Chapter 4
Assistive Technologies: Ethical Practice, Ethical Research, and Quality of Life

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4.1 Introduction

Much has been written about the benefits–for example, greater independence, autonomy, and dignity–which can derive from the use of assistive technologies with older people (Loader, Hardey, & Keeble, 2009; McCreadie & Tinker, 2005; Pols & Moser 2009). These benefits have been well researched, clearly expressed in the literature, and remain uncontested here. Apart from benefits to individuals and carers, assistive technologies can release funds for other applications, and where this is in care settings funded through public expenditure, the cost savings that might arise from their application may afford the opportunity for more effective targeting of taxpayers' resources. As the Audit Commission, the guardian of public expenditure in the United Kingdom (UK) noted, the use of technology represents the unusual possibility of providing cost savings at the same time as better service provision

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(Audit Commission, 2004). The merits then are evident. But there is a need also to be alert to the ethical questions that arise as a concomitant to the use of new technologies and to address what Mort, Roberts, and Milligan (2009) have argued is an "ethical and democratic deficit in this field which has arisen due to a proliferation in research and development of advanced care technologies that has not been accompanied by sufficient consideration of their social context" (p. 85). This chapter will raise these ethical issues, alight on the potential deficits, and highlight some of the policy and practical issues that might warrant further inquiry. It does so by addressing three key areas. First, it considers ethical approaches commonly in use and their limitations for application in the field of assistive technologies. Second, it explores the ethical issues that arise around the design and execution of research with users of assistive technologies. Third, it raises the question of whether or not assistive technologies contribute to a better quality of life (QoL) for recipients, not least because QoL is explicitly included as an intended policy outcome of the deployment of such technologies (Scottish Government, 2009; Telecare Services Association, 2010). The chapter draws its examples primarily from the experience of the UK (and its devolved polities), where the policy objectives of governments for extending the use of assistive technologies are particularly ambitious. We are mindful of the methodological pitfalls of cross-national applicability, but the discussion should have broader resonance, as ethical approaches and practices come to terms with a technologically fast-changing world. Our use of the term assistive technologies embraces the definition of any item, piece of equipment, product, or system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities (Technology-Related Assistance for Individuals with Disabilities Act, 1988 P.L.100/407); more practicably, as Cowan and Turner Smith (cited in McCreadie & Tinker, 2005) note, it refers to any device or system that allows an individual to perform a task that they would otherwise be unable to do or increases the ease and safety with which the task can be performed. We note in particular that some of the more interesting ethical challenges have arrived with the advent of telecare sensor-based technologies, which open up important issues around privacy, autonomy, and the potential for replacement of human care through remote monitoring.

4.2 The Policy and Practice Context

The policy drive toward the use of assistive technologies, particularly for the care and well-being of older people, has developed rapidly in recent years. In the United Kingdom, since 2005, there have been government programs for telecare development, with a similar program of telemedicine technologies being implemented in the delivery of health care in the community. Telecare policy now sits at the strategic heart of the delivery of care services. Care policy in the UK is a complex mix of family input, use of the private sector, voluntary organizations, and the State (see Phillips, 2007 for a useful overview). Of these, the State has long played the key role in health care provision and albeit in more complex ways in terms of funding, a major role in social care. This role played by the State in the UK should also be seen in the context of comparatively (certainly in European terms) low levels of obligation placed on family members to take responsibility, either in a legal or cultural sense, for their aging parents. Thus governments, straddled with costs but also seeing opportunities for innovative forms of care for older people are pushing the gerontechnology agenda. The telecare development program of the Scottish Government (2008), for example, proposes that by the year 2015, "all new homes, public and private, and all refurbished social housing, will be fitted with the capacity for care and health services to be provided interactively via broadband from day one of occupation (and) remote long term condition monitoring undertaken from home will be the norm" (p. 6). This policy is explicitly linked to demographic change and the rise in numbers of older people, particularly those over the age of 75, relative to the population as a whole. The nexus between an older population that may need care and a workforce able to provide this care and fund it through taxation has been expressed as the *dependency ratio* (European Union Public Health Information, 2009). A policy discourse has developed around this ratio, in which major technology providers (e.g., Tunstall, 2009) note an impending *demographic time bomb*, to the extent that this discourse readily assumes the *necessity* of technological solutions for future service delivery. This is contestable territory. To have an explicit government policy objective that telecare services grow as quickly as possible (Scottish Government, 2008) indicates that the role to be played by these technologies is already beyond debate. But there are important ethical issues raised by the increased use of assistive technologies which do indeed need the space to be debated.

