

# Ambient intelligence, ethics and privacy

J. van Hoof MSc

H.S.M. Kort PhD

Faculty Chair of Demand Driven Care,  
Hogeschool Utrecht, Utrecht, the Netherlands  
E: joost.vanhoof@hu.nl

P. Markopoulos PhD

Faculty of Industrial Design, Technische Universiteit Eindhoven,  
Eindhoven, the Netherlands

M. Soede PhD

The Institute for Rehabilitation Research (iRv),  
Hoensbroek, the Netherlands

*J. van Hoof, H.S.M. Kort, P. Markopoulos, M. Soede, Ambient intelligence, ethics and privacy. Gerontechnology 2007; 6(3): 155-163.* Networked and ubiquitous information and communication technologies (ICTs) and ambient intelligence are increasingly used in the home environment to facilitate independent living for older adults. These systems collect and disperse a high volume of personal data, which is used for assistance and monitoring by professional carers in order to provide more responsive care for high-risk individuals. These personal data are often also sent to commercial service providers. The computerisation of the home environments, while providing many positive potential uses, goes together with concerns about privacy, sensitivity of data, ethics, and the inclusion of all groups of older adults, also those with dementia. It is arguable that 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. Also, 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. While principles hold just as much for the internet domain as for ambient intelligence, the complexity and diversity of the latter call for extra care to ensure transparency for the older population.

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In the ageing populations of the industrialised world, the older adults, of ever increasing number, want to maintain physical independence, autonomy and quality of life. This is expressed in the desire to remain living independently up to a high age, even when health is already declining<sup>1</sup>. Older adults see the use of a very diverse range of technology and accompanying services as a solution to facilitate independent living and compensate for decline in vitality. Moreover, there is a

push on older people by the technology-driven society to incorporate technology, such as internet banking, into daily life. Information and communication technologies (ICTs) form a substantial part of all technology around us, and are becoming an omnipresent part of the living environment. At the same time, these ICTs collect and disperse a high volume of personal data, and are becoming increasingly intelligent and autonomous. Governments and professionals delivering services use net-

worked technologies to assist and monitor their citizens and clients. Privacy and ethical implications of networked, ubiquitous technologies in and around the home environment are of rising concern, and possible 'Big Brother' scenarios, in which industry is monitoring citizens, loom around the corner.

This paper provides a brief introduction to intelligent technology and the purposes it is used for. Moreover, the paper discusses privacy and ethical issues concerning the collection of data, as well as protection of (vulnerable groups of) older adults against misuse, and the responsibility for, and legislation concerning, this matter.

## TECHNOLOGY IN THE HOME ENVIRONMENT

From the early 20<sup>th</sup> century AD, dwellings were increasingly equipped with electrical devices to make life easier. This electrical revolution continues to the present day. Today's dwellings contain various technologies to support household activities, to provide comfort, and when needed, to assist in activities of daily living. The computerisation of our residences that started around 1980 not only led to many people having a PC, but also to the introduction of domotics or home automation systems<sup>2</sup>. In the near future homes are expected to serve as an integrated part of an ambient intelligence environment with situated and distributed services that will learn from individual users and the actual environment and can constantly react to changes in environmental conditions or user needs and capabilities<sup>2,3</sup>. The integration and use of technologies in the home environment of the current generation of older persons is somewhat challenging, but as the next generation ages this cohort will be much more familiar with, and thus potentially more accepting of, such innovations.

