

# The role of telecare in meeting the care needs of older people

Themes, debates and  
perspectives in the literature  
on ageing and technology

AKTIVE Research Report Volume 1:  
State of the Art Literature Review

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Advancing Knowledge of Telecare for Independence and Vitality in later life

Published online by Inventya Ltd, May 2013

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Bibliographic details for this volume

ACTIVE Consortium (2013) *The Role of Telecare in meeting the Care Needs of Older People: themes, debates and perspectives in the literature on ageing and technology.*

ACTIVE Research Report Vol.1, online publication: [www.aktive.org.uk/publications.html](http://www.aktive.org.uk/publications.html)

ISBN: 978-0-9570900-3-3

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## Preface

This review of the literature provides a context for the AKTIVE project. Exploring both grey and academic literature, it provides a comprehensive summary of current knowledge and baseline data to inform the other AKTIVE project activities and outputs. Its aims were to inform the development of the AKTIVE research study; familiarise the research team with evidence from a wide range of disciplines (technology, ergonomics and design, medicine, service delivery and implementation, policy on telecare, marketing, and gerontology); and to contribute to outputs for dissemination to stakeholders in industry, the voluntary sector and academia.

The AKTIVE project was commissioned through the Technology Strategy Board's 2010 competition for Social and Behavioural studies and commenced in June 2011. Its work will continue until May 2014. This literature review, which forms Volume 1 of the AKTIVE Research Report, is an online publication released to coincide with the AKTIVE mid-project conference in London on May 17<sup>th</sup> 2013 on 'Telecare and Independent Ageing: marketing, distribution, product development and user perspectives'.

## Acknowledgements

This literature review was produced by members of the AKTIVE Consortium and their associates. The authors of the chapters and the review editorial group would like to thank the experts and stakeholders who participated in early confidential discussions and interviews which helped shape the focus of the review, the members of the AKTIVE Advisory Board, whose contributions have been invaluable, and especially the following people whose role in advising, contributing to or supporting the AKTIVE project in preparing the literature review has been important and is very much appreciated: Radka Bartosova; Emanuela Bianchera; Richard Farrell-Smith; Professor Andreas Hoff; Valerie de Leonibus; Sean McDougall; and Rebecca Wilding.

*Sue Yeandle, AKTIVE Project Director*

*University of Leeds, May 2013*

## Abbreviations

|          |  |
|----------|--|
| AD       | Alzheimer's Disease                    |
| ADL      | Activities of Daily Living             |
| A&E      | Accident and Emergency                 |
| AT       | Assistive Technology/ies               |
| ALTs     | Assisted Living Technology/ies         |
| ANT      | Actor Network Theory                   |
| CSIP     | Care Services Improvement Partnership  |
| LB       | Dementia with Lewy Bodies              |
| DoH      | Department of Health                   |
| EU       | European Union                         |
| FACS     | Fair Access to Care Services           |
| FTD      | Fronto-Temporal Dementia               |
| FR       | Functional Requirement                 |
| ICES     | Integrated Community Equipment Service |
| ICT      | Information Communication Technologies |
| IT       | Information Technology                 |
| JC       | <i>Just Checking</i>                   |
| JIT      | Joint Improvement Team                 |
| LTC      | Long Term Care                         |
| MCI      | Mild Cognitive Impairment              |
| MMSE     | Mini Mental State Examination          |
| NHS      | National Health Service                |
| NHS PASA | NHS Purchasing and Supply Agency       |
| NFR      | Non-Functional Requirement             |
| NUI      | Natural User Interface                 |
| OT       | Occupational Therapist                 |
| PDD      | Parkinson's Disease Dementia           |
| PHA      | Prospective Hazard Analysis            |
| PWD      | Person / People With Dementia          |
| RCA      | Royal College of Art                   |
| RCT      | Randomised Control Trial               |
| RNC      | Royal College of Nursing               |
| SCIE     | Social Care Institute for Excellence   |
| SCOT     | Social Construction of Technology      |
| STS      | Social Technology Studies              |
| WSD      | Whole Systems Demonstrator             |



## Notes on contributors

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**Alan Roulstone** is Professor in Disability Policy at Northumbria University. He has held senior posts at the Universities of de Montford (Leicester) and Sunderland and was Deputy Director of the Strathclyde Centre for Disability Research at the University of Glasgow. Alan has been involved in numerous research projects on adult health and social care, disability benefits, disability policy, social exclusion, transitions to work and adulthood, disablist hate crimes, new technologies and social futures, older people, and disability law. He has produced many publications in these fields, including an edited collection on disablist hate crime (Routledge, with Hannah Mason-Bish, 2012), a handbook of disability studies (Routledge, with Nick Watson and Carol Thomas, 2012) and 'Understanding Disability Policy' (Policy Press, with Simon Prideaux, 2012). He is a member of the AKTIVE research consortium.