4.3 Ethical Frameworks

The ethical angle is often absent or of limited import in policy discussions around increased use of assistive technologies. This might be explained by the fact that different professions engaging in human services already have ethical codes of practice (although the codes themselves are then open to interpretation). But are these codes enough to deal with rapid and innovative technological change? A review of the ethical frameworks currently employed by the various agencies engaged in the provision of assistive technologies suggests they are limited in scope. This, in part, reflects the practical reality that ethical frameworks have to be understood by practitioners and their terminology has to resonate with the care assessment process (Bouma, 2010). In the UK context, the practice of health and social care is additionally molded by a broader canvas of managerialism and performance targets (Meagher & Parton, 2004), factors which may sit awkwardly with the imprecision and uncertainty that ethical questions pose. The key framework in widest use is grounded in a biomedical approach and rests on four key principles: autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 2001). These are profoundly important concepts, but they need to be tempered by a broader range of ethical enquiry and contextual understanding, for example, the way in which they will be understood across different cultural settings or different professions. Indeed, the essentially medical nature of this approach may suit aspects of health technology, for example, telemedicine, but sit more uneasily in social care contexts. The biomedical approach usefully illuminates ethical issues about medical interventions at specific junctures in people's lives but the ongoing, and often shifting, needs of individuals in domiciliary care require a more subtle ethical enquiry. For example, what Wilmot (1997) calls the primacy of autonomy sits at the heart of much of the assistive technologies agenda. Unpacking arguments around autonomy is rarely straightforward, and the importance placed on autonomy may underplay the significance of our interdependence with each other. Furthermore, the ASTRID framework (Frisby, 2000), drafted primarily for dementia care, notes that greater independence arising from autonomy might also bring with it greater isolation, what Wilmot would term unwanted autonomy. While there is clear evidence that the use of technology, not least communication technology and the development of virtual communities, can actually alleviate isolation among older people (Blaschke, Freddolino, & Mullen, 2009), where there is the potential for technology to increase isolation there lies the concomitant risk of higher instances of depression (see Lowe, 2009). Although the notion of autonomy has a central place in discussions around ethical practice, it takes on different meanings for different groups of people. For example, in societies where there is a Confucian tradition, the full worth of being autonomous is only recognized in relation to a more complex array of interdependence and reciprocities with others (Tao & Drover, 1997). Thus there needs to be space in the consideration around the use of assistive technologies for their culturally sensitive application, especially given that the biomedical four principles that underpin the ethical frameworks are in such common use. More evidence on how these assessment decisions, balancing care, risk, and potential harm, are in fact calculated in relation to assistive technologies is needed. As Hanson, Osipovic, and Percival (2009) note in their study of the impact of sensor-based technology: "In order to make 'sense of sensors' alongside the data provided by the devices, one needs rich contextual information that is normally accumulated through social interactions between caregivers and care receivers, a two-way communication process that can best be described as a 'dialogue of care'" (p. 111).

4.4 Alternative Ethical Approaches

The argument here is that the predominant ethical framework in use around the implementation of, for example, telecare technologies serves an important but limited function. That it remains essentially a biomedical framework but is often being used in the context of social care prompts the need for other sources of ethical enquiry. This does not necessarily mean that the already complex task of assessment for the use of assistive technologies should be subject to a further accretion of ethical codes and guidelines, but a broader range of ethical thinking should be an important part of policy formation and consideration of policy implementation around the role of assistive technologies in health and care services with older people.

One such alternative ethical approach comes from the tradition of an ethic of care (Tronto, 1994). This is particularly relevant to community-based health and social care, where assistive technologies are at the forefront of new ways of delivering care services, as it is here that interaction between professionals and service users may exist on relationships developed and sustained over a longer period than in the acute medical settings that inform the biomedical approach. Barnes (2006) notes the way in which social care workers often go beyond *tasks* to develop *relationships* over and above contractual obligations, relational approaches to care that are contextual and not necessarily rule based nor uniform in application. Some older people value independence highly and might regard being the recipient of care inconvenient, at best, and indeed potentially demeaning. Others, for example, people who are socially isolated after they have lost lifelong partners, might welcome human intervention. This relational aspect to care may thus be played out quite differently in different settings. It may also, adversely, prompt reluctance by social care professionals to engage with technology and its possibilities for the recipients of care services. In emphasizing the importance of relationships in human services, we need to guard against assumptions that technologically based care is axiomatically inferior to care based on human relationships. As Pols and Moser (2009) argue "in discussions about the use of new technologies in health care, including the most recent versions appearing as telecare, there is the fear that cold technologies will be implemented at the cost of warm human care" (p. 160). However, they conclude from their research that "the opposition between cold technology and warm care does not hold, but that there are different relations between people and technologies within different use practices allowing different affective and social relations" (p. 159). So, again, it is the *specific context* in which decisions are made that is crucial. There is a risk in polarizing this discussion around human delivery of care services and technological provision. Human care services have historically been under fiscal pressure and have often denied recipients much real choice in delivery. Indeed recent evidence from the inquiry into home care provision in the UK by the Equality and Human Rights Commission paints a bleak picture of often impersonal, very time-limited, and inconsistent care delivery in which the potential for relationships to develop between carers and older people appears to be increasingly remote (Equality and Human Rights Commission [EHCR], 2011). Holding this up as an inherently better model of care delivery, when technology might enable some tasks to be undertaken more reliably, is illogical. Of course many of the care tasks discussed in the EHCR report cannot easily be replaced by technology; nonetheless, especially as fiscal pressures on care delivery for older people increase, we should be wary of assuming that human care services as currently configured are axiomatically somehow better. That said, where technologies can provide for care needs, they will be operating in a social care agenda where greater choice is the new mantra; but if service users do not want these technologies, is this a genuine choice which can be upheld at a time when households are increasingly being equipped with connectivity as part of government strategy (Scottish Government, 2008) on meeting future health and social care needs?

