Ethics assessment in different fields

Social Gerontotechnology

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Annex 2.c.3

Ethical Assessment of Research and Innovation: A Comparative Analysis of Practices and Institutions in the EU and selected other countries

Deliverable 1.1

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1 Ethics assessment of (Social) Gerontechnology

1.1 Basic description of the field

Gerontechnology is an inter-discipline that discovers and deploys technology on behalf of people in their maturing years. Gerontechnology is a multidisciplinary and interdisciplinary research and development field that benefits from and supports inclusive design research. The term gerontechnology is a composite of two words: “gerontology”, the scientific study of ageing, and “technology”: research, development and design of new and improved techniques, products, and services\(^1\). It is concerned with research on the biological, psychological, social, and medical aspects of ageing. Technology includes all branches of relevant scientific endeavour: physical, chemical, civil, mechanical, electrical, industrial, information, and communication engineering\(^2\).

Gerontechnology is established in the 1990s, and has become an outstanding field in customising technology to individual needs of older people. The subject matter of technology and ageing has been on the research agenda for decades, already. Before 1990, the combined consideration of technology and ageing focused on human factors (ergonomics) for ageing persons and on assistive technology for people with physical restrictions. This reflected the general attitude at the time that the aged people and the handicapped could be viewed as a single group of people dependent on help and care. From the early nineties, the scope widened substantially, as the emerging concept of successful ageing was brought into discussion. Instead of using the term ‘the handicapped’, the term ‘people with a certain restriction’ was used, to indicate that it is not the particular restriction that defines preferences, ambitions, and identity of a person, whether young or old\(^3\).

Today, gerontechnology concentrates on the extent to which different restrictions can be compensated for by specific technologies. It is interested on recognising the dynamic and widely varying nature of the ageing process and developing methodologies in which ageing persons play an active part. It combines the sciences underpinning ageing (gerontology) and technology to achieve optimal technical living and working environments for ageing and aged people\(^4,5,6\). In fact, gerontechnology approach addresses all technology that is useful for daily activities of all phases of the human life span, provided that it is targeted at a high quality of


\(^{2}\) Ibid.


life of older persons. Gerontechnology aims to provide a good life with the help of technology up to a very high age and includes assistive technologies and the support of care for individuals in their dwellings. Gerontechnology research relies on laboratory based experimental studies of the ageing process and of technology use, as well as field-based studies that attempt to implement technological solutions to mitigate age-related decline in abilities.

Gerontechnology addresses five domains of daily life: 1) Health and self-esteem, 2) home environment and daily living, 3) mobility and transport, 4) information, communication and governance, 5) work and leisure. According to Bronswijk et al., it recognises four goals of technological intervention in these domains of human daily activities. They are (i) enrichment and satisfaction (attaining the highest quality of life), (ii) prevention and engagement (delaying or preventing development-associated physiological and behavioural changes that restrict human functioning), (iii) compensation and substitution (in strength, perceptual-motor functioning or cognition), and (iv) care support and care organisation. Based on the five domains of daily life and the four goals to be served by technology Bouma, Fozard and Bronswijk have introduced an impact matrix, in which various technology-defined products and services display their function for ageing people. For each of those, the systems approach helps to define what functional outcome is wanted, what the requirements are for the technology, for the user interface and for the necessary human learning, given the important notion as well as the inescapable fact that the present depends on the past.

The technology disciplines that address gerontechnology and support good ageing come from the field of communication and information, architecture and building, mechatronics and robotics, design and ergonomics, chemistry and biochemistry, and business management.

The context of the provision of gerontechnologies and services can be differentiated into state, market and non-profit organisations. The “state” reflects principles of social justice and welfare standards guaranteed for all and administered by some publicly financed system. The “market” refers to mechanisms of supply and demand allocating goods and services within a more or less liberal framework of regulations for a fare exchange. In the case of

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gerontechnology, the market is called “silver markets” or “silver economy” indicating the special nature of the target group. The “non-profit organisations” stand for associations providing goods and services for members or target groups on the basis of solidarity with those in need and of trust between providers. The characterisations reveal that social values and ethical principles are implicitly involved in each system of care provisions.

The solutions of gerontechnology include solutions for vulnerable older people. Ethical issues of gerontechnology arise in the contexts of use rather than through the characteristics of the technology as such. The solutions often involve formal care and different authorities. Hence, they have to fit in with the specific cultural, economic, political and legal contexts of different societies.

1.1.1 Underlying concepts of ageing

The four path breakers in gerontechnology, Herman Bouma, James L. Fozard, Don G. Bouwhuis and Vappu Taipale discuss in their valuable key publication ‘Gerontechnology in perspective’ different aspects of good ageing and the related disciplines. They argue that good ageing rests on the following five individual pillars: healthy nutrition, daily physical exercise, regular cognitive and mental activities, maintaining social contacts inside and outside the family, and keeping an active interest in society. These largely correspond to three main academic disciplines that in combination address human ageing: physiology including nutrition, psychology including social psychology, and sociology including demography. To these Bouma et al. add medicine, including rehabilitation for dealing with restrictions and disease.

‘Active ageing’ is a theoretical perspective, which needs to be discussed when studying gerontechnology. It investigates the active way of living associated to ageing, i.e. keeping up physical and mental capacity, social relations and participation. The concept of active ageing was launched at the Second World Assembly on Ageing in Madrid in 2002, and is getting more and more relevant as the number of persons over the age of 60 increases. It is estimated that in the world this population has reached the number of around 600 million people, and this number keeps increasing. In Europe, it is expected that, by 2020, more than 25% of the citizens will be aged more than 60.

The ‘active ageing’ theory has got more support than the so-called Disengagement theory and its latter modification the Gerotranscendence theory. Gerotranscendence means the paradigm change in the flow of life course, through which an ageing person reconstructs a totally new perspective to life. Following this view, a human being slowly separates from his or her social rights and responsibilities giving thus space to younger people. Retirement, for

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18 Ibid.
example, can be seen as a mutual withdrawal between the individual and society, and as beneficial for both the individual and society. The theory has been criticised of not taking into account that older people may not want to disengage from society.

The idea of active ageing, on the other hand, has been supported by many, and not least because of its social emphasis. In contrast to the Gerotranscendence theory, the emphasis in this approach is in the activity and participation of older persons. It is understood that the longer a person can stay active, the less she or he is expected to demand services from the society. Here, technology can play a significant role. On the other hand, stressing activity includes negative sides also if considered from an ethical point of view. It should be understood that dependency from other people is a human right, and older persons should be able to place their trust on it when their own capacities are not sufficient any more.

WHO aims at improving the health and quality of life of people of the third age (55–80) by carrying out the Healthy Ageing program\textsuperscript{21}, which defines the concept of Active Ageing as follows: “Active Ageing is the process of optimising opportunities for health, participation and security in order to embrace quality of life as people age”. When active ageing is supported both in an individual and population level, there will potentially be\textsuperscript{22}:

- Fewer premature deaths in the highly productive stages of life,
- Fewer disabilities associated with chronic diseases in older age,
- More people enjoying a positive quality of life as they grow older,
- More people participating actively as they age in the social, cultural, economic and political aspects of society, in paid and unpaid roles and in domestic, family and community life,
- Lower costs related to medical treatment and care services.

Active living improves mental health and often promotes social contacts. Being active can help older people remain as independent as possible as long as possible. It can also reduce the risk of falls. There are thus important economic benefits about older adults being active\textsuperscript{23} (WHO, 1998).

The phenomenon of ‘successful ageing’ has been under constant investigation and theoretical development\textsuperscript{24,25}. Today, successful ageing is defined by three main dimensions and the model emphasises that all of these criteria must be satisfied in order to achieve the goal of successful ageing:

1. An ageing person has good health and physical functional capacity. This means that a person has been able to avoid the decline in these areas and is able to constantly develop his or her physical activity.

\textsuperscript{22} Ibid
2. An ageing person should constantly take care of the cognitive abilities such as the faculty of problem solving, conceptual processing and linguistic abilities.