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## Introduction

*Sue Yeandle*

The AKTIVE project was established in 2011 to explore, among other related questions, how older people, particularly those susceptible to falls or who have cognitive impairments, may benefit from having access in and around their homes to various types of telecare technology.

The project operates through a partnership comprising research centres at the universities of Leeds and Oxford and two commercial companies, the telecare manufacturer Tunstall (Healthcare) Ltd and the market research and commercialisation company Inventya Ltd. The partnership is the more unique in also having strong support from its specially established Consortium, which comprises experts from a wide range of relevant professions and academic disciplines, and an Advisory Board whose expert members are drawn from across the UK and Europe.

AKTIVE began its three years of work in June 2011. One of its first tasks was to harness the knowledge and experience of its Consortium members, to ensure that its programme of new research could be implemented with the full benefit of the rich pool of talent on which it can draw.

Alongside the task of recruiting older people using telecare into the planned new study, and completing the preliminary tasks involved in preparing to conduct research with these participants (supported by consortium members in local authority telecare services at Leeds City Council and Oxfordshire County Council), the AKTIVE team's early work included consultations with stakeholders, preliminary interviews with carers and care workers, and a state-of-the-art review of relevant literature. The present volume presents the results of this literature review, a collection of six substantive chapters prepared by the two universities' social researchers, working closely with members of the AKTIVE Consortium and some of their co-researchers.

Chapter 1 of the volume draws together evidence (gathered by Dr Kate Hamblin) about the demographic changes which make support for older people living at home such a vital and urgent topic of inquiry with the knowledge and expertise of clinicians whose training and experience includes working with older people in clinical practice. This enabled the AKTIVE research team to enter the field as researchers with the support of their summaries of relevant research and knowledge. In the chapter, Dr Adam Darowski, an expert on falls, and Dr Rupert McShane, an expert on dementia, assemble evidence from the medical and gerontology literature to review how these two conditions arise, present and are treated. They also include latest thinking on what these conditions mean for the older people who live with them and their carers, and consider the place of technology in addressing their sometimes fast-changing needs for care and support.

Chapter 2 was prepared by two members of the AKTIVE project's social research team, Dr Chrissy Buse (now at the University of Kent) and Dr Emma-Reetta Koivunen, drawing on their academic expertise to consider how far the literature and theories in the disciplines of sociology and gerontology have engaged with developments in technology relevant to the needs of older people living at home. They also consider what progress had been made, before the AKTIVE project began, in understanding the sociological context in which telecare equipment and other technologies are offered to older people to help them cope, despite varying degrees of mental and physical frailty, with an often strong desire to live in their own homes for as long as possible.

In Chapter 3 the AKTIVE Consortium's experts in design, risk and prospective hazard analysis, Rama Gheerawo and Prof. Peter Buckle, have collaborated to summarise the insights, challenges and modes of working used in their fields of expertise. They consider how learning from their disciplines can help in understanding responses to telecare technology among older people and those who support them, and in imagining the scope for realising the fuller potential of telecare. This means using inclusive design, skilled assessment of prospective hazards and the integration of design and engineering principles to tackle the daily challenges faced in their domestic environments by people whose minds and bodies now work in ways increasingly unfamiliar to their younger selves.

The policy and practice environment in which developments in policy on ageing, social care and technology have developed in recent years is the focus of Chapter 4, in which researchers with expertise in assistive technology, information and communications technology and telecare - Consortium member Prof. Alan Roulstone and his colleague Barbara Harrington - worked with AKTIVE researchers Dr Gary Fry and Dr Chrissy Buse to summarise the context in which telecare and related developments have recently occurred. This chapter has made the aims, ambitions and rationales of policymakers and practitioners across the past few decades, and the thinking and evidence base behind their plans, available to inform the work of the AKTIVE team.

In Chapter 5, Dr Gary Fry and Dr Chrissy Buse have drawn together research, mainly from small-scale studies, which shows that specific benefits can be identified for people using telecare (including older people with the conditions being studied in the AKTIVE project), the carers who support them and any professional workers who attend them at home. These authors show that while some people derive considerable benefit from telecare support, how this can be achieved for most users is still only partially understood. This underscores the need for longitudinal studies of older people, like that now under way through AKTIVE, which can explore how people respond to and use telecare support of different types as their conditions and living arrangements change.