4.5 Remote Monitoring and Decision-Making

Further ethical issues arise beyond the immediate environment of technology use. The remote monitoring of service users–for example, through monitoring using home-based sensors–raises questions about the response to an alert in the control center which oversees the monitored spaces. Straightforwardly, decisions on how to triage alerts for intervention can be based on users' existing medical histories; thus, an alert from someone with a known heart condition might take priority over other signals for help. Beyond this, we need to understand how judgments based on responding to the demands of remote sensors are made. Intuitionism (Driver, 2007) offers up lines for reflection here. Human beings have intuitive responses to right and wrong courses of action in the face of immediate human dilemmas that are not based on calculation or recourse to abstract concepts. But are the care needs of service users who are monitored remotely perceived in the same way as they would be if there was immediate human involvement? Will decisions about a course of action be different when the immediacy of care needs is filtered through a process of remote monitoring and subsequent triaging? There is research from the use of telemedicine (Finch, Mort, Mair, & May, 2008) which suggests that human engagement involves sensitivity to user conditions that technology may not pick up remotely. In the social care context, for example, the replacement of a brief early morning visit by domiciliary carers with a remotely based telephone inquiry about clients' well-being might elicit the response from a service user that everything is fine. Feeling fine might be a culturally influenced response of not wanting to make a fuss rather than an accurate account of actual circumstances. However, domiciliary carers on home visits may intuitively sense when a clients' circumstances are not ideal, especially if they have developed a relationship with clients over time. Thus do remote decision-making processes make a difference to the quality of care and by what calculation do we maintain a supply of care workers for periods when remote monitoring is insufficient to the task of addressing care needs? These are particularly relevant issues in the context of older people, where conditions of health may alter rapidly in a short space of time. Equally, how robust, in the highly pressured world of service delivery, are the review processes that ensure equipment is being used properly and is still fit for the purpose it held at the time of installation?

4.6 The Virtuous Practitioner

Such is the complexity of factors–risk, protection, and empowerment–that attend the use of these technologies that frameworks of ethical practice in themselves may be of limited practical use and the *virtues* associated with working in the field of human services may have to come to the fore (Banks & Gallagher, 2009). This approach would link awareness of ethical codes and frameworks (which, in practice, are variously interpreted and variously employed) to the essential virtuousness of practitioners through their professional training and vocation, vocation being the underpinning sense that an individual might have about why they feel suited and committed to the work they do (see Cooper, 2012, for further discussion of this). Thus the difficulties of interpreting contexts for the use of technology might be less problematic in the presence of the virtuous practitioner, who might be expected to take the morally sound course of action. This might prove more difficult when it comes to assistive technologies, however, unless there is a highly developed common understanding of what constitutes a virtuous approach in relation to the use of technology in care settings. Equally, the increasingly fluid world of assessing for care needs across professional boundaries (where there may be different ethical codes, or at least understanding of these codes) may mean that recourse to virtue per se by dint of professional training or vocational calling is not a given. For example, in the UK, the greater incidence of interprofessional working has seen the development of shared assessment tools for the assessment of health and care needs. These assessment tools now include sections for consideration of the use of assistive technology-based solutions to these needs. The thrust of recent policy has been to assume that common datasets are sufficiently straightforward to collect, such that inconsistencies across professional disciplines will be minimal. However, research on shared assessment (Eccles, 2008) has noted inconsistencies in assessment, for example, understanding of consent, obtaining agreement from service users for information to be shared and in the quality of the narrative element of assessment (which might explore the social context in which technologies might be employed). The interest here, then, is in the consistency of assessment that recommends the use of assistive technology. Professional attitudes to care, ethical frameworks, and the use of these frameworks and vested interests in maintaining the status quo all suggest inconsistency of approach. This is not, in itself, surprising as the impact of professional domains has long been recognized (Irvine, Kerridge, McPhee, & Freeman, 2002) but how assessments are made and how older people have their care managed in the context of the use of technology across these different domains would merit further enquiry. Decision-making may well be virtuous, but consistency of understanding of what constitutes virtue is open to question, as is just how virtuous decision-making *can* be, not only across professions but in the wider context of a culture of different performance indicators across these professions (Loader, 2005). As previously suggested, there is a deficit around our knowledge of how ethical considerations play out in the course of technology-based health and social care practice. The provision of telecare technologies undoubtedly has the potential to offer significant benefits to individuals. However, the process through which informed consent to, for example, monitoring and surveillance is gained routinely highlights the inadequacies of the biomedical model in its neglect of social and behavioral aspects. Although emphasis is given to gaining informed consent, there are few tools and techniques in use to help people understand the far-reaching implications of surveillance (e.g., the fact that complete strangers in remote control rooms may be observing the individual's behavior in his/her own home). The significant potential benefits offered by such technologies are not in question, but the threat of radically changing the character of the home from being a space which has been traditionally regarded as safe, secure, and private (Twigg, 1999) does not appear to be acknowledged or evaluated in the context of existing models of telecare delivery. As a consequence, and in the absence of any alternative model of practice, the provision of information, meaningful explanation, and opportunities for gaining understanding and learning about the implications of implementation of telecare technologies do not appear to be an essential part of the process of gaining informed consent to the presence and use of telecare in the home. Furthermore, it does not appear to be part of the contractual arrangements between telecare/telehealth providers and customers (in the UK context), yet consent forms are routinely signed by end users (often vulnerable older and disabled people) without these issues being explained or discussed, nor without the opportunity to develop understanding of the profound implications for their lives. Relatives and or health/social care professionals generally advise or recommend accepting provision of the equipment. In some cases, older people are given to understand that if they decline such provision in their home, then the only alternative is to be put into a care home. Thus ethical questions raised by the delivery of technology-based care need to be acknowledged and debated, but the pressured world of policy making and service delivery in health and social care for older people is one in which there is unlikely to be time adequately to reflect on them.