The wide range of (networked) technological possibilities in the home environment of older people is shown by the model of Stefanov et al.<sup>4</sup> of a health smart home

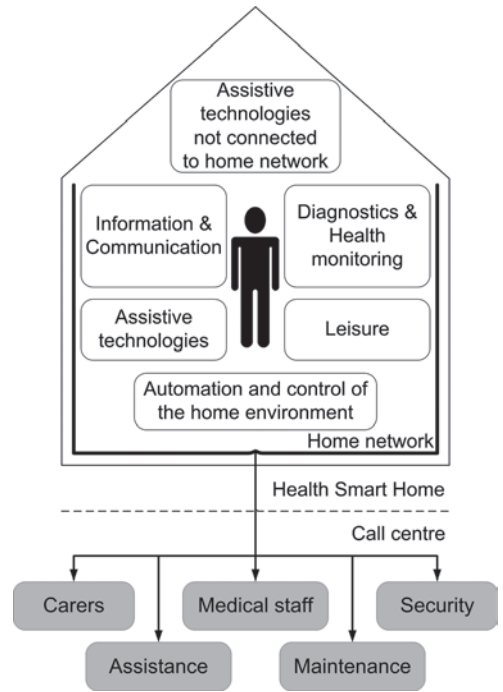


Figure 1. Various forms of technology transmitting data in an intelligent home environment. Adapted from Stefanov et al.<sup>4</sup>

(Figure 1). For the purposes of this investigation, we distinguish between two kinds of technologies: (i) assistive technologies and devices that are not connected to a network, and (ii) state-of-the-art ICT-solutions, connected to a (single) home network. In Figure 1, the home network is connected to a call centre that includes medical staff and carers along with assistance, security, and maintenance services. In practice, governments, family and yet unknown parties could also be linked to the network and have access to data.

## WHAT DATA ARE COLLECTED?

All networked packages and services in the home environment collect and transmit some form of data. These data range from simple logs of internet behaviour to more sensitive data on banking and very private or intimate data on health status. Most of the data are gathered via a broad spectrum of devices, including PCs, sensors and mobile telephones.

In Stefanov's model (*Figure 1*), the package 'diagnostics and health monitoring' includes the monitoring of vital parameters, such as heart rate or behaviour, and even advanced chemical analysis and (on-body) diagnostics. Accompanying tools can be used to facilitate care. There are many examples of telecare, telemedicine and home health monitoring via video links<sup>5,6</sup>. There is equipment available on the market place to monitor one's body temperature, body movement, and blood coagulation properties. When concerning diagnostics, data are judged by a distant medical expert. Particularly in areas with low density of professional carers, telecare offers a solution, because of reduced travel costs and saving of time<sup>7</sup>.

Assistive technologies that are connected to the home network include systems for movement assistance, fall prevention, and track & trace systems, along with devices for physical rehabilitation and fitness. Additionally, this category of technology allows for self-management by providing services for shopping, banking and dressing.

The package 'automation and control of the home environment' supports the control of the physical indoor environment, i.e., temperature, ventilation and lighting, as well as home security devices or automatic kitchen equipment.

Information and communication devices supply information to, and allow communication with, the call centre, and transfer data, images and sound.

Leisure devices give comfort to people living alone, and even enhance social networks. Moreover, these devices can provide cognitive stimulation and distraction.

All above mentioned technological packages within the model of Stefanov are part of (commercial) services for older adults. A better delivery of services could be reached by optimising profiling and

matchmaking processes. Occupational therapy offers a 3-dimensional model for generating a profile based on one's personal characteristics such as interests and abilities, environment and activities (the Person, Environment and Occupation model). These parameters form the basis of an individual profile, from which a match can be proposed by adding technology, training the person, or changing the environment<sup>8,9</sup>. Matchmaking concerns bringing individuals into couples, for instance, patients and doctors, and consumers and products. Quality of the delivery of services is determined by the matchmaking process itself, by the properties of the ICT infrastructure, and of course by the available privacy-related information.

## ETHICS AND PRIVACY

Good ethical practice involves asking questions that concern dilemmas that can arise when considering the appropriateness of technology for a certain person or groups of persons having certain characteristics. Ethics and privacy-related issues of modern ICT are closely linked to a limited awareness of the presence of these technologies due to miniaturisation and concealment. The latter two, however, are of extra importance to owners of small dwellings and those who may start to consider their dwelling more as a hospital than as a real home once it is equipped with technology needed for health monitoring after a life threatening event. If data collection takes place in an unobtrusive, non-invasive way, in the home environment that is considered to be a safe haven, one might forget about the implications of data collection and transmission. At the same time, this form of unobtrusive technology would disturb the occupant to a lesser extent than, for example, a periodical interruption by a visiting person<sup>10</sup>.