3. An ageing person takes actively part in social activities such as social networks, meaningful activity, hobbies and communities.

In this model, successful ageing is seen as the main responsibility of the individual, and structural barriers to the achievement of a good quality of life are not addressed. Social expectations can open or close opportunities for older adults in employment, education and leisure. There is also a danger of confining successful ageing only to people in good health, although dignity, respect, autonomy and social engagement should also be seen as essential ingredients of the ‘good life’, irrespective of the health and mental condition of older people.

The notion of ‘robust ageing’ entails all the above discussed notions of ageing. Robust ageing became in the 80’s and 90’s a sort of an umbrella notion for different notions related to strengths, capabilities and positive sides of ageing. The researchers (such as Garfein and Herzog26, 1995) described the main dimensions of robust ageing with such concepts as functional status (physical capacity), affective status (state of mind and mood), cognitive status and productive participation.

The notion of ‘courageous ageing’ is forward-looking. Courageously ageing persons are those who have focus, visions and who like to take risks. A person ageing courageously is a constantly developing individual and ready to meet challenges in all periods of life. Tirrito27 (2003) points out that the search for successful ageing is in the ability to be a courageous ager and describes the courageous ager as experiencing four pinnacle stages. These are transience, early old age, middle old age, and old-old age. He sums up the requirements for people in these stages to achieve their goals for ageing successfully. In the early stage, the complacency phase, or middle age (45–54), the individual should be deepening attachments and connections to the social world and developing a feeling of satisfaction. In the transience phase (55–64), the major task is to begin to feel free from many of the social restraints of the early years and to search for new heights of experience. The task is to achieve inspiration or suffer the consequences of apathy. In early old age (65–74), the task is to develop wisdom, or the ability to transcend conventional thinking and develop one’s own world view. Failure is associated with decline (wisdom development versus degeneration). In this stage, the mind takes precedence over factors related to physical functioning, and it is the spirit of the individual that helps prevail over difficulties. In middle old age (74–85), the engagement phase, there is the challenge to remain engaged in life in spite of the many changes in social roles and health status. Engagement versus detachment presents the challenge in finding new ways of self-expression. In old-old age (85 and older), the courageous agers are those who live

in the present because they have been able to make peace with the future. They remain in charge of their own lives and are in control even of their own dying.  

‘Productive ageing’ is an approach which aims to break different stereotypes of ageing and old age. It underlines the importance of ageing people as active and productive citizens of the society, in contrast to ageism. ‘Ageism is age-based discrimination, associated with the changes that ageing brings to the functional capacities of people. In this view, ageing is seen as the main and only characteristic which goes beyond all other aspects, such as values and inquisitiveness.

Gerontechnology wishes to serve positive goals of older people, add quality to their lives, and apply the best available knowledge, expertise, and methods available for achieving these goals. Herman Bouma discusses professional ethics in gerontechnology, and highlights core questions from the point of view of ethical assessment: What are the goals and ambitions of older persons and what are their physical, mental, and social situations and care environments? Bouma goes on arguing that although dignity, autonomy, and privacy are rather universal values, ageing people are heterogeneous in many respects including ambitions, education, culture, former profession, family situation, housing, health, and wealth or poverty. How to make sure that our professional actions will prove beneficial to the intended part of the ageing population without detrimental effects on themselves and others.

Bouma leans on three concepts of individual and socio-cultural lags which characterise older people in a rapidly changing technological environment:

- ‘Technology generation’ which states that the types of technology one grew up with in one’s formative years (until 30 years) remain the permanent basis on which later technologies can only be added without really replacing them. Evidence for this concept comes from user-interface studies.
- ‘Temporal discounting’ indicates the decrease with future time of subjective values attached to products and services if their realisation shifts further into the future.

37 Ibid.
‘Technology acceptance’ increasingly unravel factors that advance or hamper the use of new products and services by ageing persons.\(^{38}\)

### 1.2 Values and principles

As technology in general, either gerontechnology cannot be seen as value neutral\(^{39}\). Values are incorporated into each realised technical device or process. They are used to define the goal-function of the technology. However, they can also be found in other aspects such as tolerance of the device, i.e. the margins in which the function is achieved, or the risks of failure or side effects accepted with a specific technical solution. According to Pieper\(^{40}\) (1997), different types of technologies with different affinities pose different ethical issues:

- Low or standard technologies, i.e. the technologies which are presently becoming the standard implementations in home adaptations for the elderly reflect the guarantee of a just and minimal standard of life quality by the public authorities.
- High technology, i.e. the advanced and innovative emerging technologies, especially the applications of (ambient and ubiquitous) ICT, represents the interests of liberal producers and consumers to explore individual potentials and new social frontiers.
- Self-made devices and readily available low technologies are self-reliant in character and relatively independent of special expertise and, thus, imply little dependency on formal systems and allow for communities to control them.

Ethical values connect gerontechnology to the way older people live and to the forms of life they participate in. Ethical value also tells how technology can negatively alter people’s forms of life. Here, the issues of value are psychological and sociological. It is possible, for example, to ask what the value characteristics to a certain form of life of older people might be. This kind of analysis of attitudes, experiences, prevailing moral values and codes forms an important part of empirical, sociological or psychological research on attitudes. This information is valuable, because when developing new technical solutions for a particular form of life it is important that the technology also fits and improves the value climate of a form of life.

There is also an additional perspective opened up by values which is not an empirical one. This is the question of what kind of technologies we should design for older people’s forms of life to improve its moral standards. A moral designer may put herself the question whether my work really promotes the quality of life of people? This means that one must ask questions about the human consequences of one’s work\(^{41}\).

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There is a variety of ethical principles that serve as the ethical foundation for gerontechnology design and implementation. Naturally they do not offer clear answers to all the questions of ageing and technology. Instead, one moral principle may support one solution whereas another principle may yield quite another recommendation to the same problem. Depending on which principle to give a primacy to it would be possible to arrive at relatively different solutions. If only one principle were to be adopted or even systematically given primacy, we would most likely arrive at unacceptable solutions of gerontechnology. Thus, in all phases of gerontechnology design and adoption, a process of analysis and reflection is needed in order to see what principles are in conflict and what possible solutions could be presented by assigning different weightings to different principles.

In the following part, the main ethical values and principles concerning gerontechnology are discussed.

1.2.1 Dignity

In addition to understanding that technology should not violate dignity and integrity of an old person, the core question in gerontechnology design, introduction and adoption is to understand and to be aware of the underlying idea of man in these contexts. This includes the following views to consider:

- Is the old person considered as an outcome of her culture who is not capable and willing any more to face new challenges in life?
- Or is she/he considered as a person who is capable of undergoing new processes and development of the self and eager in finding something new?
- Is she/he considered as an expert of her own life who is capable of speaking for her own part?
- Is she/he considered as a valuable and valued person?
- Is she/he considered as a research target or as a co-designer of gerontechnology?

1.2.2 Informed consent

People have a right to consent to technological intervention (adoption and usage of technology). Informed consent has three major components: 1) It requires that information is provided the person about her options and the consequences of each option; 2) That consent is voluntary and not coerced; and 3) that the person has the competence to reason the options.

Acknowledging the difficulty with obtaining informed consent from people with memory disorders or dementia, it would be possible to use preventive ethics which could include a variety of approaches. These can be, for example referring to people’s life preferences, introducing a policy of “substituted judgement” where a surrogate decision maker is appointed to decide what the person would have decided in the situation, or living wills or advanced

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directives, or making the decision early on in the disease process according to person’s values and preferences.\textsuperscript{44}

- How ethical is it to ask for informed consent? Is it possible that the question in itself can create confusion and insecurity?
- Should there be a board of experts that would give consent to the use of gerontechnology for surveillance? Who decides in the case surveillance technology includes legal issues?
- Although many people with mental disabilities, including those with dementia, are capable of giving informed consent, this is not a straightforward matter in all cases. In order to give consent, it is generally understood that a person should have the information required, be able to make a decision, and understand the implications of the decision.\textsuperscript{45}
- In considering ethical issues arising from the use of technology for people with mental disorders, questions that often help include:
  - Can the person with mental disability consent to this technology?
  - Who benefits from the technology?
  - Is the technology being used instead of human input?\textsuperscript{46}

### 1.2.3 Beneficence and non-maleficence

The principle of beneficence refers to doing good for others; the prevention of harm and active intervention to positively benefit another\textsuperscript{47}. It tells us to care for persons and their needs, to look after their good, interest, and well-being. In recent years issues of beneficence have been re-examined in bioethics and business ethics, although the value extends to many other areas of moral philosophy. After reviewing recent and traditional views of this value, Beauchamp\textsuperscript{48} (2008) states that the term beneficence is understood:

...to include effectively all forms of action intended to benefit or promote the good of other persons. The language of a principle or rule of beneficence refers to a normative statement of a moral obligation to act for the benefit of others, helping them to further their important and legitimate interests, often by preventing or removing possible harms.

