Chapter 5
Assistive Technologies and Issues Relating to Privacy, Ethics and Security

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Abstract Emerging technologies provide the opportunity to develop innovative sustainable service models, capable of supporting adults with dementia at home. Devices range from simple stand-alone components that can generate a responsive alarm call to complex interoperable systems that even can be remotely controlled. From these complex systems the paradigm of the ubiquitous or ambient smart home has emerged, integrating technology, environmental design and traditional care provision. The service context is often complex, involving a variety of stakeholders and a range of interested agencies. Against this backdrop, as anecdotal evidence and government policies spawn further innovation it is critical that due consideration is given to the potential ethical ramifications at an individual, organisational and societal level. Well-grounded ethical thinking and proactive ethical responses to this innovation are required. Explicit policy and practice should therefore emerge which engenders confidence in existing supported living option schemes for adults with dementia and informs further innovation.

5.1 Introduction

For the person with dementia, information and communication technologies (ICT) can support community-based alternatives to long-term institutional care (Hughes 2002; Baldwin 2005). As disease progression adversely affects individual cognition, functional ability may decrease and risk scenarios for the individual increase. Technological devices potentially have a strong and positive role to play as part of an integrated supported living option. Within this paradigm ethical issues emerge

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which require sound thinking to generate robust policies and secure systems to underpin practice and ensure privacy.

Whilst technology items per se can be considered as "neutral" devices, the application within services generates care scenarios that are often complex. Within these complex scenarios ethical issues can occur when technology is used as an intervention in the life of the person with dementia. Major concerns are the right for protection of personal data (privacy), the rights of the elderly, and integration of persons with disabilities (Stanford Encyclopaedia of Philosophy 2005). For any intervention, the principles of free and informed consent of the person concerned must be respected, taking also into account that persons with dementia should be assumed to be vulnerable (Stanford Encyclopaedia of Philosophy 2005).

Information security must be built into any assistive technology to ensure confidentiality (privacy), data integrity, availability and accountability. In particular personal information must be stored securely, and devices for accessing this information must be secured against unauthorised access to information.

Finally, ethics, privacy and security are not possible unless the system fulfils some basic quality criteria. Of particular concern is providing functionality corresponding to user needs, usability to ensure that the needs can be fulfilled, and reliability to ensure that the system is available, does not have security weaknesses and adheres to agreed quality assurance protocols such as ISO 9126-1 quality assurance for software engineering.

5.2 Technology Options from a User Perspective

This chapter presents information on a wide spectrum of technologies that are, or will be, commercially available to support adults with dementia. These range from single stand-alone devices to fully networked integrated systems. Various contributors have suggested ways to conceptualise the technology components, most of which assume a technology perspective. For example, Dard (1996) focuses on the flow of information within the home, Barlow and Gann (1998) concentrate on the technology and Jedamizik (2001) emphasises the control and information available to the user. Aldrich (2003) proposes a hierarchical classification, from the users perspective, which retains a focus on the functionality of the technology. Various levels of communication attainable are highlighted and differentiation between systems is affirmed between those systems which can learn from those that can't; and those systems which retain a constant awareness of tenants and those that don't. The Table 5.1 below outlines the five hierarchical classifications and the devices and applications emerging within social care.

Within literature diverse terms are applied when disseminating information relating to technology use for people with dementia. On occasions a technology descriptor is used as in *social alarms* or *preventative technology*, whilst sometimes a descriptor for the resulting service applications is applied, for example, *smart homes*, *telecare*, *context aware home*, and the *ubiquitous home*. It is possible that

Table 5.1 Five hierarchical classes of smart home (Aldrich 2003)