Nowadays, several data are already collected of which citizens are not aware, such as on energy and water use, telephone calls and time of internet banking.

Citizens are less aware about the data collection by health assurance companies in order to gain more insight in the use of health care and in order to profile their insurance policy. In case of daily shopping, citizens make an active contribution to data collection by supermarkets by use of their customer cards. In the latter case, privacy apparently is not the most important issue for citizens. This will, however, not always be the case when health data or data on care use are collected. The question remains to what extent data collection is privacy-sensitive? Older adults attach important value to security in and around their home. Qualitative studies by care professionals found that in relation to video monitoring, some older adults even prefer being monitored in the bathroom while being naked, than running the risk to fall or lie unconscious, incapacitated or even dead. In our society, such a situation is ethically totally unacceptable. We find it intolerable to leave a person undiscovered, whether he or she is still being alive and in need of care and contact, or deceased. In case of emergency, when human lives are at stake, the ethics and privacy situation should change and the closest person, a neighbour or anyone passing by, should be informed about such a critical situation.

## Misuse and protection

There are three core issues related to the misuse of technology designed to protect people: (i) safety and reliability, (ii) data security, and (iii) human integrity.

At a basic level, the protection of people starts with the safety and reliability of the equipment. Sensors used should be non-invasive, reliable and sustainable, easy to maintain in case of defects, and able to identify and communicate with the user<sup>11</sup>. Moreover, technology should be easy to use, and have maximum resistance against improper use by experienced or first-time users. It is of the utmost importance that people remain in control of the monitor-

ing and data streams, even when individual control options seem to disappear from sight.

When collecting and transmitting large volumes of personal data via ICT, another key issue is how to deal with security and protection of the data and information against misuse by government, professionals, relatives or criminals? Technology has provided solutions such as firewalls, digital user identification and authorisation. Sadly, these systems can be overruled, and data can be accessed for misuse by others, leading to fraud or unwanted monitoring. Worries about Orwellian notions of Big Brother are frequently mentioned, pertaining to the fear that central governments or local authorities are excessively monitoring their citizens. The argument has been made that, at least in some democratic societies, a more actual threat might be that industry or commercial services breach ethical rules<sup>12</sup>; in such cases the governmental reaction might be a firm legal framework to prevent future misuse. While the breach of rules is dealing with the same data and information that is used by intelligent and autonomous systems, the end result will be blocking innovation and thus blocking better systems for everybody<sup>13</sup>.

Another issue is how to protect human integrity and value. In electronic tagging, the very personhood of people who are being watched over is under pressure. Modern ICT is a very acceptable means of supplementing care giving, but should not be directly used as the sole substitute for proper personal care and face-to-face contact. One could therefore question whether data collection should be carried out by a care centre that has many interests to serve, such as achieving a certain level of productivity and targets. Care centres could in fact stimulate contact with clients by having insight in the lifestyle of citizens. Another point is that clients do not only need care or care-related contact, but also

support or access to other platforms for leisure or for contact with other citizens. Information should be presented in such a way that a third person does not have access to a person's heart rhythm files, but that separate information is combined to determine a pattern of behaviour: what food are you buying as a chronically ill patient, are you regularly taking your medicine, do you refrain from taking necessary rest or refrain from activity programmes? For instance, a health insurance company should not have access to certain data that might lead to adjustments to one's insurance premium.

## Dementia

A particularly vulnerable group of older adults are those with dementia. This ever increasing group, an estimated 24.3 million people worldwide<sup>14</sup>, has specific needs given their physical and cognitive status. According to carers, the complexity of contemporary technology plays a role in loss of abilities and can have a disabling effect on the person with dementia syndrome<sup>15</sup>. Some studies have been conducted on the utility and usability of technology for older adults with dementia in home care situations<sup>16,17</sup>.