The principle close to beneficence is the one of non-maleficence which refers to the will of refraining from causing harm to others and is common in medical ethics. Beneficence can become paternalism when a person’s actions or wishes are over-ridden for the beneficent reasons. A care-giver may feel that she/he as the expert knows better what the real needs of a person are and that she/he is therefore justified in adopting a paternal – ‘we know best’ – attitude toward the old person. In cases like these, beneficence may conflict with the principle

\textsuperscript{44} Downs, M., “The emergence of the person in dementia research”, \emph{Ageing and Society}, 17, 1997, pp. 597–607.
\textsuperscript{46} Ibid.
\textsuperscript{47} Kelly, T.B., “Paternalism and the marginally competent: An ethical dilemma, no easy answers”, \emph{Journal of Gerontological Social Work}, 23(1/2), 1994, pp. 67-84.
of autonomy. In many cases of gerontechnology, the principle of beneficence needs to be considered together with the principle of justice.

To what extent can technological innovations and services supply safe, robust, acceptable and sustainable solutions? How do we assess if they really match the needs, taking in account diversity of contexts …/… and ethical & legal issues concerning responsibility?

To what extent do these solutions constitute progress and represent a fair compromise between freedom, respect of dignity, efficient security support and relief for care givers?

1.2.4 (Social) justice and equality

The principle of justice aims at finding out what members of a community are entitled to, and to answer the question of how burdens and benefits ought to be distributed among the members of a given community. Justice also deals with the allocation of resources in an efficient manner so that everyone in society – especially those who are weakest – will also benefit. According to the principle of justice, technological intervention in an older person’s daily life is justified if this solution contributes to the fulfilment of a basic need (which everyone is entitled to).

Depending on what type of a theory of justice a community or society subscribes to, it may arrive at very different solutions in distributing resources for gerontechnology. It may stress the notions of equality, security and solidarity, or the values of individual freedom and efficiency (or utility) thus offering a very different framework of allocation of resources. In any case, the purpose of justice is to prevent arbitrary treatment of individuals. Thus, the notion of equality underlies the concept of justice. However, Rauhala-Hayes (1997) argues that the principle of equality works poorly in care work as it cannot be in accordance with the spirit of justice to allocate equal amounts of care to two persons who differ in the relevant respect that one of them is sick and the other is quite healthy. Rauhala-Hayes suggests interpreting the principle of equality as a demand to treat individuals as equals (rather than treat them equally). Then, it would be possible to consider the special needs of older people and justify special policies for allocation of resources for gerontechnology.

In the context of gerontechnology, the philosophy of justice may also advocate for helping other people to make connections. Gerontechnology may improve access to services, inclusion into the digital world, and even provide a platform for older people to use their intellectual skills to enhance their quality of life.

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51 Ibid.
53 Ibid.
In social situations, elementary relations may be symmetric and non-hierarchical (i.e. between peers) or represent some source of asymmetrical influence, power, or hierarchy. Pieper (1998) suggests that ethical issues of autonomy and justice are linked to this difference. Membership in a network depends on a relationship to any one person in the network, whilst membership in the group depends on some membership criterion which is in principle shared by all members. Ethical issues of individual responsibility vs. group solidarity easily can be attributed to this difference. According to Pieper (1997), as social relations have to be realised through interactions and communications, relations can suffer from three basic problems of communication: misunderstanding, conflict of goals, and distrust. These problems can reliably be solved only by the appeal to some “third party”.

1.2.5 Autonomy

The principle of (respect for) autonomy is a moral requirement to respect the autonomy of others. Designing for autonomy includes showing respect to the user and treating her as a valued member of society. The quality of life of older people is largely determined by their ability to maintain autonomy and independence. The principle of autonomy refers to the right of the individual to make decisions for herself. It is the perceived ability to control, cope with and make personal decisions about how she/he lives on a day-to-day basis, according to her own rules and preferences. It is the basic element of human rights which should be seriously taken into account when designing gerontechnology. The principle of autonomy tells us to respect the will of a person and to respect her choices even when we think these choices are inconsistent with what we believe is for the person’s own good.

According to the principle of autonomy, intervention of gerontechnology can be justified only if the old person has been presented with meaningful choices and sufficient information concerning her options and their consequences. This principle would not allow the instalment of any devices against the person’s will.

Respecting the autonomy of a person means that we are not allowed to override her will by coercion, threats, or e.g. restricting her freedom. In gerontechnology this means that an old person has a right to sufficient information to make decisions concerning the adoption and use of technology. Rauhala-Hayes (1997) argues that from an old person this requires competence, that is, the possession of a number of cognitive skills, such as a capacity to receive and understand information, to deliberate based on such information, give reasons for a decision, and to carry out a decision. In this sense an old person is autonomous when she/he is competent but also has a fairly stable conception of herself and her values. Another interpretation would be that

59 Ibid.
that autonomy is a freedom of action and the old person should be given a possibility to act according to her own wishes without interference from others\textsuperscript{60}.

Autonomy is strongly related to coping in life. Older adults, like any other citizens, should have the right to choose what kind of technology they accept in their everyday life. The choices may relate to the quality of technology, the amount of it and the purpose of its use. However, in the case of older people, the consolidation of autonomy and care is an ethical issue that often comes up. These problems are most visible in the case of people with memory disorders. For example, every person has a right for privacy, but when a person has an impaired memory it might be difficult to perceive what is the best for herself.

The value of autonomy has also been identified as important in other areas of design. For instance, Friedman and Kahn\textsuperscript{61} (2003) address the need for trade-offs between values, including between autonomy and security.

- There is clearly a point when the responsibility to carry out decisions in relation to adoption and use of technical devices shifts from the old person to informal or formal carers. Who decides when this point is reached?
- Is there a danger that stressing autonomy too much would lead to isolation, loneliness and depression of the old person?
- Should cultural differences be taken into account when discussing autonomy?

1.2.6 Privacy and trust

A focal ethical principle in developing technology for older people is privacy\textsuperscript{62,63}. In order to efficiently serve citizens in the society, technical applications and systems increasingly collect private information about people. A citizen should have a right to decide upon the usage of her personal data and to protect her physical, mental and social intimacy.

The issues concerning privacy are perhaps most visible in cases where it is possible to monitor the user of technology\textsuperscript{64,65}. For example, when the technology is used for supporting the independent living of a person with memory disorders, one might be forced to choose between privacy and safety of the person. For instance, the relatives of an old person may be faced with

\textsuperscript{60} Rauhala-Hayes, M., “Ethics of care work”, in S. Bjorneby and A. van Berlo (eds.), Ethical issues in use of technology for dementia care, Akontes Publishing, Kneusel, 1997, pp. 73-86.


a situation where they either have to accept a monitoring system at home to monitor the person or alternatively place the person to a nursing home.

When discussing the privacy of the user we should consider at least the following issues:66:

- Only very essential information about the user should be gathered.
- The user should be able to easily verify the information about herself.
- The user should be aware of the span of the storage of information concerning herself, and this span should be abided by.
- The information gathered for a specific purpose cannot be used for another purpose without the permission of the user.
- All information gathered during the usage of a service should be considered as private (except in case of suspecting a serious crime).
- The user should be informed about the content of the data gathered during the usage of a service and for what purpose and how this data is exploited.
- The user should be able to easily cancel her or his permission of the gathering and usage of information related to herself.