The final chapter, Chapter 6, also written by the team who collaborated on Chapter 4 - Prof. Alan Roulstone, Barbara Harrington, Dr Gary Fry and Dr Chrissy Buse - considers the existing literature on the barriers to the adoption and use of telecare. This draws on evidence about some of the factors which may deter some older people from accepting or using telecare. It considers the issues which can make it difficult for their carers - family, friends and neighbours - to support older people in accessing or using assistive technology, and highlights evidence from the still rather slight literature on the social care workforce, whose engagement with, training in using and understanding of how telecare might contribute to improving the conditions and organisation of their work in older people's homes remains limited.

Assembling these insights from this body of knowledge across numerous disciplines has already been a support, inspiration and challenge for the whole AKTIVE team, and especially the social researchers who, during 2012-13, are studying telecare use in the households of some 75 older people who need support because their health and daily lives are affected by either cognitive impairment or increasing frailty which makes them prone to falls. We hope this collection will also be of value to other researchers studying the lives of older people and trying to identify effective ways of offering them support to live independent, active lives for as long as possible in their later years. Members of the AKTIVE Consortium will be contributing to three further volumes of the AKTIVE Research Report, due for publication in 2014. These will present our research methods, study findings, and the insights of AKTIVE Consortium members.

## Chapter 1

# Demographic ageing, falls and dementia

*Kate Hamblin, Adam Darowski and Rupert McShane*

This chapter considers the social, economic and financial costs of falls and dementia and provides an overview of demographic changes, highlighting the ageing of the UK's population and how this changing demography is expected to affect the prevalence of falls and dementia. It also explores risk factors relating to these conditions and how they are experienced, and their financial and social costs for the state, for older people and for carers.

## 1.1 Societal ageing, demography and care

The UK population is ageing as a result of increased longevity and reduced fertility<sup>1</sup>. This change is not new (between 1984 and 2009 the proportion of the population aged under 16 fell from 21% to 19% of the whole and the share of the population aged over 65 increased from 15% to 16%), but its pace is accelerating. By 2034 it is estimated that the population over 65 will significantly outnumber that aged under 16 (23% and 18% of the whole, respectively). So far the greatest increase has been seen among the 'oldest old' (those aged 85 or above), whose numbers rose from almost 660,000 in 1984 to 1.4 million in 2009. This age group is also projected to grow faster in future, numbering 3.5 million people by 2034 and making up 5% of the total population (ONS, 2010).

Older age is correlated with chronic diseases such as diabetes, arthritis, congestive heart failure and dementia (explored below) and with disability. An ageing population thus increases the need for social and health care (Bardsley et al., 2011) and, as the 'failure of success' thesis regarding longevity and morbidity argues, while people are now living longer their extra years are often characterised by frailty, disability and illness (Victor, 2006). Fries (1980) and Vita et al. (1998) nevertheless assert that the ageing of the population need not lead to a dramatic rise in health costs if the onset of the first chronic condition can be postponed to later in life, producing a 'compression of morbidity'. It is also relevant to consider, as in this volume, the place of technology in meeting older people's needs, and its role in mitigating some of the costs of population ageing.

While population ageing is increasing demand for care, several other demographic changes are reducing the number of potential caregivers. Fertility has declined, compressing the UK's dependency ratio (Figure 1.1) and family formation has altered, as patterns of marriage, divorce, cohabitation and parenting have changed. Greater geographical dispersal and women's increased participation in paid employment also have implications for care provision within the family. Families have become increasingly diverse in terms of their structure, moving towards a 'verticalisation' in which people are part of three- or four-generation