Especially for this vulnerable group, technology and equipment should (i) not require any learning, (ii) look familiar, (iii) not remove control from the user, (iv) keep user interaction to a minimum, and (v) reassure the user<sup>16,17</sup>. Ambient intelligence may meet all five criteria, in particular because the support devices are invisible to the user, and since ambient intelligence forms a self-learning part of the environment where one lives itself.

Investigations of needs of users by Orpwood et al.<sup>17</sup> resulted in a number of key issues to be addressed in the technological home environment. These include the support for use of cookers, baths and hand-basins, support to prevent leaving the house at inappropriate times and sup-

port for finding lost items, and reminders about daily activities, as well as communication with friends and relatives. To cope with the problems accompanying wandering, a potentially lethal behaviour associated with dementia, track & trace systems are used, which are said not to put an unethical restraint on people. It is argued that a slight loss of liberty is acceptable in order to increase safety<sup>18,19</sup>. At the same time, electronic tagging arguably satisfies an ethical principle and decreases stigma<sup>19</sup>.

Bjørneby et al.<sup>20</sup> and Van Berlo<sup>10</sup> state that the following questions should be considered in the use of technology: (i) the purpose of introduction, (ii) degree of involvement and consent of the person with dementia, (iii) who is to benefit most, (iv) is technology replacing human input, and (v) effects on the person with dementia.

Although abilities of people may vary considerably depending on the stage of dementia and past experience with technology, it is expected that most, including many of the current generation of older adults with early dementia, do not fully comprehend to what extent autonomous ICT collect and transmit data, and by whom this data can be accessed. This makes persons with dementia, and their partner when living together in the same households, vulnerable to misuse, criminal activities, privacy breaches, and possible dehumanising treatment. An issue of concern in autonomous technology and its use with persons with dementia is obtaining informed consent, for instance, in relation to having aspects of personal health routines and other behaviours tracked. Whereas persons without cognitive impairment can decide for themselves, persons with dementia may require help from (family) carers, and periodical re-evaluation of their will to cooperate.

Current ethical practice in the field of technology and care already involves



people with a disability in will, intention and judgement, such as young children and the mentally disabled. However, the most difficult problem in ethical decision-making for dementia seems to be the degree of dementia and, for instance, the fluctuations in cognition, skills and behaviour around an average pattern that pose limitations to the degree in which technology can be understood and thus applied.

## PROTECTING PRIVACY

In many ways it appears as if privacy regulation lags behind technological developments. Data protection laws address the privacy concerns raised by the creation of databases during the 1960s and 1970s by government organisations and eventually private enterprises. This legislation put forward responsibilities for these agencies and rights for the individual, but assumed the necessity of the relevant records and the feasibility of enforcing related legislation.

These assumptions are challenged in the era of internet use, and even more so as we move into the era of ambient intelligence, which promises to intensify data collection in kind, frequency and volume. Private individuals are confronted with ever more contexts in which they are invited to impart personal information in order to use a particular service. Privacy researchers have debated the choice between self-regulation by the industry and the introduction of new legislation. A middle ground proposed in the USA has been the definition of privacy standards, such as the P3P<sup>21</sup>, and the development of 'privacy critics' as technologies that would support users in assessing whether different services do or do not comply with their personal privacy preferences. These privacy critics should provide an early warning system regarding potential privacy breaches. The argument behind such technologies is that individuals will show preferences to companies complying with their personal privacy preferences, and market forces will

ensure that companies applying sound privacy policies are rewarded for doing so. In practice, however, this has not turned out to be the case.

In the context of internet use, but also in transactions of daily life, people often opt for fast gratification, enjoying a service at the moment it is offered and only appreciating privacy implications later on and usually only after problems arise. Older adults in the current cohort may not be able to appreciate the nature of the privacy implications of disclosing information about themselves, either because of the technological complexity or because of lack of awareness of how information is used and misused in a networked society. Currently, privacy researchers are examining how such technologies can transcend the domain of internet services and enter the arena of ambient intelligence<sup>22</sup>. The questions facing the use of such technologies for the benefit of older adults are how to communicate the nature of the privacy risks that older adults face, how to communicate the options they have, and how to exercise control over the information capture and dissemination capabilities of the environment they live in.