Of the new technologies, mobile devices in general and mobile phones in particular, are facing the challenge of ensuring the privacy and security of the users, the two aspects that are often in conflict with another. For example, emerging mobile payment and ticketing solutions require secure transmission and storage of financial information, while electronic health records and access certificates can include highly sensitive personal information in these devices. Securing interaction when using mobile devices is challenging, as typically there are no shared information such as passwords, addresses, or PIN codes between the phone, the user and the service to be used.

People have to be able to trust that private information in different systems and services is protected and that no-one can use this information (such as a personal code or account information) in a wrong way. In case of smart cards for example, users need to be confident that the system will reliably and correctly identify them while not permitting access to other users.

Present privacy regulation lags behind technological developments, especially with society moving into the era of ambient intelligence, which promises to intensify data collection in kind, frequency and volume.67

2 Ethical issues

2.1 Justification of technology

Typical to engineering disciplines is the fact that there has not been much effort to develop ethical tools for the practical work. Georg von Wright speaks about technological imperative

meaning, stating that the development of technology has autonomy, i.e., its own logic, in which individual actions or hopes are of secondary value. He takes as an example computers, the efficiency of which has put aside many earlier production methods. Changes in the way of producing goods and services have led to changes in consuming patterns and to a creation of technological life style. Technological cultures have set aside traditional values and the role of values as legitimating entities for our actions. Consequently, a justification crisis has emerged, as much of the new technology is in want of legitimating values. Von Wright argues that the question of the justification of technology has not been presented clearly enough, and as a consequence our ultimate goals are becoming unclear. If technology is being misused it is due to the fact that we have lost the very essence that once justified and guided human action.68

The ethical issues concerning the adoption and use of gerontechnology are often raised and solved in a social, political and economic context69. How the ethical dilemmas are solved depends on this context and attitudes and views of different stakeholder groups involved. Because of this, the ethical issues related to introducing, adoption and usage of gerontechnology should always be contextualised. Eccles, Damodaran, Olphert, Hardill and Gilhooly70 (2013) demand for dialogue between the carers and care targets and contextual understanding from the carers’ side.

Pieper71 (1997) speaks about social triangles, that is, social relations to which the use of gerontechnology is usually connected. These social triangles (ST) should be considered as the basic target units or target group in any gerontechnology implementation. The ST incorporates three roles: (1) the client, consumer or patient as the focal person in home care, (2) the informal caregiver, usually a spouse, family member, friend or neighbour, and (3) the formal caregiver representing the social and health care services. These roles may be occupied by more than one person, and in special care situations the roles may not be enacted by persons present (virtual presence).

In elderly care, gerontechnology may be able to free time for the caregiver so as to increase the time for positive, personal interaction with clients. But there can be also imminent threats in the technologisation of elderly care: Technical solutions may be cost effective, but they may also allow staff cut-downs and hence less human contact between clients and care givers.72

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68 Wright von, G.H., Humanismi elämänasenteena [Humanistic stands in life], Otava, Helsinki, 1981/2007 [In Finnish].
Pieper (1997) discusses the locus of control in relation to impact of technologies that require expertise in using them. For example for the treatment of wandering and depression in Alzheimer’s Disease, the nature of expertise in technology shifts the ethical considerations of measures to the formal caregiver (physicians) who are the only persons really qualified to evaluate the positive and negative effects in a particular case.

### 2.2 The interpretation of good (life) and social shaping of gerontechnology

ICT has brought many useful things to the everyday life of people but along with its positive effects its usage may lead to many risks, also, in respect to information complexity, security, and privacy, among others. For example, ICT applications have provoked ethical discussion in such areas as online medical consultations and home monitoring of older people. Ethical questions related to these, concern, for example, confidentiality, data protection, civil liability for medical malpractice, prevention of harm, informed consent, and patient confidentiality.

Ageing and older people also experience technology and adapt it in a manner that many times contradicts that of the young. Technology can be found stigmatising and may even violate privacy. From this point of view gerontechnology design should include consideration of the ethics problems that may be created, transformed, or exacerbated by technology. Here the main question pertains to the interpretation of ‘good’. What can be considered good, from whose perspective, and what kinds of choices generate an increase in goodness? In any event, interpretation of ‘good’ leads to discussions of moral rules and of people’s rights and responsibilities. They may have significant consequences for human well-being and should always be resolved within the design decisions.

One way to examine ‘the good of man’ is to focus on the concept of good life. What is a good life where an older person can express herself in order to accomplish valuable goals? The ethical questions related to technology should thus not be examined only in the light of negations, such as losing privacy or autonomy, but consideration should be given to how technology can help in enhancing the degree of our autonomy and independent living, and, in general, how it can facilitate good life.

In ICT development, ethical design is grounded in information (or ‘computer’) ethics, the field of academic study that examines actual and possible impacts of information and communication technologies on important human values, such as life, health, psychological and physical well-being, happiness, abilities, peace, democracy, justice, and opportunities. The overall goal is to advance and defend human values in light of the possible and actual impacts of ICT. Ethical design means, first of all, conscious reflection on ethical values and choices with respect to design decisions. Secondly, it means reflection on the design process itself and the choice of design methodologies. In addition, ethical design involves what is ethically acceptable. Finally, ethical design must consider the issues of what are ethical goals – i.e., what constitutes the good of man.

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With respect to ethics considerations in design decisions, there are two aspects to consider. Firstly, one should examine what the prevailing moral rules and the users’ norms are and what kinds of impacts they have on the design decisions. Secondly, one should be aware that also the moral norms of the designers themselves may greatly influence the design. The developer or designer does not work in a vacuum, and the values in her or his life will also affect the design decisions. When this is fully acknowledged, it is possible to take into account the importance of values as an integral part of the design and exploit value-oriented methodologies for the design as well.

An important ethical question in relation to R&D processes of gerontechnology is, in a sense, the superficiality of user studies. The difficulty with many product development projects is that often, in the prototyping phase, it is possible that only a very limited number of users are involved in the evaluation of the prototype. The budget of the development projects is often too restricted and can cover mainly the technical development work, leaving out profound user evaluations, such as long-term user studies. In addition, the increasing speed of the development cycle brings additional challenges to the design, such as how to deliver the vital information about the users, their values and expectations in such a way that it would be available in every phase of the design process and for every designer.

During a short-term development process of a product or service it is possible to assess the influence of technology on, for example, users’ health, physical capacity, or independent living. But it is not possible, within short-term user studies, to evaluate the influence of the product or service on people’s life and on the actual quality of everyday life.

In general it can be said that when introducing gerontechnology interventions, the following questions should be asked76:

- What is the problem which the technology has been introduced to address? Why? For whom is it a problem?
- What interventions have been tried to address this problem?
- Who decided on technology as a solution?
- Whose needs does it serve?
- What are the benefits and drawbacks of the technology for the person in question?
- Are the users ready and willing to adopt the technology?
- Is the environment ready and willing to accept the users of the technology?

In the following, ethical issues most often discussed in the literature for gerontechnology are introduced. It should be noted that gerontechnology ethics in literature mainly discusses older people who are to some extent objects of care. Not much literature can be found on ethical issues concerning gerontechnology for life settings of active ageing people.

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2.3 Digital divide

‘Digital divide’ is a phenomenon caused by the failure in technology development to sufficiently consider democratic accessibility and adoption of products and services. There has been a lot of academic discussion about the growing emergence of digital divide\textsuperscript{77,78}, of technological ‘haves’ and ‘have-nots’\textsuperscript{79,80} or the ‘information rich’ and information poor\textsuperscript{81,82} and also of ‘digital natives and digital immigrants’\textsuperscript{83}. That divide is no longer seen merely as an issue of access to hardware. Instead, there is now growing concern that the lack of design foresight is creating social exclusion. Unequal adoption of and access opportunities to ICT exclude many from benefitting from the advantages related to the introduction of technologies in many fields of social life.\textsuperscript{84} As technologies have evolved and their use also changed qualitatively, the divide is seen as separating users from non-users, and distinguishing different types of users. There is not just one digital divide any more, but multiple divides which relate to a variety of factors, such as living and work conditions, ethnic background, gender and age.