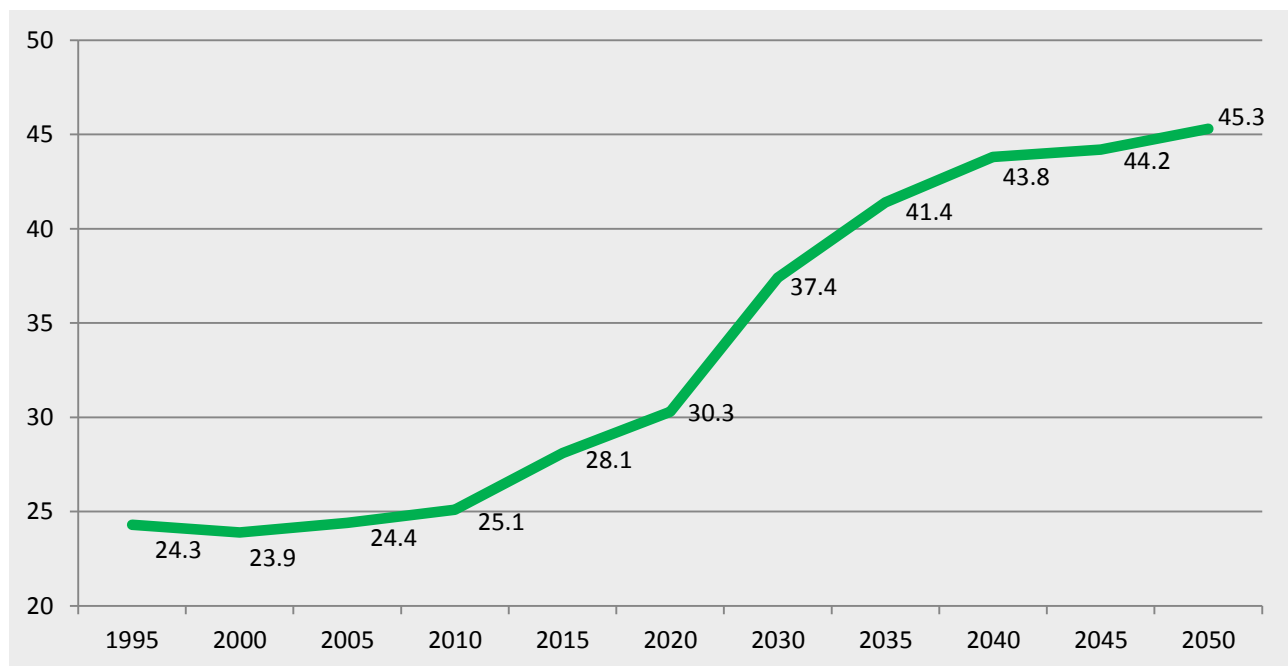
<sup>1</sup> Fertility in the UK has declined in comparison with 1960 when there were 2.80 live births per woman; by 1980 this had fallen to 1.83 and again to 1.64 by 2000. However, in recent years it has begun to rise with the fertility rate reaching 1.96 by 2011 (ONS, 2011; Eurostat, 2013).

families due to increased longevity (Harper, 2006b) and tend to live at greater distances from one another (Green and Canny, 2003; Dennett and Stillwell, 2010; Smith, 2011).

Women's increased employment arises from changing societal norms, financial pressures on households and rising demand for labour. As predicted (Phillips, 1995) women aged 40 to 50 have become the group most in demand, both by employers and by their own family members who need care. Thus as the share of the aged population has increased, so too the need for care has also risen; yet at the same time, the number of potential caregivers is declining.

Figure 1.1

UK Old-age dependency ratio, 1995-2050



Source: Eurostat (2007).

## 1.2 Falls and dementia: risk factors and preventative measures

Falls and dementia are major risks to health and wellbeing which become more significant as people reach older ages. They usually trigger at least some loss of independence and the need for greater support from others. These conditions were chosen as the focus of the AKTIVE project because of their prevalence among, and consequences for, older people, and because of their human and other costs. This section presents insights from clinical specialists with extensive experience of how these conditions arise and present and of the symptoms sufferers typically display, considering how they affect older people and their carers. This specialist knowledge offers important contextual information for subsequent chapters of the report in which existing evidence about the potential of technology in helping older people manage these conditions and supporting those who care for them is reviewed. Section 2.1 outlines current knowledge of these conditions, while later sections focus on their prevalence and on their economic and social costs.

## Falls

From the age of 65 the rate of falls and the severity of the injuries falls produce increase exponentially due to a variety of factors. Berg et al. (1997) report that older people are more likely to suffer from problems with their vision, balance or gait, making them more susceptible to falls (the major reason for disability in people aged 75 and above). The main cause of falls is a slip or trip, which older people are less likely to respond to quickly and effectively (so as to merely stumble). The causes of falls can be divided into four groups (Box 1.1) and most people who fall have contributory factors from two or more of these groups.

Older people fall for many reasons. They have accidents at the same (or a higher) rate than younger people, but in addition, when faced with a situation in which a young person would correct their balance and stumble, an older person is likely to fall. This loss of ability to respond quickly, accurately and powerfully to a threat to their balance has several possible causes, including:

- Impaired sensory input to the brain.
- Reduced ability of the brain to process information.
- Impaired ability of muscles and joints to carry out the desired movements quickly and forcefully.