Classification	Description	Application
1. Homes which contain intelligent objects	Single stand-alone appliances and objects which function in an intelligent manner	Talking calendars; big button picture telephones http://www.atdementia.org.uk
2. Homes containing intelligent communicating objects	Appliances and objects function intelligently and may exchange information between one another to increase functionality	Hillmount Close Supported living option for people with acquired head injury and complex physical disability http://www.cedar-foundation.org
3. Connected homes	Internal and external networks may be present allowing interactive and remote control of systems. Access to services and information from both within and beyond the home may be facilitated	Sydenham Court technology enriched supported living option for people with dementia, Belfast Northern Ireland
4. Learning homes	Patterns of activity in the home are recorded and the accumulated data are used to anticipate user needs and to control the technology	Adaptive Home Colorado http://www.cs.colorado.edu/~mozer/house
5. Attentive homes	Activity and location of people and objects within the homes are constantly registered and this information is used to control technology in anticipation of the occupants needs	The Aware Home Colorado http://www.awarehome.gatech.edu/

two similar services integrating the same technological components are described in very different ways! This can be confusing when trying to source information to assist with service innovation and development.

5.3 Ethics

Ethics can be described as the constructed norms of internal consistency regarding what is right and what is wrong. From this a systematic reasoning of how we ought to act in a given situation should emerge, where reasoning is guided by our internal values and morals, the expectation of wider society and the codes of ethics that govern professional practice. Dubois and Miley (1996) suggest a distinction between microethics (principles and standards that direct individual practice) and macroethics (which deal with organisational arrangements and social policy).

Ethical theories encourage consideration of dilemmas from differing perspectives. Dentological theories of ethics suggest that interventions should be considered in relation to pre-existing duty-based requirements within the given scenario. Within this paradigm the measure of rightness or wrongness of an action is not considered in relation to the consequences it evokes. Legislation often supports the dentological approach, consider, for example, the values embedded within the articles of the European convention on Human Rights; right to life is protected by law, no one shall be subjected to inhuman or degrading treatment, everyone has the right to liberty and security, everyone has the right to respect for private family life, home and correspondence.

In contrast consequentialist theories suggest that in reflecting on the ethical aspects of a scenario the consequences of the action should assist with decision making. Within this approach *ethical egoism* suggests that an action is morally right if the overall consequences are favourable for the person carrying out the action; *ethical altruism* considers the consequences for everyone except the person carrying out the action.

Hughes and Baldwin (2006) suggest that when considering ethical issues in relation to dementia care, rather than choose between a theoretical approach, it is appropriate to take a principle-based approach. The principals that should inform ethical practice in this subject area stem from the four principles of medical ethics (after Bjørneby et al. 1999):

- Autonomy: people should be able to decide what they want to happen or be done to them.
- Beneficence: we should try to do good to the people we care for.
- Non-maleficence: we should try to avoid doing people harm.
- Justice: people should be treated fairly and equally.

5.4 Privacy

Privacy as a concept is neither clearly understood nor easily defined and yet the fear of a loss of personal privacy, specifically related to information and communication technology receives a lot of media attention (Tavani 2007). Specific concerns relate to the amount of personal information that is gathered, the speed it is transported (raising concerns about its accuracy), the duration of time that personal information is stored and also the kind of information to be transferred. Tavani (2007) summaries three views of privacy as

1. Accessibility privacy: which is physically being left alone or being free from intrusion into your physical space.
2. Decisional privacy: relates to the freedom to make personal choices and decisions.
3. Informational privacy: which concerns control over the flow of personal information, including the transfer and exchange of information.

Moore (2000) considers that an individual has privacy in a particular situation if they are protected from intrusion, interference and information access by others. It becomes possible to differentiate between having the right to privacy and having privacy in when particular conditions are satisfied. Moore also states that privacy is an outward expression of the core value and personal desire for security.

To protect the privacy of the user of assistive technology, the aim of assistive technology and the way it is used by service providers or care organisations, as well as how personal data will be handled by care personnel and processed electronically, must be described explicitly in a privacy statement and communicated to the user.

The privacy statement should include the name and function of the person who has final responsibility for the daily processing of the personal data; the location where the data are stored in paper and/or electronic form; the specific aim, content and usage of the data and the person(s) who informs the user about this; the person(s) that can be contacted if personal data prove to be incorrect; and measures that are taken to prevent inspection, mutation or removal of data by unauthorised persons.