There are numerous difficulties and obstacles for efficient adoption of gerontechnology. The needs of older people are obvious, but the technology needed is not always available or is not designed from the point of view of ageing generation. In the cases where technology exists, older people often face difficulties in using it.

In the case of ICT usage by older people, one can even speak of under-use\textsuperscript{85}. Technophobia is often used as an explanation for that older people have not adopted new technologies\textsuperscript{86}. The development of new technology outside the older people’s world of experience and the partial mystification of technology make older people feel agony. Mystification is, among other things, a consequence of advertising, technological snobbism and technical jargon\textsuperscript{87}. Indifference has a specific meaning in this context: it is the unconcerned attitude in design processes towards older adults and the needs arising from their everyday life.

\begin{thebibliography}{99}
\bibitem{78} Wills, M., “Bridging the digital divide”, \textit{Adults Learning}, 10-11 December 1999.
\bibitem{79} Howland, J., “The ‘digital divide’: are we becoming a world of technological ‘haves’ and ‘have-nots’?”, \textit{Electronic Library} 16, 5, 1998, pp. 287–289.
\bibitem{82} Wilson, A., “The information rich and the information poor”, \textit{ASLIB Proceedings}, 39, 1, 1987, pp. 1–6.
\url{http://www.cre8ivemultimedia.com/thesis/BirmanThesis110205.doc}.
\end{thebibliography}
2.4 Independent living

Independent living at home is an ever-increasing issue and value in gerontechnology. It easily opens the debate on publicly guaranteed minimal standards of care and the environment in which they can be realised most effectively and efficiently, under the pressure to agree to a just distribution of the public resources (of technologies) among a large group of people in need of services. Technology holds great promise for supporting ageing people to continue living at home. The ethical dimension is implicit in the goal of technology for independent living, as independence relies basically on social relations.

Safety and feeling safe are one of the basic areas in independent living and, e.g., one of the basic needs in Maslow’s88 (1954) hierarchy of needs. Facilitating and enhancing one’s personal safety is one of the central areas in which older adults wish to be supported by technology. The need for safety is related both to activities inside home as well as outside home.

Ethical practice is not ‘recipe knowledge’ by which simple definitive answers can be provided for complex issues and problems. It is about asking questions that shed light on the various dilemmas that can arise in considering what is appropriate for a certain person or not. In the case of technology there is a danger that complex issues of risk and safety may be seen as being amenable to instant technological solutions. A technological fix may be given priority at the expense of a thorough appraisal of the person, the context, and the reasons for behaviour that cause risk to the person or to others. If this occurs, the use of technology will almost certainly be unsuccessful.89

2.5 Social nature of gerontechnology

Social interaction with relatives and friends becomes more and more important in old age. However, running daily errands and maintaining close contacts with people may become difficult with the declining sensory and motor processes. Technology may offer help in this. Consequently, the expectations for new technologies are high. Technology for maintaining communication and social relationships already exists, but we need easy-to-use versions of it for older adults.

For older people, the ‘worth’ in communications technologies is in that they allow practical use of the technology90. One of the practical needs is keeping up social relations and meeting friends and relatives. Technology development should strive for enabling contacts and social interaction between people, thus reducing risks of loneliness and social isolation. Meeting other people and being able to share memories and experiences with them is remarkably important to humans. Through the feedback received from social contacts with others, people can reflect upon their identity and maintain it at a level which promotes psychological well-being91.

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Ethical issues of gerontechnology in this context may evolve out of social situations, gain practical importance as conflicts of interest, and have to be solved as decision dilemmas of the relevant actors involved. Pieper92 (1997) talks about the “social triangle of home care” and by this refers to the relations of different actors involved e.g. in the home care of memory impaired people. Also Widdershoven93 (1998) argues that ethical issues in this field cannot be discussed apart from the social context in which the issues arise and the decisions have to be made. In the usage of gerontechnology, the individual always has to rely on some social support. Visualising the individual as a liberal consumer neglects the fact that everybody needs support in the selection, implementation, use, maintenance, and disposition of technologies.94 The adequate social relations must always be implemented together with technological solutions for elderly people.

Technology may have many different effects on the quality of life of the persons involved: the old person may experience an effect of support, the informal caregiver may experience the effect of relief in the burden of care, and the formal caregiver may experience the effects of increased effectiveness and efficiency of care which should also increase professional satisfaction.95 Proper care depends on adequate use of technology which may change the roles and rules of interaction.

Traditionally, in the case of formal caregiver, the professional has had the power to define what constitutes “help”, “health”, and “user needs”, with the insuring ethical issues of, for instance, patient autonomy.

In many cases of informal care, the (family) caregiver has to carry most of the burden of e.g. care of a demented person, and receives only little professional guidance and support. When introduced in these cases to support home care (instead of institutionalised care as an alternative), technology may make the informal caregiver more effective, for instance, by means of safety alarm systems, and at the same time prolong the burden of the informal caregiver. Informal caregivers can respond to this challenge differently depending on past experiences and acquired coping strategies.

2.6 Coping in life and self-efficacy

Information and communication technologies and new media have a central role in modern gerontechnology, in promoting coping in life. With the help of new interactive technologies older people can obtain information quickly, conveniently, in an encouraging manner and confidently, and solutions can persuade people to improve their lifestyle together with other people. The basic elements of applications for coping in life include awakening of an

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95 Ibid.
individual’s own will, motivation and determination, receiving expert guidance and information, and gaining social and peer group support.

Self-efficacy is an essential factor in older adults’ coping in life. In using technology it arises from the experience of competence, i.e., from the feeling that I can and know how to use a new system or device. It is associated with everyday experiences, which can be influenced by, for example, work experience, education, income, locality, health, disabilities and gender. These experiences are also influenced by complexity and versatility of the technology and the support facilitated by social networks (family members, service providers, technical support of the work place, etc.).

An important issue in relation to self-efficacy is the one that gerontechnology which requires learning processes on the part of the user (most technology does) have to be introduced very early in the process, so that the person in question is able to thoroughly learn to use the technology. In general, the need for learning processes should be as limited as possible, since every change in the everyday life situation may disable ingrained habits of the old person.

2.7 Loneliness

Loneliness is a factor that in most cases essentially decreases the quality of life. Many older people experience loneliness: up to 32% of adults over 55 report feeling lonely at any given time. Loneliness is unlike social isolation, which appears often simultaneously with loneliness. Our social networks can usually be objectively measured, but loneliness is always a subjective feeling. For example, living alone does not necessarily mean that a person is lonely, whereas someone can feel lonely even when surrounded by many people. It is clear that loneliness can provoke depression in the way that a person without contacts to other people can become depressed and turn inwards.

Depression amongst older people is often a consequence of isolation. It can sometimes even lead to suicidal thoughts, and thus be the main reason for the decision for institutionalised care. There are different ways to prevent depression; physical exercise and social relationships are some. Studies show that physical activity strengthens the essential components of a

mentally healthy human being. These components include self-confidence, self-appreciation and self-assertion. It is also known that loneliness can have physiological consequences. Loneliness is a stress factor, which in turn has links with many aspects of our bodily health. Blood pressure, sleep problems, adrenocortical activity, diminished immunity, white blood cell count, cardiovascular disease, obesity, and cholesterol are examples of the physiological problems associated with loneliness. Even cognitive decline and Alzheimer's disease are a part of the problematic consequences. It is thus evident that loneliness can be serious and problematic for a human being, and interventions are needed to decrease the feeling of loneliness.

Technology should be applied to support the strengths of older people and to facilitate their participation in society. The knowhow gained during the course of aging is a remarkable asset, which should be utilised in society in different ways. Older people have tacit knowledge of life, which is meaningful and beneficial for the whole community. This is why technological solutions should be facilitating the usage of this knowledge for the common good and increasing the role of and participation opportunities for older adults as members of society.