### Box 1.1

#### Major causes of falls

##### *Accidents*

Slips and trips, which can occur at any age. If such accidents recur, an underlying cause should be sought. Up to a half of all falls are accidents (Masud and Morris, 2001).

##### *Illness*

Falling can be the presentation of almost any illness in older people. Typically those with urine and chest infections may present with falls.

##### *Impairments of gait, balance or vision*

These may involve an intrinsic tendency to fall: causal factors include:

- Neurological disease
- Musculoskeletal degeneration
- Disability caused by chronic disease (most commonly stroke, Parkinson's disease)
- The effects of medicines or alcohol.

##### *Paroxysmal events*

- Fainting and feeling faint
- Seizures
- Vascular events – stroke, myocardial infarction, pulmonary embolus
- Vertigo
- Rarities – e. g. cataplexy

Source: Darowski, 2008



By far the majority of excess falls in older people is due to impaired gait and balance. Of all attendees at the Oxfordshire Falls Clinic, for example, about 25% are thought to have a cardiovascular cause for their fall, commonly drug induced and iatrogenic; about 1% have a previously undiagnosed neurological condition (most commonly Parkinson's disease or stroke) (Oxfordshire Falls Prevention Service, 2009).

The key to fall prevention is an assessment that diagnoses the underlying cause of falls in that person. The National Institute for Clinical Excellence (NICE) advises (2004) that a plan of what can be done, and what the patient wishes to do, should be discussed with the patient. Available interventions consist of:

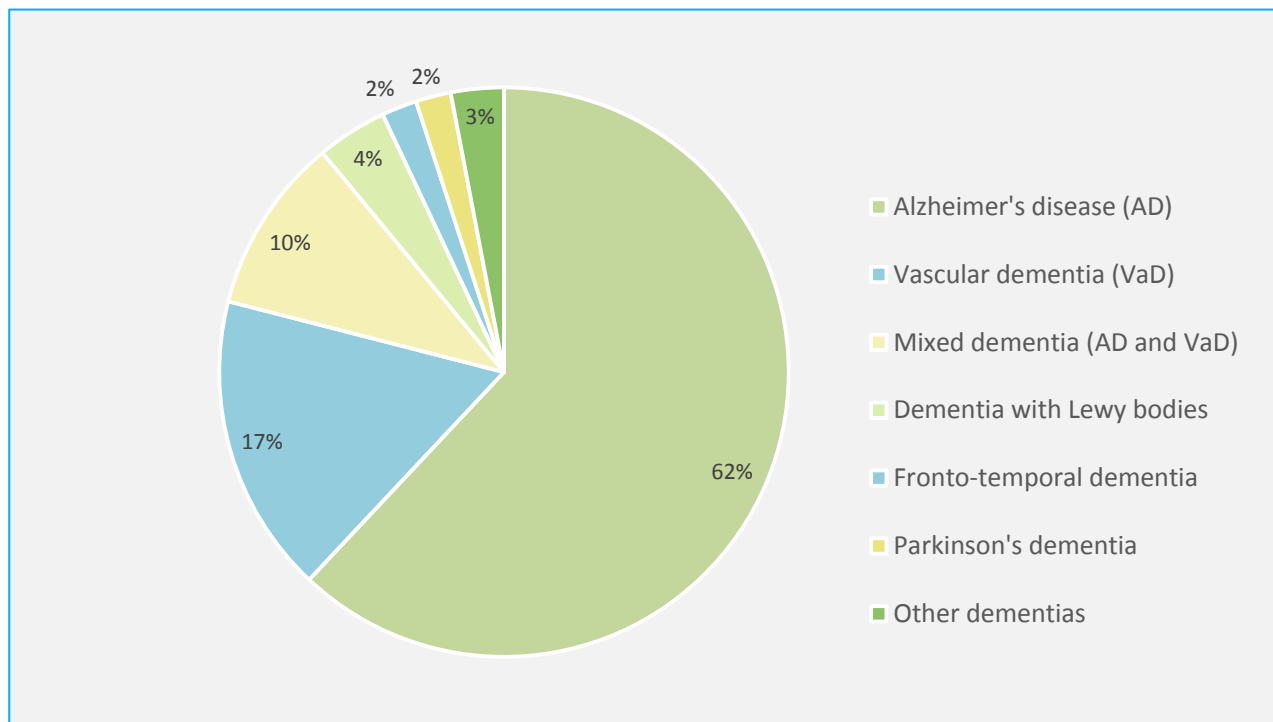
- **Exercise:** This has the most robust evidence base (NICE, 2004). Exercises must strengthen the legs and challenge balance to be of any value (chair-based exercises may improve confidence and stamina, and are frequently offered to frail older people, but there is no evidence that they prevent falls). Exercise programmes based on walking are also of no benefit in preventing falls, for reasons that are not immediately clear (possibly they increase exposure to additional falls risks in the outside environment) (NICE, 2004). Most patients attending the Oxfordshire Falls Clinic have multiple problems, both physical and cognitive, and only 15% are willing and able to complete an exercise programme (Oxfordshire Falls Prevention Programme, 2011).
- **Medication review:** Falls can be caused by any drugs that act on the nervous system or the circulation. Any medication that causes sedation will slow reaction times and cause unsteadiness. Any tablet that reduces the blood pressure or slows the pulse has the ability to cause fainting. The worst culprits are antidepressants and alpha blocking anti-hypertensives. Stopping psychotropic drugs and stopping cardiovascular drugs have both been proven to reduce falls by 50% or more in suitable cases (Alsop and MacMahon, 2001; Van der Velde et al., 2004; Van der Velde et al., 2007).
- **Diagnosing the causes of fainting and faintness:** For the 25% who (according to Oxfordshire Falls Clinic data) have a cardiovascular cause, this needs to be diagnosed and treated.
- **Walking aids:** Getting the patient to accept the use of a stick or a walking frame can make a great difference to their falls risk.
- **Education:** Older people who have fallen often live in fear of further falls and the injuries they might sustain (Fletcher and Hirdes, 2004). The excess dependency caused by fear of falling is estimated to be as great as that caused by fall-related injuries (NICE, 2004). Education about why they fell and what can be done to prevent falls in future reduces this fear, and encourages activity, leading to falls reduction.