4.7 Research on Assistive Technologies

We now turn to ethical issues that arise more specifically from research around the use of assistive technologies with older people. We start by noting the inconsistencies of approach in ethical considerations around assistive technology research in UK universities before discussing research in the human–computer interaction (HCI) design field in the higher education and commercial sectors and the telecare delivery sector.

There continues to be a growth of interest and attention to research ethics internationally. In the UK, this came about in large measure as a result of the wider impact of the Alder Hey inquiry that reported in 1999. The findings revealed by the inquiry were that hospitals within the National Health Service (NHS) were retaining patients' organs without family consent. The inquiry was sparked by the death of 11-month-old Samantha Rickard, who died in 1992 while undergoing open-heart surgery at Bristol Royal Infirmary. Questions about the quality of pediatric cardiac surgery at Bristol led to a public inquiry. The inquiry learned about the large number of hearts held at the Alder Hey Children's Hospital in Liverpool. An investigation was opened in December 1999, and in January 2001, the official Alder Hey report (also known as the Redfern report) was published. It had been found that the unethical and illegal stripping of every organ from every child who had had a postmortem had been ordered by pathologist Dick van Velzen, while he was in post at the hospital. It was also found that over 104,000 organs, body parts and entire bodies of fetuses, and still-born babies were stored in 210 NHS facilities in addition to 480,600 samples of tissue taken from dead patients (BBC News, 2001).

Although this inquiry was concerned with *clinical* research, its impact and ramifications have since been felt more generally across the social sciences. In 2010, the UK Economic and Social Research Council (ESRC) produced a second ethics framework that must be followed by researchers bidding for research funds (ESRC, 2010). This framework includes stipulations such as:

- Research staff and participants must normally be informed fully about the purpose, methods, and intended possible uses of the research; what their participation in the research entails; and what risks, if any, are involved.
- Research participants must take part voluntarily, free from any coercion.
- Harm to research participants must be avoided in all instances.

The importance given by research councils who provide funding is clear thus, for example, the ESRC (2010) notes:

> Breaches of good ethics practice … could result in the immediate suspension of the individual project and other projects based at or under the co-ordination of the contracting institution, and a halt to the consideration of further applications from that institution (p. 4).

Other reasons for the heightened interest amongst social scientists of ethical concerns, particularly regarding research involving older people, may include fear of litigation in the event of negative consequences, growing concern about the scale of care provision required for older people, and the associated drive to implement telecare technologies as a response.

In line with this growth of interest and attention to research ethics internationally (UNESCO-CEPES, 2004) and in the wake of the Research Assessment Exercise (RAE) of 2005 in the UK, Higher Education institutions established Research Ethics Committees (RECs). All proposals for research involving people now have to be approved by the REC of the researcher's institution prior to data collection and/or fieldwork commencing. However, as will be seen, the many ethical frameworks that have evolved in higher education institutions are diverse in the approach they take and in the underpinning principles they reflect.

4.8 Older People's Participation in Research

The ethos regarding the participation of older people in research has changed over the past decade from one where they are regarded primarily as *subjects*, required to provide data for research, to a far more inclusive approach where they are seen as research *participants*. This change has brought with it the growing recognition among some of the research community that the needs and characteristics of older participants in research are deserving of respect and due consideration. It might reasonably be expected that the increased emphasis given over the past decade to the formulation of ethical frameworks and procedures would reflect this concern to safeguard and promote the physical and psychological well-being and dignity of these participants. Recent research (Sus-IT Project, 2010) into the ethical frameworks of a sample of eight UK higher education institutions sheds light on this. It should be emphasized that the documentation scrutinized may not have been the primary ethical policy/procedure documentation available from these institutions, but nevertheless, it was the documentation that participants were aware of and considered most relevant to their work. The documentation was examined for text on four key considerations each of which was considered essential for the ethical engagement of older people in research and informed by long experience of several of the investigators, established expertise of colleagues at the University of Dundee and by key literature (ESRC, 2010; The Belmont Report, 1979; The British Psychological Society, 2009; The Nuremberg Code, 1949). These four principles were:

1. The risk of harm: significant psychological or emotional distress to participants
2. Maximizing benefit (principle of beneficence)
3. Principle of respect for persons, that is, acknowledgement of the dignity of individuals
4. Special consideration of older people in research practices, procedures, and methods

How were these principles used in conducting research in the UK universities under consideration? Drawing on the first category, the attempt to minimize risk to research participants, it appears to be standard practice for participants to be risk assessed in terms of their physical and mental health prior to participating in any research study. The ethical procedures did in most cases explicitly state that any risks that may arise during the study must be explained to participants prior to the study. The ethical framework documentation varied, with only two institutions giving brief instructions regarding how to complete an ethical research protocol. Some ethical framework documentation also mentions the risk that the researcher can pose to the participants. The framework supplied by one university specifies that it is necessary for the researcher to undergo Criminal Records Bureau checks and reference checks prior to consent being given for them to conduct research. The second key consideration, the principle of beneficence, was not mentioned in five of the eight sets of ethical framework documentation. The third key consideration, respect and dignity, did not feature in four out of the eight ethical frameworks examined. The fourth key consideration, explicit consideration of the needs and characteristics of older people, was found in only three of the eight sets of ethical documentation received. One institution clearly states that people over 65 years of age are, by definition, *vulnerable*, but what is meant by vulnerable groups can vary from university to university, and it is not always apparent whether or not older people are automatically considered to be in this category. This is relevant because ethical procedures for dealing with vulnerable people are more demanding. Thus for all the extra layers of ethical safeguards imported into the research process in recent years, there remain significant variations in how research with older people is scrutinized in its ethical dimension.

