental experience? Will our understanding of it remain the same in 10 years' time? What silent signals are circulating in our time? How could they be better considered in the care of the elderly? What kind of skills are needed to do this?

The results of our research show that the debate on informed consent is easily left ambiguous. On the other hand, it is easy to extend it in many directions. This study sought to examine the issue from pre-defined perspectives. The dialogue was moderated in an open and informed manner, exploring different perspectives in an atmosphere of mutual respect between researchers.

We summarize the main observations that emerged from our focus group discussion as follows:

1. The ethical and practical challenges associated with the secondary use of health data must be opened to debate when considering the advantages and disadvantages of using mass data. A generally accepted, trust-based approach to assessing and governing the ethicality of further data use needs to be built.

2. Where the principle of informed consent is chosen as an approach, consent must be developed as a process.

3. The home care process should include time to discuss the risks and benefits of technology and the meaning of informed consent with the client.

4. Ethical evaluation and governance of home care technology should be an ongoing activity in our society.

5. The changing values of society must be discussed and examined proactively and openly, as values influence how and by what means different technological solutions are accepted and what is ethical to ask for consent in the first place.

Discussion

Home care technology, such as monitoring systems, has been assessed to increase the quality of life of older people living at home. However, the use of technology, especially AI, raises ethical issues related to the collection and sharing of mass data, privacy, confidentiality, data security and protection, prevention of harm and the realization of the right to self-determination [2,13,26-29]. Factors affecting the health status of older people, such as mobility impairments and dementia, may increase concerns about ethical issues when using technology [30].

The right to self-determination of the elderly is promoted through the practice of informed consent. This practice has been introduced specifically for research purposes. In the context of home care, the principle should be a prerequisite for the adoption and acceptance of technology. It requires that the person is informed of his or her options and the consequences of each option, that consent is voluntary and not coerced, and that the person has the capacity to consider the options presented [3,16].

Technology and informed consent in older people's homes should be seen as a cross-cutting issue, guided by a shared goal of well-being for older people. Co-development should be used to find solutions that allow the different actors' competences and perspectives to be made visible and coordinated. We align with the findings of De Sutter et al. [5], affirming that electronic informed consent has the potential to improve the research consent process, even among older individuals. However, it is imperative to comprehensively address and integrate ethical, legal, regulatory, and user interface considerations for the future implementation of electronic informed consent.

Our aim was to bring together researchers to discuss informed consent and emerging smart technologies, to gain a better understanding of how informed consent practices might need to change. In further research, we believe it is important to include not only researchers in the discussion, but also those who would implement the technology and those who would be affected by such decisions: end-users (older people) as well as service providers and care professionals. The development of a technology-related culture requires a continuous debate on values and attitudes, building knowledge through trusted networks, multi-professional cooperation, communication, and sparring. Ethical discussions should be part of a multidisciplinary dialogue that anticipates the impact of technological innovations and their positive and negative consequences [31]. This is particularly important when technology is used in decision-making for vulnerable people.

Conclusion

Informed consent should be seen as a living process. Obtaining consent from a research subject for the collection of research data or from an elderly person for the use of technology in home care services does not just mean signing a permission slip. The key is to embrace the idea that consent is not a one-stop shop, but rather a living process designed to respect people's autonomous choices and protect them from risks. It is thus not a "one size fits all" method and should always be tailored to the context so that the person seeking and giving consent must have sufficient time to clarify the content of the consent. This process emphasizes the

importance of understanding the agency of the consent giver. At the same time, as circumstances change, consent may also need to be reconsidered. If the nature of the use of the data collected from the individual changes substantially in the future, for example as technology develops, the consent collected from the individual should also be updated to reflect this change. For example, if artificial intelligence technology would allow the data already disclosed to be processed in a new way or for a new purpose, the issue of consent should be reviewed before the new use of the data.

Further research is needed on the freedom of choice in the adoption of smart technologies for home care of older people and how it can be expressed. Freedom means autonomy in a sense that the person is not only free to choose between different alternatives, but also that the conditions of choice are not manipulated. Ideally, autonomous choices of ends and actions are freely made. Closely linked to this is the question of how to enable the conditions that maintain and enable human equality, which is a prerequisite for freedom.