## Dementia

The term 'dementia' refers to the syndrome of progressive cognitive impairment of a degree which affects social or occupational functioning. The most common cause of dementia is Alzheimer's disease (AD). Many people with AD do just have AD pathology, but Alzheimer's pathology, even if not enough to attract a label of AD, is usually present in those with vascular, Lewy body dementia and Parkinson's dementia. Upwards of 73% of people with dementia have AD pathology (Figure 1.2).

2010 Figure 1.2

Incidence of dementia according to type, UK:



Source: Alzheimer's Society (2011a: 2).

The pathological signature of AD is of amyloid plaques and neurofibrillary tangles. As these features accumulate, they are accompanied by loss of synapses and nerve cell death. Amyloid plaques are accumulations of clumps of insoluble protein which are deposited in brain tissue outside the neurons. Neurofibrillary tangles occur when the linking elements of the scaffolding in neurons become sticky and form into fibrils.

Scientists still do not know exactly which of these pathological features, if any, actually cause the dementia. While the density of plaques correlates with the degree of cognitive impairment, many older people with no obvious cognitive deficits also have significant amounts of amyloid deposits. Such 'normal elderly' people do, however perform slightly worse on average than those without such deposits. Also, on average, those people with pre-dementia mild cognitive impairment who have amyloid plaques are more likely to decline over the next few years than those without plaques. Removing the amyloid in people who already have dementia does not reverse the dementia. However, it is not yet known whether preventing its accumulation would prevent dementia. In contrast, neurofibrillary tangles form inside neurons and it is therefore not altogether surprising that their presence correlates better with cognitive impairment than the presence of amyloid plaques.

Cerebrovascular disease is a major contributor to cognitive deficits in dementia. Blocked blood vessels and bleeds (stroke and transient ischaemic attacks) can result in abrupt damage to any part of the brain and the concept of 'multi-infarct' dementia was based on the idea that the more this occurs, the more likely dementia becomes. While this is undoubtedly true, clinicians now tend to refer to 'vascular dementia'. As a 'pure' entity, in which there is no coexisting AD, this is rather uncommon (<5% of dementia). Damage to

smaller vessels also makes an important contribution to cognitive impairment, but tends to develop more gradually. As with infarcts, the presence of small vessel disease is associated with AD more commonly than expected. The reason for this association of cerebrovascular disease with AD probably relates to how AD develops, although this is not yet fully understood. Good brain circulation – perhaps supported by exercise – may help to ‘flush away’ the amyloid precursors preventing their build up and formation of the signature amyloid plaques. Conversely, poor circulation means that existing neurons are damaged or function less well, which may predispose the release of amyloid precursors from the intracellular into the extracellular compartment.