Personal data should be processed only after explicit informed consent of the user. Access to personal information, and sharing with other professionals involved in the care provision, should be well controlled, with protective measures explicitly articulated to the person with dementia and – to a varying degree – the informal carer(s) (Martin et al. 2007). Consent to such access and sharing of information can be given, withheld or withdrawn at any time. Situations of non-consensual disclosure of personal information must be highlighted to the person with dementia and their carers and the point of seeking consent to use the device or service. It must be clearly stated in which scenarios or situations this would be deemed to be a necessity, and how this decision is reached weighed against attendant risks of non-disclosure.

Additional measures to recommend are to store personal data in devices only if necessary for the goal of assistance or care and for as long as necessary, then deleting them or transferring them to a secure central location if there is reasonable expectation that the user will benefit from it in the (near) future.

5.5 Security

Computer security has been defined as having three elements of confidentiality (protecting against unauthorised disclosure of information to third parties), integrity (preventing unauthorised modification of data and files) and availability (preventing unauthorised withholding of information from those who need it when they need it) (Kizza 2003). The concepts of privacy and security are often linked. Security issues can be considered under three broad categories:

1. Data security – which is either resident in or exchanged between computer systems
2. System security – relating to hardware and software

3. Network security – including networks and the internet (Spinello and Tavani 2004; Tavani 2007).

Making technological systems secure is a complex task and should therefore be done in a systematic manner; for example, following standards such as ISO-17799, used as a code of practice for information security management. When developing and field testing pervasive healthcare services and technologies for people with dementia, the main security themes to consider are System Access Control, Computer & Network Management, Security Organisation, and a Security Policy that ensures Compliance with regulations and user requirements. In addition, good practice for systems development and risk analysis should be used.

Healthcare systems for people with dementia will be accessed by different stakeholders, for example, carers (staff and relatives), the persons with dementia themselves and technicians. Access should be protected by strong passwords or better mechanisms. The person with dementia presents a special difficulty, as requiring a password would be difficult for them to remember and use. Therefore automated authentication methods must be considered, for example wearing a wireless authentication badge or face recognition.

All computer and network equipment must be protected from theft and misuse. In particular computers in the home must not retain the sensitive personal data of the person with dementia any longer than absolutely necessary, deleting it, making it inaccessible or transferring it to a central secure storage. All communication between physical nodes must be strongly encrypted.

A security policy should be created that ensures that ethics and privacy issues are respected, and that information security is not breached. A security sub-group could be created that checks that the security policy is not violated, and assists personnel involved in the operation of services to maintain security.

Schneier (2004) considers it appropriate to view security as a process not a product of the technology. He argues that risk assessment is key to this process and that attaining perfect security would in effect render a system useless. This is contrary to the view of Kizza (2003) who considers that complete security can be achieved if mechanisms for deterrence, prevention, detection and response are in place.

5.6 Discussion on Ethical Practice and Technology Use

Ethical issues clearly exist in the use of technology with people who have dementia. As stated previously technology devices are neutral; however, the integration into care scenarios for people with dementia makes it complex. Whilst this could be argued for all services that utilise technology the confounding factor when supporting adults with dementia is the altered cognitive capacity of the person receiving the service. Within the legal framework supporting service developments/delivery and the generic rights of citizens within democratic societies it is therefore crucial that ethical concerns are debated thoroughly and resolved in a transparent manner.

At an organisational level it is crucial that the use of technology to support people with dementia is informed by an ethical framework, which is translated into explicit organisational policies and procedures, informed by legislation and national policy. This activity needs to be undertaken in advance of thinking about what products or systems could be used. Organisations need to educate and empower their staff for the responsibilities of using technology and think through how it is to function in the care model.

All practicable efforts to seek informed consent should be sought. The different stages of the dementia condition, variance in cognitive function, the environment (Day et al. 2000) and even the time of day (Jacques and Jackson 2000) can affect the individual's capacity to understand and consent to a particular intervention. However, it is unacceptable not to have ensured that all efforts have been taken to seek consent and provide information to the person with dementia, unless this right has been designated to another person (Bartlett 2005).