The issue of replacing social relationships with technology has many times been brought up in discussions about older adults and technology. This is of course, possible in cases where the already limited contacts of a lonely person are replaced by, for example, new solutions utilising ubiquitous computing and ambient intelligence. However, technology should be seen also as a facilitator for social networks. It cannot remove isolation, but it can remove the feeling of loneliness by creating social networking possibilities for people who are not able to leave their home due to a motor disability. This is why each case should be examined from the point of view of individual needs in relation to opportunities provided by technology.

2.8 User needs

Ethical issues of social justice always arise in concrete social interactions and relations and have to be solved in their context. Reliance on market mechanisms has brought a new trend where user needs are transformed into needs of consumers, and even gerontechnology is articulated in decisions of consumption or non-consumptions of goods and services rather than in aspects of good life. But the market may not provide the goods and services for everybody in need, since not everybody has the economic or other resources or competence to effectively enter the market. The goals of gerontechnology are placed and depend much more on real user needs than consumer needs, and thus on the principles of social justice which should be defended based on collective decisions.

User needs in gerontechnology from ethical point of view can be phrased in terms of abstract principles like “maximum of utility for all”, or “respect for autonomous individual self”.


105 Ibid.
According to Harrington and Harrington\textsuperscript{106} (2000), in case of gerontechnology, the golden rule “do unto others as you would have them do unto you”, requires another minor modification. Give unto others things they want to have, not things that we want to give. Harringtons\textsuperscript{107} see gerontechnology as in part a “helping” movement: it is human nature to want to give as much as possible when trying to help someone. So there is the common danger of giving too much, giving things that aren’t wanted, or things that will be unpleasant or turn out to be even harmful. Harrington and Harrington argue that in gerontechnology, the large arsenal of ideas and devices and methods especially predisposes to this, the “bear’s favour”, a Russian expression for favours gone wrong. They continue that in some countries good Samaritans are even legally responsible for all the ill effects of bad favours.

To avoid the bear’s favour Harringtons\textsuperscript{108} (2000) suggest that one has to determine carefully and exactly what is needed, but therein lies yet another problem. People often do not know what they actually want because all of the options and their advantages and consequences are not obvious.

### 2.9 User control

User control is an essential factor when designing technology. The user should be able to trust that the system or device functions as it should and remains in a full operational order. When consciously adopting technology, the person should also be able to trust that she/he can decide whether to operate the system or device or not and, for example, turn the system off whenever she/he desires to do so.

These issues may, however, produce new problems along with the adoption of new technologies. When a service is developed, for example, to support activities in daily living with the help of new technologies, such as ubiquitous technology and ambient intelligence, the technology in a way operates in the background unnoticed and reacts to a person’s activity only according to the pre-set premises. In case of older adults, services like these may bring substantial enhancements in the quality of and coping in life. In these applications, however, the user control diminishes and the person cannot be aware of the functionality of the technology all the time. It is also important to notice that the usage of these kinds of sensing technologies developed may lead to a decrease in human contacts and human interaction. This in turn may lead to a decrease in the person’s own control of the technology.

In the case of family caregivers, the informal carers may end up to a situation where they are expected to take the control over the inmate’s life and decide on the inmate’s behalf about e.g., adoption of technology. They can even be driven into precarious responsibilities where the issues of autonomy and “independent living” have to be reconsidered since the role of the caregiver is strengthened. Pieper\textsuperscript{109} (1997) highlights that in situations like these there can sometimes be a need for additional support which may be introduced in the form of persons of trust. The basic premise in this solution is that the inmate can no longer effectively represent

\textsuperscript{107} Ibid.
his or her interests, and that these interests may conflict with the interests of the informal caregiver or the formal caregiver. Ethical issues arise regarding the legitimate procedures to establish incompetence of the inmate and adequate ways to determine her “real” interests and needs.110

Personal control by older users is becoming ever more laborious to exercise in ambient intelligence environments. A combined agenda of technological and legislative developments is needed to support, as well as inform, the wider public and especially the older population about the legitimacy and the appropriateness of the data collection for the service provided.111

2.10 User involvement in the design

If values and ethical implications are implicit in each technology, it should be guaranteed that potential users of the technology have influence on each stage of the product development life cycle. Their influence should not be reduced, for example, to the decision to adopt technology. The process of design, production, implementation, use, and disposal should all be open to some form of user participation. In addition, products have to be open, flexible, or adaptable to specific user needs and situations.112

User participation in the design process promotes empowerment, which suggests that the user is a relevant “co-producer” of life quality113,114. The important questions here pertain to the influence on and the participation in a socially just distribution of products and services.

Empowerment goes hand in hand with “new-consumerism”, where older people are seen as autonomous consumers with different needs and differences in life styles. Here, the individual’s right to pursue her own interpretation of happiness and quality of life is a core idea, which, in turn, highlights the issues of autonomy and control, as well as issues of fairness and just distribution.

In addition to the view of co-producers of their own life, there is a community perspective to co-design. In the design of products and services the tacit knowledge of older people’s experience world should be exploited for the benefit of not only older adults themselves but all citizens in the society. When designing only from the perspective of younger people there is a danger that we lose the essential experience knowledge of life that older people have and that is valuable in the information society. The need for this tacit knowledge increases all the time as in the societies there is a strong demand of understanding entities instead of single matters. This understanding evolves within the course of life and is thus typical for older people.

113 Ibid.
2.11 Ethicality of technology adoption

For older people, gaining trust between the customer and the salesperson in the purchase situation is highly important. A problem in these situations is often that the older person is not able to express precisely her or his needs. (S)he usually trusts the sales person, especially in case of technical matters. In many cases the sales person of technical devices is a generation or two younger than the aged customer, which might create difficulties in understanding each other’s experience world. The sales person should be able to look at the situation from the older person’s perspective and consider the need of a device from this point of view. Also, she or he should be able to tell about the product properties in a language that the older person understands. The worst case would be if the older person makes the decision to purchase the product based on the eloquence of the sales person and finally, when at home, finds out that the product does not fit in her or his needs.

An essential part of the purchase situation is to inform the older person about the additional costs that the product would bring to the person. These are, for example, costs related to the usage and updating of the product or system.

In order to gain a feeling of self-efficacy, an older person needs time to digest the information that is delivered. This is why the sales person has to have enough time for the sales event. There has to be time to guide the older person how to use the product or system and to be sensitive in understanding the needs of the customer in terms of listening to the questions and answering them in an understandable way.

3 Organisations

3.1 International Society for Gerontechnology

The International Society for Gerontechnology -ISG encourages and promotes technological innovations in products and services that address older peoples' ambitions and needs on the basis of scientific knowledge about ageing processes including cultural and individual differences. ISG’s vision is to work toward the realisation of a society fully served by technology that is as accessible to ageing people as it is to people in younger generations. The values of ISG include innovative technology that serves an enabling role for ageing people by:

- Maintaining their independence and equality including considerations of residence, mobility, safety, security, communication, activities, and quality of life,
- Supporting their well-being and health as defined by the WHO,
- Realising their individual and collective/social ambitions and needs,
- Keeping them embedded in their changing socio-cultural environment,
- Enhancing their dignity,
- Supporting their caregivers.

The strategies of ISG include:

- Advancing world-wide communication between scientific, technological, and social disciplines relevant to human ageing in a sustainable society, through a
variety of means including international and regional conferences, an international peer-reviewed journal, and an Internet forum,

- Establishing and improving university and professional education in gerontechnology by textbook and Internet-based educational material, curricula, courses, and master classes,
- Supporting the introduction of gerontechnology into a wide range of disciplines and professions that impact on the well-being and quality of life of ageing people,
- Advancing learning opportunities for ageing people to use new technology,
- Applying insights from ageing processes to technological innovations,
- Encouraging technological innovations that meet ambitions and needs of ageing people.

The means of ISG include:

- Gerontechnology journal (Delayed Open Access for all contributions (embargo of 12 months or 4 issues) and immediate Open Access on demand),
- Biannual international conferences,
- ISG Master Classes for young scientists.