Future research should also focus on the use of digital consent methods in the context of Big Data collection and the ethical issues involved, particularly from the perspective of older people. It is also an important topic for future discussion how consent could be 'informed' if the data subject does not know at the time of data collection for what possible future uses the data are being collected. Future research would benefit from including the views of both clients and home care professionals.

Conflict of interest

The authors have no conflict of interests.

References

[1] McConnell MV, Ashley EA. Mobile Health Research — App-Based Trials and Informed Consent. N Engl J Med. 2017:376(9):861-863. https://doi.org/10.1056/NEJMra1603773

[2] Zhu J, Shi K, Yang C, Niu Y, Zeng Y, Zhang N, Liu T, Chu CH. Ethical issues of smart home-based elderly care: A scoping review. J Nurs Manag. 2022 Nov;30(8):3686-3699. https://doi.org/10.1111/jonm.13521

[3] Grady C, Cummings SR, Rowbotham MC, McConnell MV, Ashley EA, Kang G. Informed Consent. N Engl J Med. 2017 Mar 2;376(9):856-867. https://doi.org/10.1056/NEJMra1603773

[4] Finlex. Medical research Act 488/1999. 488/1999 English - Translations of Finnish acts and decrees. Ministry of Social Affairs and Health, Finland; 1999. Available from: https://www.finlex.fi/en/laki/kaannokset/1999/19990488

[5] De Sutter E, Zaçe D, Boccia S, Di Pietro ML, Geerts D, Borry P, Huys I. Implementation of Electronic Informed Consent in Biomedical Research and Stakeholders' Perspectives: Systematic Review. J Med Internet Res. 2020 Oct 8;22(10):e19129. https://doi.org/10.2196/19129

[6] Miettinen J, Mäkinen M, Leikas J, Jutila T, Veko T. Vastuullinen toiminnanohjausjärjestelmän kehittäminen kotihoidossa. FinJeHew. 2020 Mar 5;12(1):70–83. https://doi.org/10.23996/fjhw.77883

[7] Leikas J, Launiainen H. (eds.). Anni ja Onni. Huomaamaton teknologia arjen apuna. Miina Sillanpään Säätiön julkaisusarja B:41. Miina Sillanpään Säätiö; 2016. Available from:

https://www.miinasillanpaa.fi/wp-content/uploads/2014/12/Anni_ja_Onni_sisus_www_final.pdf

[8] Friedman B, Kahn PH Jr, Borning A. Value sensitive design and information systems. In: Zhang P, Galletta DF (eds.). Human-Computer Interaction and Management Information Systems: Foundations. 1st ed. Routledge; 2006. https://doi.org/10.4324/9781315703619

[9] Rauhala-Hayes M. Ethics of care work. In: Bjorneby S, van Berlo A (Eds.). Ethical issues in use of technology for dementia care. Knegsel: Akontes Publishing, 1997. p. 73–86.

[10] European Parliament. EU AI Act: first regulation on artificial intelligence. European Parliament; 2023 [cited 03.06.2024]. Available from: https://www.europarl.europa.eu/news/en/headlines/society/20230601STO93804/eu-ai-act-first-regulation-on-artificial-intelligence

[11] Leino-Kilpi H, Välimäki M, Dassen T, Gasull M, Lemonidou C, Scott A, Arndt M. Privacy: a review of the literature. Int J Nurs Stud. 2001 Dec;38(6):663-71. https://doi.org/10.1016/S0020-7489(00)00111-5

[12] Leino-Kilpi H, Välimäki M, Dassen T, Gasull M, Lemonidou C, Scott PA, Schopp A, Arndt M, Kaljonen A. Perceptions of Autonomy, Privacy and Informed Consent in the Care of Elderly People in Five European Countries: general overview. Nursing Ethics. 2003;10(1):58-66. https://doi.org/10.1191/0969733003ne571oa

[13] Nurmi SM, Kangasniemi M, Halkoaho A, Pietilä AM. Privacy of Clinical Research Subjects: An Integrative Literature Review. J Empir Res Hum Res Ethics. 2019 Feb;14(1):33-48. https://doi.org/10.1177/1556264618805643

[14] Ienca M, Jotterand F, Vică C, Elger B. Social and Assistive Robotics in Dementia Care: Ethical Recommendations for Research and Practice. Int J of Soc Robotics 2016;8:565–573. https://doi.org/10.1007/s12369-016-0366-7