4.9 Research in the Human–Computer Interaction Design Field: Higher Education and Commercial Sectors

The significant changes in the social, legal, demographic, and economic landscape over the past 15 years present considerable opportunities for the human–computer interaction (HCI) design community to better support people who previously were underrepresented in and consequently whose needs were insufficiently considered in technology design (Newell & Gregor, 2002). There are, however, specific issues around the participation of older people in research, particularly when technology is also involved. These range from effective choice and application of research methods to dealing with discovery of potentially sensitive data and situations involving participants. HCI research rarely reflects demographic reality. Twenty percent of the population in the developed world is over age 60, yet most HCI research is focused on younger people, often university or college students. Rather than representing the population as it actually is, much experimental HCI research is skewed heavily toward the characteristics (and attitudes) of the highly educated young (Dickinson & Gregor, 2006). Equally, not all HCI methods are suitable for use in contexts involving older people as participants, given that older people have an extremely wide range of characteristics and impairments compared to other age groups of participants. Older people are a heterogeneous group. They vary widely in their ages and lifestyles and in their levels of education, independence, and income. They also vary in their range of physical and cognitive abilities (skills). Conducting research with older people gives rise to many challenges. For instance, challenges may arise as a result of individuals' visual impairment, auditory impairment, cognitive changes, and mobility difficulties. Indeed, individuals may be affected by one problem or a combination of several which may increase over time. A user-centered design approach may recognize diversity in characteristics between user groups, but may be less focused on identifying diversity within groups, and particularly so for older people, diversity within an individual's capabilities over the short and long term. The effects of aging will be manifest at different rates relative to one another for each individual. This pattern of capabilities varies widely between individuals and, as people grow older, the variability increases (Myatt, Essa, & Rogers, 2000). In addition, any given individual's capabilities vary in the short term due to a variety of causes including illness, blood sugar levels, and just plain tiredness.

Aging is associated with specific changes in characteristics such as visual and auditory perception, fine motor control and some aspects of memory and cognition (see Hawthorn, 2000 for an overview). While many of these changes are only apparent in psychological tests, some can influence participants' ability to read or hear experimental instructions, use a mouse, or remember steps through an interface. The cultural and experiential gap can be particularly pronounced when involving older people in the development of new technology (Eisma et al., 2003; Malik, Alistair, & Edwards, 2008). Conversely, superior social skills can mean that older participants may be more likely to involve the facilitator in the task (Dickinson & Gregor, 2006). This collection of phenomena presents a fundamental problem for the designers of interfaces to computing systems, whether they be generic systems for use by all ages, or specific systems to compensate for loss of function (Zajicek, 2004), but also has more general implications for researchers involving older people in their research. Age-related capability change has implications for research method selection and design. A lack of familiarity among researchers and designers working with older people can often mean there is a lack of sensitivity in the way in which research with older people is conducted. Although there are data to show that older people can be successfully recruited into beneficial health promotion programs, it is often challenging. In planning health promotion studies, investigators need to be aware of the numbers of older people they may need to screen and different strategies for increasing recruitment success.

There are some key characteristics of older people which need to be reflected in the conduct of research in which their participation is sought, and hence user research methods involving older people should be carefully chosen so as to ensure participants are treated in an ethically sound manner while also maximizing the quality and fidelity of data gathered. Dickinson, Arnott, and Prior (2007) provide some valuable advice, based on personal experience, of conducting HCI research with older people in an ethically and experimentally sound manner, covering selection of appropriate research methods, recruitment, research location, and management of participants before, during, and after the research activity. It is also important to consider user involvement. Lack of user involvement is one of the factors that have been found to lead to abandonment of traditional assistive technologies (Damodaran, Olphert, & Hardill, 2010). An important component of older people's participation and engagement in the design process is decision-making, and its implementation requires the adoption of a participatory approach to socio-technical design. Therefore, older people who are the main intended beneficiaries of specific digital assistive technologies should be able to participate in decision-making not only concerning the technical aspects and system features but also in relation to the policies that affect the delivery and availability of the digital assistive technology (Olphert, Damodaran, Balatsoukas, & Parkinson, 2009). Research, including innovative work on the Sus-IT project has demonstrated the enthusiasm and ability of some older people to participate in codesign activities and to shape design and policy decisions.