Evidence exists to demonstrate that people with dementia are repeatedly excluded from consultation about aspects of their care (Allan 2001; Clare 2004). A predominant culture remains within which what people with dementia say is viewed as unreliable or lacking content (Weiner et al. 1999). The move towards consulting and listening to people with dementia is slow and involves changing from an emphasis on the pathology of the condition to the potential of the individual (Reid et al. 2001; Dröes 2007). If consent is to be really sought from the person with dementia then the organisation seeking to use an assistive technology must have ensured that staff are trained in a range of communication methods; otherwise the person with dementia has been denied their rights.

The ethical framework applied to the use of assistive technology in dementia care cannot be limited to the care organisation or individual responsible for a piece of equipment. The technology companies who make and supply devices also carry ethical responsibility for their practice. Technology products can at times appear to be a quick and easy solution to a problem. A technology company has an ethical responsibility to fully inform those considering a purchase of the possible implications of use. In the context of people with dementia, an ethical technology company should seek to find out what the problem is and support the customer in thinking about all the possible solutions before encouraging the sale of an assistive technology.

5.6.1 Explicitness, Legal and Procedural Context

The prevalence of supported living environments with embedded technology to support older people with cognitive impairment is increasing. At the meso/macro level the coordinating organisation should be explicit how electronic assistive technology is used within care options. The aims and objectives of using such technology need to be explicit and the legal and procedural context in which it can be considered also needs to be understood.

5.6.2 Person-Centred Approach

It is preferable that a person centred approach to care is followed and it should be an easy assessment process to identify all the tenant's care needs and why assistive technology is being considered. These points are very important, especially with equipment that is monitoring or gathering data on a person. The use of technology should not be considered as a separate part of an individual's care, but additional to the care offered by professionals and integrated into the overall care planning process.

5.6.3 Care Staff Training

At an operational level care staff need to be trained in how to care for and respond to people with dementia and how the technology is integrated into the care process. Approaches to supporting the person with dementia need to be well established. For example, in some home-based caring scenarios rather than have a sensor switch to disable the cooker at all times, support staff could either check after meal times that the cooker has been switched off or provide a member of staff to accompany the vulnerable older person during meal preparation if required.

   Location technology has been used both in the community and institutional care settings for people with dementia. "Tagging" is at times still used as a term to describe this or similar devices. This technology can be used in a variety of ways; it can alert the care provider if the vulnerable person is approaching an exit to leave the building, it could enable staff to locate the person if he or she is out, unattended, in an agreed area. This may well enable the older person to remain an independent walker; however, it could also be that on occasions the person is amenable to be accompanied when walking. Tagging technology is one that has attracted substantial adverse media publicity (Clarke and Keady 2002). The risks associated with independent walking to the user may be high. Based on the recent evidence, it has been established that nearly 25% of people in care homes who "wander" experience a fatal or serious injury (Stanford Encyclopaedia of Philosophy 2005). On the other side fall incidents can also be diminished when, e.g. during the night, assistive technology alerts the caregiver to offer support to the elderly person who goes to the bathroom (Lauriks et al. 2008). A blended approach to technology integration into care seems to be a more appropriate approach, rather than a prescriptive application in all scenarios.

5.6.4 Protection and Paternalism

The theories of ethics, and principles of good practice outlined above can help to establish a good ethical approach to services, as they provide both an organisational macro-ethical framework and consider issues in relation to the individual. However, how can these issues be adequately considered if the service user either doesn't or hasn't the mental capacity to consent to technology use as part of her care package?

Is it then justified for the care providers or relatives to promote this approach on the basis that the individual will be better off living in this supported housing scheme (rather than institutional care), or that the technology will ensure the person will be better protected from harm?

This raises the issue of "paternalism" which is the interference of a state or individual in relation to another person, either against their will or when the interference is justified by a claim of better protection for the individual. This is important in applying ethics into situations of reduced cognitive capacity. Does a trade-off exist with regard to the desire to put in place best practice to benefit the welfare of the service user and their right to make their own decisions?