ISG forms a standing committee of the IAGG (International Association of Gerontology and Geriatrics), and is a supporting Partner of the AAL Forum (Ambient Assisted Living).

ISG web link: http://gerontechnology.info/index.php/journal/pages/view/isghome

3.2 Research organisations

Key actors in the field of gerontechnology research are at least:

- Eindhoven University of Technology
- King’s College, London, UK
- Eindhoven technical university, The Netherlands
- Gerontology Research Centre, Simon Fraser University, Harbour Centre, Vancouver, BC, Canada
- School of Aging Studies, University of South Florida
- Division Primary Care, University Liverpool, Liverpool, Merseyside, UK
- Institute for Ageing Studies, Brunel University, Uxbridge, Middlesex, UK
- University Center for Social and Urban Research, University of Pittsburgh, Pittsburg, PA, USA
- University of Sheffield, UK, Centre for Assistive Technology and Connected Healthcare Florida State University, Tallahassee, FL, USA
- University of Miami Miller School of Medicine, Miami, FL, USA
- Information Technology and Social Research Group, Department of Information Science, Loughborough University, Loughborough, UK
1.1 Institutionalisation

National Advisory Board on Social Welfare and Health Care Ethics\textsuperscript{115}

In Finland, the National Advisory Board on Social Welfare and Health Care Ethics (known as ETENE), serves as governmental ethical assessor of gerontechnology in that it gives recommendations on ethical issues. The purpose of ETENE is to discuss general principles in ethical issues in the field of social welfare and health care and concerning the status of patients and clients as well as to publish recommendations on them. Gerontechnology is discussed inside the field of social welfare and health.

The National Advisory Board on Social Welfare and Health Care Ethics ETENE operates under the Ministry of Social Affairs and Health. It was set up in 1998. Initially its brief concerned ethical issues in health care, but in 2009 this was broadened to include social welfare. The Advisory Board was set up pursuant to the Act on the Status and Rights of Social Welfare Clients (812/2000, 657/2009) and the Act on the Status and Rights of Patients (785/1992, 658/2009). The duties and membership of the Advisory Board were defined by Government Decree 667/2009. The Government appoints the members of the Advisory Board for a term of four years.

ETENE submits initiatives, publishes statements and provides expert assistance, prompts public debate, and disseminates information on national and international ethical issues in the field of social welfare and health care. ETENE works with the Ministry of Social Affairs and Health, Parliament, and other ministries and government agencies. Meetings and other events for facilitating cooperation are also held with other national ethics advisory boards and regional actors, and ETENE further engages with scientific and education institutions, NGOs, the media and private citizens. ETENE monitors and publicises international trends in ethics and participates in international events as necessary. There is bilateral cooperation primarily with the Nordic and Baltic countries.

ETENE launched a debate on ethical issues in technology use in 2009, incorporating the issues relating to the development of electronic document management. Technology is here understood to refer specifically to technology in the sectors of social welfare and health care, having to do with professional and informal care, preventing and inhibiting the diminishing of functional capacity and weakening of strength, and compensation and rehabilitation. Technology is used in professional and informal care, in institutions and at home, in independent and assisted use. It requires a strong cross-discipline, multi-professional and client-oriented background. This report is intended for ordinary citizens, for social welfare and health care professionals, and for political elected officials and decision-makers. The purpose of the report is to guide social welfare and health care professionals to ethically sustainable practices. In this report, ETENE highlights the ethical issues of increased reliance on technology. The ethical reflections in the report apply to technology acquired for the social welfare and health care sector, but not to biotechnology or medical technology.

View of ETENE on making use of technology:

\textsuperscript{115} http://www.etene.fi/en
• When used in social and health care, technology contributes to supporting a good life, human dignity, right of self-determination, inclusion, and humane care and caring.
• The necessary technology is equitably and easily available, and it is only resorted to by the user’s informed consent.
• The use of technology is agreed on together with the user when drawing up the service plan. The plan presupposes a comprehensive review of the user’s needs and life situation.
• Technology must be naturally suited to the person’s everyday life, and the disadvantages and risks related to its use should be assessed and the user guided and supported, as appropriate.
• The social and health care information systems are reliable and safe, and the integrity of the clients and patients is respected and secured in their use. People have access to the information concerning them so as to be able to check it, and professionals assist them as necessary in interpreting the information and examination findings.
• At its best technological monitoring enables an independent and safe life. The parties involved agree on its use together. Its use does not violate personal integrity, nor restrict human contacts.
• Development, assessment, purchase and utilisation of technology presuppose diversified expertise and cooperation. The personnel need to be educated. Uniform national recommendations are also needed.

View of ETENE on use of technology in social welfare and health care:

• Increasingly many disabled and elderly people require support and assistance. Diverse technological potential and support are increasingly needed. Technology is used in social and health services for instance to prevent health problems and illness, to assess functional capacity and compensate its deficiencies, to counsel and advise patients and clients, to document cases, and to improve employee ergonomics.
• The technology requirement is recorded in the care and service plan of the client or patient. The use of equipment acquired for social welfare and health care institutions and homes must be monitored to ensure their safety and reliability. Technology must not be allowed to replace social contacts. However, technology may serve to reinforce social networks. It may not be a cure for loneliness, but it can alleviate a sense of isolation by allowing people to contact others more easily, for instance through the social media.
• The use of monitoring technology has increased in social welfare and health care, to improve the safety of clients and personnel and to help in the technical maintenance of facilities. Ideally, technology can help provide both safety and an independent and meaningful life. There are assistive devices for independent functioning and monitoring technology for disabled persons. It should be noted that technology may also have a negative impact on a disabled person: too much monitoring and supervision can restrict their lives. Sufficient resources must be provided for maintaining technology that supports home services. Innovative and creative uses of technology should also be considered, as well as its unexpected and unplanned advantages and disadvantages.
• The availability of assistive devices has been reasonably well ensured in the health care system. By contrast, clients consider the system for applying for, granting and
financing assistive devices to be complicated. Service vouchers are problematic in all services in the same way: they are most effectively used by those who have the most information, skills and financial resources. Competitive tendering has reduced the range of client choices, as only the models that have won bids are offered, and these may not suit everyone. The opinion of the client/patient must be respected in acquiring assistive devices, regardless of the outcome of any competitive tendering. Practices must be harmonised, and service guidance must be enhanced.

View of ETENE on ethical principles in evaluating the use of technology for health and functional capacity:

- The ethical issues and problems related to the use of technology are very similar to those arising in social welfare and health care services in general. Ethical problems arise because of the ambiguity and diversity of situations in real life.
- All actions are based on identifying, acknowledging and respecting human dignity, the premise being that every human being has an intrinsic equal and unique value that does not need to be earned. Respecting human dignity involves humanity, confidentiality, privacy, good interaction, honesty and the right to information and self-determination. Human dignity and respect for it are tested particularly in situations where a person needs more help and support than usual. The ethics of professional and informal care focus on human vulnerability, identifying that vulnerability, and encountering and accepting human beings as they are.
- Social welfare and health care services are predicated on the principle of doing good and doing no harm, which requires each situation and solution to be assessed with regard to their benefits and disadvantages. Doing good prompts a search for solutions that support persons needing help or care. The principle of doing no harm specifies that a client/patient, or persons close to him/her, must not incur disadvantages through the use of technology, or at least the benefits must clearly outweigh any disadvantages.
- Fairness dictates that people requiring the same care are treated equally regardless of their age, location, social status, native language, gender, ethnic background or culture. The rights of vulnerable groups such as children, the disabled or the elderly must be particularly considered. Fairness also includes the requirement of not squandering shared, limited resources but instead using them effectively in striving to provide a good life.
- Self-determination and autonomy have to do with freedom of choice. Self-determination is the right to make one’s own decisions based on one’s life philosophy, values and ideas. Decisions to use technology are based on conscious consent, and such solutions must be to the benefit of the individual. The will of the patient or client must be acknowledged and respected, and any solutions must be sought in consensus. If a person is incapable of expressing his/her own will, treatment and care must be provided in consensus with his/her legal representative, family member or other involved person.
- Privacy protects the physical, mental and social intimacy of an individual as well as his/her personal data. Technology may be used to protect privacy and to prevent personal data from being disclosed to outside parties. Privacy protection requires professionals to exercise confidentiality and discretion.
3.3 Ethical principles: conflicts and solutions

Ethical principles may guide actions in conflicting directions. In case of a conflict, usually it is the option that would cause the least harm that must be chosen. It is difficult to investigate and demonstrate the benefits of technology where the technology involved is not actual medical technology. Therefore, decisions regarding technology must be based on balanced background information; also, the grounds for decisions must be recorded and their results assessed afterwards.