Related to the issue of dynamic diversity and age-related capability change, and the implications on research methods used, is the ethical issue of how this can be accommodated in information and communication technology (ICT) and other product design in a way that allows objective research involving older people. Pairing individuals who have accessibility needs with the assistive technology most appropriate to these needs is a particular issue. Aside from any economic difficulties in procuring and using a particular assistive technologies, there is a fundamental issue of awareness. It is assumed that an ICT user with a severe, congenital disability is likely to be fully aware of the assistive technologies they need and has had appropriate support in procuring, installing, and learning to use this technology. However, the obscurity of assistive technologies, and an unwillingness to recognize and address an accessibility need, mean this is less likely to be the case for someone whose visual acuity, dexterity, and short-term memory has gradually declined over many years. The visibility issue is a paradox, given that accessibility features of an ICT can benefit more than people who might be covered by conventional definitions of *disabled* (Forrester Research & Microsoft Corporation, 2003). Dynamic diversity, the unexpected variations over time in an individual's visual, motor, and cognitive capability (Gregor, Newell, & Zajicek, 2002), has been recognized as a key complication in supporting more efficient HCI, and this is most acutely present when considering the unpredictable impact of the aging process on capability. One approach to accommodating the dynamic nature of human capability and the affects it can have in performance with respect to ICT use is to combine user profiling with adaptive interfaces (Gajos, Wobbrock, & Weld, 2007; Sloan, Atkinson, Machin, & Li, 2010). Monitoring user activity and making minor adaptations to system behavior, for example, by giving added prominence to recently or regularly used documents or applications, is a common approach to improving usability, and extending this approach has clear potential for enhancing accessibility.

The ethical challenge to supporting inclusion, through user profiling and adaptation, centers around the capture, storage, and analysis of performance-related data. In a system where regular capability measurements are taken while an individual is using the system, either through automated or semiautomated means, and minor adjustments are made (see Sloan et al., 2010), the altruistic motivation is to allow an existing ICT user to continue to use their ICT independently and successfully and to minimize the chance of age-related capability decline leading to technology abandonment. The technical quality of such a system is dependent on the accuracy of capability measurement made and the success of the reasoning process undertaken to apply an appropriate solution to accommodate an identified capability change; in other words, the system should correctly identify the capability change experienced and apply the best possible solution to ameliorate any negative effects of such change. The result should be a series of fine-grained adjustments that are effectively imperceptible to the user, allowing them to continue to interact with their ICT without significant loss in productivity or enjoyment. An example of such fine-grained change is the system identifying that the user is now having difficulty reading small text sizes and accommodating such difficulties by enlarging the text across the system. Gathering and storing performance-related information in this way has implications, however, particularly given that the data gathered may illustrate an individual's changing capabilities over time—most likely to be a reduction in capability. Further, there is a possibility that regularly sampled capability data may point to an underlying medical condition. To what extent should a system designed to optimize a user's interaction with an ICT deal with data of medical significance? How can a system minimize the negative implications on personal sense of well-being of an individual reviewing data showing their personal capability decline over time? In a study by Sloan et al. (2010), older participants did not raise significant concerns regarding the implications of the data being gathered by the profiling and adaptation system. But longer-term exploration of the impact on personal sense of well-being is an essential aspect of the evaluation of any such system. Possible approaches to addressing the ethical implications of these questions might include:

1. Seeking informed consent after their first use of a capability monitoring and adaptation system
2. Seeking approval for every adjustment made based on a capability measurement, although depending on the frequency of interruptions, this approach may have negative implications on productivity
3. Secure and anonymous storage of profile information
4. Presentation of profile information in a way that minimizes misinterpretation by the individual concerned or any other approved viewer
5. Limiting capability measurements to those that directly map to an accessibility adjustment supported by the host system

The first step in this process is to identify the potential implications of a system aimed at sustaining independent access by people with accessibility needs and consider carefully the data to be collected, in terms of nature, analysis, and storage.

There is thus a need for a paradigm shift from current ICT design approaches that focus on technical aspects of system design (e.g., based upon a waterfall model) and that would engage older people at specific stages of the design process, such as usability evaluation or task-requirements analysis, to a socio-technical approach that values human participation throughout the design process and elaborates on the dynamics of older people's needs across time. Socio-technical theory approaches technology as a complex system, where technical elements interact with social and organizational aspects of the system. Thus, the social or organizational context can influence the development and implementation of technology. Older people should be an integral component of the socio-technical system, and their role within it should be extended from merely participating in the evaluation of assistive technologies to decision-making, learning, and knowledge sharing as well as communicating their beliefs, aspirations, and expectations about these technologies to other groups of stakeholders (Olphert et al., 2009).

4.10 Assistive Technologies and Quality of Life

As noted at the outset of this chapter, there is an assumption in the UK that increased deployment of assistive technologies with older people can positively impact on QoL. The term is employed explicitly, for example, in government policy documents and in research papers on telecare provision. The final section of this chapter examines this assumption. The idea of QoL as an ethical issue emerged with Aristotle in his Nicomachean Ethics, which argued that the study of ethics was essentially about the (in Aristotle's case, virtuous) pursuit of human well-being and in finding ways to improve people's lives. Thus, the policy documents that espouse a QoL connection are broaching a deeply ethical question. Thus broached, we now ask in what way, if at all and if measurable, might assistive technologies actually impact on QoL? Unless we can be clear about the criteria that underpin QoL measurement itself, and how assistive technologies might connect to this, the claim that the use of assistive technologies can enhance it is a bold one, as although the term *quality of life* pervades discussion of health and social policy, there is little consensus on what the term means, how best to measure it, and how best to increase it at an individual and national level. Here, we explore definitional and measurement challenges associated with QoL, and reflect on research about the role of assistive technologies in QoL in old age.