Dworkin suggests that certain conditions can be considered when aiming to establish if paternalism is present (Stanford Encyclopaedia of Philosophy 2005). These conditions concern the service user (X), the care provider (Y) and the use of technology (Z).

- Does the application (or omission) of technology (Z) interfere with the liberty or autonomy of the service user (X)?
- Does the care provider (Y) use technology without the consent of the service user (X)?
- Does the care provider (Y) use the technology (Z) because of a belief that it will improve the welfare of the service user (X)?

Can the care provider demonstrate that the use of tagging technology doesn't limit the liberty or autonomy of the user rather than justifying its use under both a duty-based approach to care and considering the consequences of not using available technology? Is paternalism always wrong? Is it plausible that paternalism in the case of some individual users is acceptable when the act of using the technology is intended for their benefit? In this instance it is crucial that the means by which ethical issues are addressed and the good brought to the service user can be highlighted.

Paternalism aims to protect people from themselves, assuming their safety is more important than their liberty. This contrasts with "harm principle" suggested by Mill which cites that limiting liberty can only be justified to prevent harm to others, not self harm although this can only be applied in circumstances of clear cognitive ability.

It is conceivable that a paternalistic approach emerges as the predominant ethos within a technology enriched supported living option for people with dementia, if attempts are not made to establish the individuals' beliefs and values in relation to living in this type of care model. How then can the care provider clearly demonstrate application of the four principles of medical ethics described above?

5.6.5 Information, Demonstration and Individual Consent

Consider then again a service user who is planning to move from home to a supported living option. It would be good practice for this person and his or her main

family/carers to visit the facility beforehand. A prearranged visit provides the opportunity to experience the living space, meet with staff, other residents and see the technology on offer. At this point service staff could give the user information on the facility, outline technology on offer and specify why it is used. An individualised profile of preferred assistive technology might also be discussed. The provided information should capture both the organisational ethical approach, and in layman's terms explain the ethical approach used in relation to individual service users.

Information could be provided in printed copy to take home, and a demonstration of the technology in use should be available during their visit. Scenarios of technology use could also help clarify the potential of the devices and the consequences of their use; for example, the benefit of a picture phone which may enable independent contact with close family members. However, for the relative it could also generate a high volume of calls on a regular, unmonitored level if memory problems result in the user forgetting previous contact.

In relation to the sensor data that are gathered the operational implementation of this could be explained. How the data are kept safe, so that privacy is guaranteed, who has access to the computer system, and who has the authority to alter sensor functions or generate reports. It should be clearly explained how the data will be used, and when it will be shared with other professionals involved in care provision. Again scenarios can be used to explain this to both the user and her family so they fully understand how the technology is integrated into the overall care process. A discussion on the importance of consenting to live in the type of supported living option could be initiated at this point, to include highlighting implications for the service user and her family as cognitive capacity declines. In relation to this it should also be explicitly discussed with the persons with dementia and their carers that assistive technology cannot prevent people with dementia from all problems and risks that are a consequence of the disease (such as dangerous behaviour, falls, wandering at night, disorientation). This means that risk factors associated with the disease and with the execution of daily activities will be prevalent, also with the use of assistive technology.

Kurzweill (2005) suggested the ELSI (Ethical, Legal, Social Implications) model as guidance to the development of an ethical framework to guide researchers. However, others (Weckbert and Moore 2004) consider that this ethics-first approach may have problems as it requires thorough determination of the specific harms a technology may do in advance, arguing (specifically in relation to nanotechnologies) that a continually reflection on ethical implication is required.

5.7 Summary and Conclusions

Ethical issues abound in all aspects of interventions to support adults with dementia. Whilst technology may have a positive role to play in supporting people with dementia, it may not be appropriate for all individuals, or it might only be considered for some individuals, some of the time.