[15] Tori K, Kalligeros M, Shehadeh F, Khader R, Nanda A, van Aalst R, Chit A, Mylonakis E. The process of obtaining informed consent to research in long term care facilities (LTCFs): An Observational Clinical Study. Medicine (Baltimore). 2020 May 22;99(21):e20225. https://doi.org/10.1097/MD.0000000000020225

[16] Downs M. The emergence of the person in dementia research. Ageing Soc. 1997 Sep;17(5):597-607. https://doi.org/10.1017/S0144686X9700665X

[17] Boven WR. Engineering Ethics. Springer; 2009.

[18] Denzin N, Lincoln Y (Eds.). The SAGE Handbook of Qualitative Research. Fifth Edition. Sage; 2018.

[19] Beauchamp T, Childress J. Principles of Biomedical Ethics. Oxford University Press; 2002.

[20] Gill P, Stewart K, Treasure E, Chadwick B. Methods of data collection in qualitative research: interviews and focus groups. Br Dent J 2008;204:291–295. https://doi.org/10.1038/bdj.2008.192

[21] Parker A, Tritter J. Focus group method and methodology: current practice and recent debate. International Journal of Research & Method in Education. 2006;29(1):23-37. https://doi.org/10.1080/01406720500537304

[22] Zhang Y, Wildemuth BM. Qualitative Analysis of Content. In: Wildemuth BM (Ed.). Applications of Social Research Methods to Questions in Information and Library Science. Second Edition. Bloomsbury Publishing; 2017. p. 318–329.

[23] Mäki-Petäjä-Leinonen A. Mitä on vanhuusoikeus. In: Mäki-Petäjä-Leinonen A, Karvonen-Kälkäjä A. Vanhuusoikeuden perusteet. Alma Talent; 2017.

[24] Froomkin AM. Big Data: Destroyer of Informed Consent. Yale Journal of Health Policy, Law, and Ethics. 2019;18(3):27-54.

[25] Mittelstadt BD, Floridi L. The Ethics of Big Data: Current and Foreseeable Issues in Biomedical Contexts. Sci Eng Ethics 2016;22:303–341. https://doi.org/10.1007/s11948-015-9652-2

[26] Milossi M, Alexandropoulou-Egyptiadou E, Psannis KE. AI Ethics: Algorithmic Determinism or Self-Determination? The GPDR Approach. IEEE Access. 2021;9:58455-58466, https://doi.org/10.1109/ACCESS.2021.3072782

[27] Rosenlund M, Kinnunen UM. Ikäihmisten kokemukset terveydenhuollon sähköisten palvelujen käytöstä ja kokemusten hyödyntäminen palvelujen kehittämisessä – kuvaileva kirjallisuuskatsaus. FinJeHeW. 2018;10(2-3):264-284. https://doi.org/10.23996/fjhw.69136

[28] Leikas J, Sigfrids A, Stenvall J, Nieminen M. Good Life ecosystems - Ethics and responsibility in Silver Economy. In: Rauterberg M. (Ed.). Culture and Computing. HCII 2020. Lecture Notes in Computer Science, vol 12215. Springer, Cham; 2020. p. 105-122. https://doi.org/10.1007/978-3-030-50267-6_9

[29] STM. Laatusuositus hyvän ikääntymisen turvaamiseksi ja palvelujen parantamiseksi 2020–2023 Tavoitteena ikäystävällinen Suomi. Sosiaali- ja terveysministeriön julkaisuja 2020:29. Sosiaali- ja terveysministeriö ja Suomen Kuntaliitto; 2020. http://urn.fi/URN:ISBN:978-952-00-5457-1

[30] Lancioni GE, Desideri L, Singh NN, O'Reilly MF, Sigafoos J, De Caro MF, Taurisano P. Use of technology to sustain mobility in older people with cognitive impairment and dementia: a scoping review. Disabil Rehabil Assist Technol. 2023 Jul;18(5):635-649. https://doi.org/10.1080/17483107.2021.1900935

[31] Lanne M, Leikas J. Ethical AI in the re-ablement of older people – Opportunities and challenges. Gerontechnology. 2021;20:2. https://doi.org/10.4017/gt.2021.20.2.26-473.11