Dementia with Lewy bodies (DLB) is an overlap disorder of Parkinson’s and AD. Lewy bodies are the Parkinson’s disease equivalent of the intraneuronal tangles of AD and are probably caused by anything which disrupts the cellular ‘dustbin’ system for dealing with degraded proteins. The clinical features of both DLB and Parkinson’s disease dementia (PDD) are driven by the balance of pathology in the two main affected neurotransmitter systems: the cholinergic system, deficits in which reduce attention and cause illusions, and the dopaminergic system, deficits in which affect fluency of movement. The brain’s main cholinergic nucleus is in double jeopardy from both the tangles of Alzheimer’s and from Lewy bodies. For this reason, drugs which boost this system (i.e. all the cholinesterase inhibitors such as Donepezil) are, if anything, slightly more effective in DLB than in AD. Lewy bodies also prominently affect the autonomic nervous system, deficits in which are associated with abrupt changes in blood pressure, and the olfactory system. Clinical features are very similar to those of PDD, from which it is distinguished by definitional convention only: in PDD the Parkinsonism precedes cognitive problems by at least a year.

As aforementioned, dementia is not a single disease but rather a syndrome or group of related symptoms. The symptoms which have the highest impact on caregivers are repetitive questions, apathy, getting lost, aggression and incontinence. Apathy is the commonest and most pervasive behavioural change seen in dementia. When previously active minds start staring into space, spouses start to feel powerless, frustrated that they cannot cajole their partner into activity. Apathy in dementia has several causes, some biological, some social.

Dementia has been described as a ‘disconnection syndrome’, which highlights the fact that as the neurodegeneration progresses, the links which sub-serve thought (both between and within brain areas) are lost and those remaining pockets of function become harder to access or stimulate. Thus:

- The ‘volition’ centres in the frontal lobe are damaged, which is why apathy is particularly prominent in frontotemporal dementia.
- The inability to sustain attention and interest in previously enjoyed activities is due to the prominent degeneration of cholinergic nuclei.
- Dementia is associated with depressed mood which further undermines motivation, partly because of degeneration of serotonin function.
- Reduced noradrenaline function due to degeneration of the midbrain locus coeruleus results in lower levels of arousal.
- Disrupted sleep patterns mean that tiredness and daytime dozing are common.
- The cognitive impairment also means that it is more difficult for spouses and families to maintain meaningful conversation, which results in their withdrawal and reduced stimulation.

- The lack of activity contributes to physical de-conditioning though it is plausible (but not yet proven) that lack of physical activity in established dementia contributes to more rapid cognitive decline, perhaps as a result of poor cerebral perfusion.
- Inactivity in the day, as well as degeneration of the nuclei sub-serving sleep, means that patients find it difficult to stay asleep which contributes to daytime tiredness and dozing.

From this it will be clear that maintaining physical activity, social stimulation and sleep hygiene may be useful ways to interrupt the cycle of apathy. Unfortunately, attempts to do this often fail. This may be because biological causes remain, because they are instituted too late, or because the patience, perseverance and ingenuity of their carers have been overwhelmed. Linked to this, inactivity due to apathy can disturb sleep rhythms. More commonly, sleep disturbance arises in people with dementia who are already active. It is particularly problematic if the person with dementia tries to 'go to work' in the middle of the night, or needs help with mobility to prevent falling. Its unpredictability means that exhausted carers often complain that they lie half asleep listening for trouble.

Anxiety coupled with poor short term memory can result in repetitive questions. When severe, this taxes the patience of carers. It is sometimes hard for carers not to get to the point where they ignore the questions. At this point, they not infrequently feel guilty that their failure to respond is contributing to the separation and loss which is slowly overtaking the relationship. Of all the 'behavioural' symptoms, getting lost is the one most likely to result in admission into residential care (McShane et al., 1998b; Scarmeas et al., 2007), yet its importance is under-appreciated. Aggression takes several forms in dementia. It is commonly preceded by depression (McShane et al., 1998a). In early dementia, it can appear to be an exaggeration of personality traits which existed before the illness. The extent of the aggression often depends on how tolerant and skilled the carer is. A common problem is that carers confront patients with the inaccuracy of their beliefs. This is sometimes based on an unspoken assumed analogy with the experience of bringing up children: one should take a reasonably firm line in order that they will learn what is right. In the early stages, this is a particularly difficult judgement to make, since patients can learn – just not very well. In general, the routine advice is not to contradict and not to ask the patient questions to test them. This is not always possible if the patient's mistaken and rigidly held beliefs lead them into embarrassing, risky or time-consuming situations. Later, some patients become routinely aggressive. Again, this is typically in the context of being thwarted or in the context of intimate care, but it can also be associated with suspicious and unprovoked hostility. This then suggests an underlying psychosis requiring drug treatment.