Organisations should give ethical consideration to using technology enriched care provision to reflect both organisational ethos and the service approach at an individual level. If an organisation is to use assistive technology they need to have informed policies and procedures using an ethical framework that is defined by their national legislation on the protection of the rights of citizens with dementia. Such a policy must be integrated to the overall care approach and not be considered as a separate intervention. If such structures are in place then technologies are more likely to be used to positively support the lives of people with dementia avoiding a paternalistic delivery of care.

Appendix: Checklists to Assist Using Technology with People Who Have Dementia

When technology is used checks need to be in place that ensures the following questions are addressed:

- Has consent been sought from the person with dementia about the use of technology in their care, using skilled personnel and appropriate communication methods?
- Has a date been set to review the use of this technology intervention? Is it accepted by the user and does it support the care process?
- On what aspects is the effectiveness of the assistive technology in the care of the person evaluated and by what methods?

For Professionals and Field Test Personnel

- Professional carers and system administrators must have knowledge of key principles of healthcare confidentiality: privacy, explicit or implicit consent, and conditions for non-consensual disclosure.
- Since persons with dementia are vulnerable, they shall be given all necessary support to understand the confidentiality issues and express their wishes. The individual's ability to understand, retain and weigh up information as well as communicate their decision should be examined.
- The consent should be given until end-of-service, i.e. until end of user test, death or explicit withdrawal of consent, so that the consent also covers later stages in the disease when the person with dementia might be incapable of giving consent.
- Personally identifiable data shall be deleted and made non-recoverable on the test equipment as part of uninstallation.
- Using staff from other agencies requires explicit consent and possibly formal information protection agreements.
- Necessary secondary uses of information (for example, for payments or management) requires explicit consent.

- The basis for the configuration of the device should at all times be the subjective needs and wants of the person with mild dementia.
- The benefits of information sharing with the informal carer should be discussed with the person with dementia.
- In emergency situations minimum necessary confidential user information may be used or disclosed.
- Confidential data relating to persons with dementia shall be stored on secure computers, with up-to-date protections against unauthorised access and malware.

For Developers

- Security analyses should be performed at unit and system levels. It should be performed at the specification stage, and as part of evaluation. The security analysis should address requirements for confidentiality, data integrity, availability and accountability. It should specifically analyse malware threats and the potential for system abuse by users.
- An authorisation model should be defined so that any access to identifiable personal data is strictly controlled. Person with dementia access should be made by means of implicit or automatic device authentication. Accesses by all other users (e.g. carers, researchers and administrators) should require user-level authentication.
- A service model should be defined so that the persons with dementia and their carers can be informed of what kinds of information is being recorded and for what purposes.
- Build the system so that it minimises the potential to stigmatise the user. This means that devices should preferably be perceived and used as normal technology artefacts, also by people that do not suffer from dementia.
- There must be a generic way to access stored data, for system administrators (for research, emergency or legal purposes), and for the person with dementia's access to own stored data (as guaranteed by Data Protection laws).
- Data should be stored with as little identifying information as possible. If possible, the system should be partitioned into one part where identifiable personal data exist, and other parts where it is impossible to trace to which physical person some data belong.
- The personal codes that are used in data collection for research purposes, must NOT be reused in the normal operation of the system.
- Only near-future data should be cached in other nodes than where the original data reside.
- Data that are not needed anymore for the operation of the system should immediately be made inaccessible.[1]

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[1]By deleting the data, or by one-way encryption where decryption keys are stored in external protected systems.

- All communication links should be secure. Encrypted files and databases must be used for storing identifiable personal data.

For Researchers

- Researchers that execute the evaluation of the prototype with user dyads shall have no business dependencies themselves with commercial organisations within or outside the project consortium.
- Personally identifiable data must be stored in encoded form.
- Mapping collected data to individuals must use keys stored separately in locked closets.
- Only encoded data will be transmitted between sites.
- Be sensitive to the changing clinical phases of dementia that may influence the subjects' autonomy and capacity.
- Under no circumstances permit reporting of details during dissemination that would allow the identification of any subject involved.

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