Research on QoL began in the first half of the twentieth century and was aimed at measuring population well-being, with measures such as gross domestic product per capita considered to be aspects of life quality. However in the 1960s, there was a shift to much broader indicators and the inclusion of QoL as a characteristic of persons as well as national prosperity (Rapley, 2003). In tandem with this, there was greater acceptance of the role of government in actively shaping societal structures for the greater good. A second phenomenon occurring in the 1960s was an increase in the number of expensive medical treatments for a variety of diseases and chronic conditions. Many of these treatments could not cure. Questions began to be asked not only about how these interventions could be evaluated but how cost-effective they might be. The late 1960s saw the introduction of the *quality-adjusted life year* movement in medicine, and while it was accepted that many treatments could not cure, they could perhaps be shown to increase patients' QoL. The findings from early studies were, however, paradoxical. Study after study found that people in poor living conditions reported high life satisfaction and people with serious disabilities reported a high QoL. Moreover, increasing wealth across the world was not increasing perceptions of increased QoL, except amongst the very poor. It was clear that social comparisons and aspirations were influencing perceptions of QoL. The many instances of the satisfaction paradox and the disability paradox led to programs of research to delineate the domains of QoL. One of the biggest and most expensive of these was the World Health Organization's (WHO) Quality of Life Project that was initiated in 1991. This project identified the following broad domains: physical health, psychological health, social relationships, and environment (WHO, 1993). The scales developed within the WHO project were designed to consider the context of the culture and value systems of those who were rating, as well as personal goals, standards, and concerns. Other research projects have found similar domains, for example, Nazroo, Bajekal, Blane, Grewal, and Lewis (2003) revealed six factors influencing QoL at older ages: having a role, support networks, income and wealth, health, having time, and independence. These attempts to determine the domains of QoL result in, or are a consequence of, a confounding of predictors and domains. Researchers often determine the domains from findings about predictors; only a few have started with a theoretical perspective. Blane, Wiggins, Higgs, and Hyde (2002) are among the few that have; their QoL measure was based on the theory of needs satisfaction and included the domains of control, autonomy, self-realization, and pleasure. Broadening the scope of the term QoL to include a number of domains has left us with a slippery, complex concept which is now used to describe everything (Rapley, 2003), but which has no agreed definition. With no agreed definition, there can be no agreed method of measurement.

Given the difficulties in defining and measuring QoL, it is not surprising that it has been challenging to find research evidence that assistive technologies enhance QoL. Compounding the definitional and measurement problems is the wide range of assistive technology available and the poor quality of many of the studies that have been conducted. For example, in a recent review of the literature on environmental control systems and smart home technologies, Brandt, Samuelsson, Toytari, and Salminen (2010) found 1,739 studies, but only five effect studies and six descriptive studies met their criteria for selection. Of these 11 studies, only one examined QoL, and it was not a study of older people. Dickinson and Gregor (2006) published a critique of the value of personal computers to older people's QoL and well-being in which they concluded that computer use appears not to lead to improved well-being. As was the case with the review by Brandt et al. (2010), they found few studies to review, and those that were available had many weaknesses. Dickinson and Gregor (2006) also examined how the authors of secondary papers cited the findings and the extent to which they offered a sound critique. What was particularly interesting was that many authors citing the original studies suggested that computers had indeed made a positive impact, when in fact the original studies could not or did not support such claims. A literature review by Ridley and Young (2005) examined the effectiveness of e-health implementation in the care of elderly people. The review identified 647 primary articles, and 66 met the review criteria. Most of the studies focused on teleconferencing for particular health conditions. Ridley and Young concluded that there was sufficient evidence that these technologies had positive outcomes. QoL was not actually measured in most of these studies. Instead, the impact on QoL could only be inferred from outcomes such as patient control, psychological support, greater functional independence, reduced accident and emergency admissions, reduced levels of depression, and reduced need for patient travel. The small numbers in most of the studies reviewed, however, limited the impact of the studies. Studies on the impact of telemedicine on the health and QoL of older adults were reviewed by Jennett et al. (2003), who concluded that telemedicine can improve the QoL and health of older people. However, a large number of telemedicine initiatives have failed because they have been set up in isolation and without thought as to their cost-effectiveness (Macduff, West, & Harvey, 2001), let alone their impact on QoL.

4.11 Why Assistive Technologies Are Unlikely to Influence Quality of Life Ratings

There are a number of ways of looking at the research findings on the impact of assistive technologies (ATs) on QoL ratings. It could be, particularly in the face of so little evidence, that ATs correlate positively with QoL ratings:

- ATs might have specific effects but not general effects.
- ATs do not influence QoL.
- QoL is a meaningless concept, and hence, it is nonsensical to assess the impact of ATs on QoL.