Unfortunately, the current state of affairs on the feasibility of such solutions is far from encouraging. Lacking knowledge regarding privacy risks, older adults are not able to appreciate the different choices offered to them. In a recent survey<sup>23</sup> of older and young individuals suffering from chronic and life-threatening illnesses, the seniors appeared nonchalant regarding their privacy, not being able to conceptualise how their information could be misused. Privacy critics assume the ability of users to comprehend and make decisions regarding their privacy preferences and the privacy policies of different services. Mahmud et al.<sup>24</sup> conducted an extensive survey study involving 127 middle-aged and older participants. The comprehension of simple statements regarding the privacy

policy of a hypothetical health care service was evaluated. The statements were very simplified versions of OECD guidelines for data protection<sup>25</sup>. When requested to judge whether a particular privacy policy was applied, participants' answers were only 70% correct, even when this privacy statement was repeated verbatim from the system description. It seems that the very nature of privacy and the related descriptions of privacy policies require some fine nuances to be made that are lost in the common sense use of terms such as purpose of data collection, description of intended use, purpose of data collection, and so on.

Some privacy researchers have suggested that the most important consideration from a user's perspective is to provide control for their own information<sup>26</sup>. In the context of ambient intelligence, this control becomes ever more laborious to exercise, relies on understanding complex concepts, and even requires a technological awareness on uses and misuses of this information- that cannot be assumed for the current generation of older adults.

## RESPONSIBILITY AND LEGISLATION

Since technologies are becoming an omnipresent and integrated part of the daily lives of older adults, offering a diverse range of functionalities that to some extent require the collecting and processing of personal data, good ethical practice demands for a number of actions. These include a discussion on the responsibility for these processes, the appropriateness of technology and inclusion of all types of users, the protection of users from misuse and the creation of awareness regarding privacy-sensitive matters, and, most importantly, upgraded legislation pertaining to all these aspects of home technologies.

Monitoring individuals in and around their homes imposes responsibilities upon various parties, including governing agencies and professionals. The issue of accounta-

bility and proper treatment of data is a sensitive matter. Increased government supervision often is accompanied by a loss of personal freedom. The issues concerning the responsibility of ICT are manifold, for instance, who is responsible when data is lost, or when due to a lack of electrical power, vital information is not collected or transmitted? At what time should data be destroyed by the authority in charge? Moreover, the quality of technology and maintenance it requires become increasingly important.

Technicians may acquire a new role in health care at home, and become direct players in facilitating care of care-dependent seniors. Guidelines delineating to what extent society should accept a temporary decrease in the quality of care or life in case of failure of the technology involved will become essential. The same guidelines could account for the quality of communication, stating who is in charge of treatment and who is responsible for quality and equal access to health care for all, including those without internet connections.

A combined agenda of technological and legislative developments is needed to support the wider public and especially the older population. This support could pertain to elucidating and helping these individuals appreciate the nature of the choices they make regarding the disclosure of their personal information, the legitimacy of the information disclosure they are requested to make, and the appropriateness of the data collection for the service provided. While these principles hold just as much for the internet domain as for ambient intelligence, the complexity and diversity of the latter call for extra care to ensure transparency for the older population that is in need of the comfort and security these technologies promise to provide.

The issue of privacy and ethics is not easy to address. Lack of privacy and breach of

ethical behaviour are seen as very serious. This results in a tendency to keep away from 'experimenting' around a borderline, which is still to be defined. Profiling a person can be a good method for presenting the best individual services. However, a profile can be easily misused for commercial and even criminal purposes. When a profile is used in a positive sense it should

be based on very clear decision structures and protocols. In this era of rapid developments related to privacy and ethics there is an urgent need for total transparency and clear definitions. These decision procedures and protocols are to be based on thorough research, which currently is not getting sufficient attention.

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