The balance between doing good and doing no harm is complicated by risk management for instance in restricting movement or functionality. Demonstrating benefits and identifying risks are difficult to do in advance. Services for the elderly and for mental health patients and rehabilitees have largely shifted from round-the-clock institutional care to homes or home like environments. Doing good in the use of safety devices requires that personal assistance is available, that danger situations generate alerts and that help is available quickly.

The lack of privacy is often a problem in care environments. Privacy protection must thus be considered in technology solutions, too. Monitoring technologies may help protect privacy yet also convey information on the alertness, mobility or immobility of the client/patient in case they need help.

In institutional care, damage may be avoided by using locks, bed rails, patient overalls and restraints (on chairs or beds). Any restrictions imposed on residents/patients must be based on clear operating instructions, which must include provisions for consulting the resident/patient and for the decision-making and implementation processes for any restrictive measures, including the determination of the responsibility for them, their monitoring and their duration. Restrictive measures may be reduced by using monitoring technology. Restrictive measures are always a last resort, as they encroach on the self-determination of the individual. They may also prevent a person from exercising his/her abilities and violate his/her privacy. Restrictive measures are only justified if it can be demonstrated that their use affords clear benefits.

The assessment of confidentiality is becoming increasingly relevant as information gathering is expanding with the introduction of new technologies. Whereas social welfare and health care services used to suffer from a lack of information on clients/patients, the situation is now quite the opposite. What is essential for the ethics of information systems are the issues of the need to collect data, the right to inspect data, the handling and deleting of data, responsibility for the correctness of data and for rectifying incorrect data, and ensuring data confidentiality.

For a good life, the functionality of assistive device services and the availability of such devices are essentially related to fairness and self-determination. The weaker a person’s independent functional capacity is and the more dependent she/he is on outside help, the more she/he needs assistive devices and technical equipment to help her/his function. This does not mean just having individual assistive devices but also having an obstacle-free environment both physically and virtually.

There are many people who need assistive devices, and not enough service instructors, or else there is not enough time to provide advice and information. An assistive device is tantamount to a life partner, particularly for a person disabled from birth. Therefore it is important to
consult the disabled person her-/himself and consider his/her needs when selecting assistive devices. If a person feels that her/his assistive device is practical and necessary, he/she will feel positively about it and will use it often and willingly. Fairness issues related to the use of technology include the disparity of the service system, the segregation of services, the sufficiency of services provided, and the socioeconomic status of users. Technologies that adapt flexibly to client needs may help reduce inequality.

4 International frameworks and protocols

4.1 Inclusive Design

Inclusive Design principle addresses designing products and services such that the weaker members of the target group can use these. The understanding of accessibility and user needs is emphasised in the inclusive design principle (also known as eInclusion, digital inclusion, design-for-all (DfA), accessibility and universal design) which is said to promote socially sustainable development\(^{116,117,118,119}\). The concept stresses that if a design is directed toward users with lower skills, those with higher skills can also easily use it. This design principle is concerned with designing mainstream products, environments, and services in a way that would make them accessible to and usable by as many people as reasonably possible and by an as diverse group of users as possible, in a wide variety of situations, and to the greatest extent possible without the need for special adaptation or specialised design. Accessibility in this context is related to the barriers that might inhibit full participation in the society by all citizens. These barriers can be physical, social or economic.\(^{120,121}\). The high speed of the development of ICT technology poses new problems on how to incorporate inclusive design in the development process.

Inclusive design brings legislative pressures for the development of systems which are accessible to older and disabled people. The 1990 Americans with Disabilities Act (ADA) asserts the individual’s right to use products and services on an equal access basis. In 1995, the United Kingdom implemented the Disability Discrimination Act (DDA) to a similar effect. European governments have also recognised that enabling legislation for combating discrimination is necessary for the promotion of independent living, extending quality of life and promoting the concept of participation in the “information society”.\(^{122,123}\). Generally, this

approach is justified, because it does not only recognise the needs of older people but also increases the potential market. However, design-for-all-solutions cannot always be the best ones for the ageing population. In many cases solutions for older adults need to be customisable and adaptive.

Inclusive Design can be seen as a value-oriented design approach, although the added value is strictly focused on accessibility. The approach has been criticised because of the fact that it seems to imply that a well-designed product is suitable for everyone\textsuperscript{124}, and thus does not address design for different types of people.

4.2 International standardisation

The main relevant base standardisation document for gerontechnology is ISO/IEC Guide 71 which should be translated into more concrete design rules\textsuperscript{125}. The importance of standardisation is evident from the point of view of great many products in which this is already applied such as in car control, and in a negative sense from products where this has not yet been achieved such as in domotics. It is commonly known that in practise it can take several years until standardisation is actually implemented. For older adults this can be in many cases detrimental since learning of new skills becomes more difficult in old age. From this point of view, for example, new types of products should not try to distinguish themselves by a new type of user interface unless it would be remarkably easier to use than alternative solutions. Standardisation should be grounded not only on the technology but on proper insights on the broad target groups of users as well\textsuperscript{126}.

4.3 Technology acceptance

An influential theory of acceptance towards technology is the Technology Acceptance Model (TAM)\textsuperscript{127}. It states that the behavioural intention to use a product is determined by its perceived usefulness and ease of use. Bouma et al.\textsuperscript{128}, argue that both of these are subjective constructs, and may deviate considerably from more objective measures of usefulness and usability. They continue that in that sense the TAM model is a somewhat indirect measure of the tendency for real technology adoption by older adults. Nevertheless, perceived usefulness has been consistently found to relate strongly to usage intentions\textsuperscript{129}.

\textsuperscript{123} Government offices of Sweden, \textit{A barrier-free society}, Regeringskansliet, 2009. 
http://www.regeringen.se/content/1/c6/11/96/31/c8390e9e.pdf.
\textsuperscript{126} Ibid.
\textsuperscript{127} Davis, F.D., “Perceived usefulness, perceived ease of use, and user acceptance of information technology”, \textit{MIS Quarterly} 13(3), 1989, pp. 319-339.
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5 Journal and conference series

Gerontechnology Quarterly Journal is the main international journal focusing on gerontechnology issues. It includes Delayed Open Access for all contributions (embargo of 12 months or 4 issues) and immediate Open Access on demand. The society behind Gerontechnology is International Society for Gerontechnology (ISG).

There is no special journal focusing on ethical issues of gerontechnology. The aim of Gerontechnology journal is to provide a forum for reporting original research, review papers, and personal perspectives on the broad area of fitting technological environments to support changing life goals and lifestyle preferences into advanced age. Research outcomes reported in the Journal form the basis - for designers, architects, standards developers, builders, engineers, marketers, manufacturers, medical doctors, pharmacists, decision makers, and related professionals in the health, social, business and technology professions - to provide the proper environment for the greatest number of people in society. When searching the archives of Gerontechnology Journal with keywords ‘ethic’ and ‘ethics’, a variety of articles can be found. These discuss mainly Alzheimer’s disease and dementia, domotics, and ambient intelligence.


6 Key publications

Key publications of gerontechnology ethics include:

- Journal of Gerontechnology
- Discussion site: http://www.linkedin.com/company/884176?trk=prof-exp-company-name
- Basic literature:
  - Pieper, R., M. Vaarama, & J. L. Fozard (eds), Gerontechnology: Technology and aging: Starting into the third millennium, Shaker Verlag, 2002

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130 http://www.gerontechjournal.net