Each of these hypotheses will now be considered in turn. It could be that ATs have specific effects, and indeed, there is some evidence to support this view. Alternatively, it could be that the current QoL measures are simply too remote, blunt, and multifactorial to be affected by ATs. It could also be that a high QoL brings about an interest in and use of ATs. This is certainly likely to be the case with personal computer use. In all correlational research, we must be vigilant not to read the correlation in only one direction. There is also a need to explore ways in which a technological divide may exist between older people who are familiar and comfortable with technology and those who are reluctant to embrace it or find it harder to access. Technology might lower QoL for the latter. Returning to the previously discussed telecare development agenda in the UK, we can note the presumption in the policy that telecare will enhance older people's lives. But exploratory research across different geographical areas of telecare implementation suggests a varied picture of the willingness by older people to engage with technology, a key element here being prior exposure (e.g., in the workplace) (Eccles, 2010). It should also be noted that health, wealth, and social relations consistently emerge as factors that predict ratings on QoL scales. Young people without chronic health problems have been found to be somewhat less likely to rate health as a prime determinant of QoL. For older people, however, poor health accounts for a high proportion of variance. Given that age is the main risk factor for almost all illness, aging without experiencing poor health is rare (Manton, 1989; Wood & Bain, 2001). Thus, while the exponential rise in disease incidence indicates a greater need for ATs in old age, the impact of poor health may be so great, and account for such a high proportion of the variance in QoL ratings, that it becomes almost impossible (statistically) for ATs to make an impact on QoL ratings.

In addition, as people age, social relations (particularly those with family members) become very important. As people become frail and in need of family support, social relations may suffer or become problematic. It is now fairly well established that negative social relations have a greater impact on psychological well-being than positive relations. Older people want to be independent and may resent offers of help from adult children. Older people are frequently embarrassed at having to ask for help. Another interesting possibility is that happiness and/or QoL is a dispositional characteristic (Costa & McCrae, 1980; Costa, McCrae, & Zonderman,

1987) that is not only stable across the life span but may be biologically determined (Diener, 2000). Returning to the ethical issue—if QoL has no agreed definition, and there are serious measurement issues, is it sensible, or indeed ethical, to view improved QoL as an outcome of policy interventions involving ATs? As Rapley (2003) notes, to use the QoL construct to gauge the success of ATs when QoL is viewed as an individualized aspect of the modern psyche is paradoxical. If QoL is individualized how can a case be made to assess it in the same way for everyone? We suggest a more nuanced enquiry might be: What are the predictors of QoL, and how might ATs connect to these?

4.12 Conclusion

This chapter has raised a number of issues around ethical research and ethical practice in the design and application of gerontechnology. As in any field where there is rapid technological development with an application to human services, there is the potential for ethical issues to arise that could not easily have been anticipated and for the limitations of existing approaches to ethical codes to be exposed. This in itself is not problematic. The issue is how this can be addressed, particularly when technological advances continue apace, not least through the agendas pursued by equipment manufacturers, but where ethical enquiry remains a less mainstream pursuit. We note evidence of the profound impact that gerontechnology can have in improving some people's lives. We note also the concern that where its uptake is stymied by poor awareness, or adherence to long established ways of working in the field of social care, this in itself may pose an ethical problem, as it means that older people might not be gaining these advantages. We argue, furthermore, that there is a risk of creating a false dichotomy between technology-based care and human care, as if one is inherently superior to the other. Context is important here, and independence is highly prized and may be impinged upon by reliance on carers, the inconvenience of care organizations' schedules, or the inability to age in situ. Assistive technologies clearly confer benefit here. This said, we note a number of areas where, drawing on our experience primarily of the situation in the UK, we suggest that there are deficits and potential problems in ethical engagement. These are fourfold. First, there is a need for more phenomenological research into how people experience the use of technology. We note the proliferation of ethics committees involved in the research process but a concomitant weakness with their understanding of some aspects of qualitative research, and we note also the apparent risk-averse nature of ethical approval in some universities, where older people may automatically be classed as vulnerable participants. Second, we have raised the concern that technological solutions represent too much of an ideal fix for the twin policy challenges of demographic change and rising costs of elder care. A powerful discourse has developed here, evidenced particularly in the literature of leading AT corporations and in policy forums of social care budget holders, where the potential offered by these technologies becomes subsumed by assumptions of their necessity.

We believe, drawing on the UK context, policy on the introduction of care technologies to be ill-served by the performance indicator regimes put in place by government which may encourage an emphasis on rapid expansion of deployment at the expense of suitability and context. An additional factor here is the often rapid change in the circumstances of older people and the need for personnel to oversee regular review of the suitability of technologies that have been installed. Third, we believe the ethical frameworks employed by agencies that carry out assessments for older people to be limited. There is a balance to be struck here between ethical codes that are overly complex but are nonetheless fit for purpose. That notwithstanding, the biomedical parameters predominantly in use lack sophistication in their application to the complexities of long-term care conditions and additional ethical enquiry based on, for example, more relational approaches would be worth exploring. The ethical issues here are compounded by the increasing moves toward interprofessional working, where similar tasks may be carried out by one of a number of agencies, each with their own particular codes of professional inquiry. Fourth, we note the explicit connection in government policy documents between the deployment of ATs and enhanced QoL. There are important issues raised here, not least equity of access to technology and assumptions that technology use will be equally well embraced, or readily useable, by older people. Equally, measuring QoL indicators and connecting these to specific technological interventions is fraught with methodological complexities. We would thus urge caution in the way that this term is employed. There is certainly evidence that some people in some circumstances enjoy better lives through the use of assistive technologies. To make broader claims on this issue at this stage risks the ethical deficit of foreclosing further critical enquiry and reflection.

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