There are symptoms which are specific to particular types of dementia. The key characteristics of DLB, which are not always all present, are:

- **Parkinsonism:** Difficulties getting started (e.g. rising from a chair) and tremor (less common). Falls are common, particularly later, and can be due to failure to maintain blood pressure on rising or while walking, trips because of shuffling gait, or abrupt changes in level of consciousness.
- **Visual disturbances:** Hallucinations (of unwanted guests), illusions (e.g. seeing faces in swirling fabric, seeing fire, smoke or water instead of a neutral carpet or a monochromatic painted wall), visuo-spatial problems (e.g. 'missing' the edge of the chair and falling; having trouble seeing the food on the plate), shouting out during sleep because of vivid dreams.

- **Loss of attention:** (E.g. 'running out of steam' and rambling off topic, forgetting what the point of the sentence was, getting muddled on waking, more muddled when tired or cognitively challenged). These fluctuations can be particularly bewildering to families because the patient will sometimes appear bright and orientated but at other times seem confused.
- **Olfactory impairment:** This feature is probably also present in AD, but is more profound in DLB. It may precede the onset of DLB or PDD by many years, but is a non-specific sign.
- **Memory function:** This is commonly rather well preserved until later.

Fronto-temporal dementia (FTD) is a family of clinical diagnoses given to syndromes characterised by apathy and loss of drive, loss of social inhibitions, increased appetite (typically for sweet things), loss of ability to understand the meaning of concepts and progressive difficulty in generating spontaneous speech. As in other areas of medicine and psychiatry, a degree of fashion surrounds the diagnosis of FTD. Rates of diagnosis of FTD are rather different in different settings depending on the attribution that clinicians assign to symptoms such as apathy and disinhibition, which are common in all dementia. Distinctive pathologies are apparent in a minority of patients, but the neuropathological substrate of these clinical syndromes is probably most commonly AD.

The idea that there may be much that we can do about our risk of developing dementia may be fanciful. No treatments are available to slow the progression of AD or other dementias. Cholinesterase inhibitors boost attention and cognitive function a little across the range of severity, but tend to cause loss of appetite. Age is the dominant risk. AD, like most chronic conditions, is multifactorial in aetiology. However, by comparison with age, all other risk factors are small: 45% of those over the age of 95 have dementia (Brayne et al., 2006). There is no evidence of regional variation in the incidence across the UK (Matthews et al., 2005). The prevalence is higher in women, and not only because of differential survival, as the slightly lower incidence in men may arise because men who survive to advanced ages may be more resistant against dementia (Fratiglioni et al., 1997). This may be because men are frequently exposed to risk factors, such as head injury, and so realise their risk earlier; and also because oestrogen levels are slightly higher in older men than in older women.

There is no good evidence that attempting to modify any risk factor is of benefit. However, it seems sensible to promote good vascular health, in order to reduce the risk of cardiac or cerebrovascular disease, which itself may precipitate AD. Regular walking and fish consumption can reduce the risks of decline, but once dementia is established are probably of little benefit. Even moderate alcohol probably increases risk and is unlikely to be protective. There is no robust evidence of benefit of B vitamins.

A few (<1% of dementia) people develop AD as a result of a mutation in one of three genes involved in the processing of amyloid. When this occurs, the patient inevitably develops dementia before the age of 65, sometimes as young as 30. For the majority, the risk of developing dementia is increased if a first degree relative (sibling or parent) is affected (Mayeux, 1991) and is increased further if more than one such relative is affected (Lautenschlager et al., 1996). An important genetic factor, which interacts with modifiable risk factors, is the apolipoprotein E gene. Theoretically, those who have two copies of  $\epsilon 4$  (ApoE4) have the most to gain by paying attention to the vascular risk factors, which all also contribute to the risk of developing AD: high blood pressure, high cholesterol, diabetes, smoking, exercise. However, because not all people with two copies of  $\epsilon 4$  will develop dementia, the current, perhaps rather paternalistic advice, is that routine genetic testing should not be available for apolipoprotein E.

There are also modifiable factors, such as:

- **Smoking:** Although smoking was initially thought to be protective, this was later shown to be due to a survival bias. It now appears that, amongst non-carriers of ApoE4, smoking increases risk (Merchant et al., 1999). In older adults, quitting smoking results in better cognitive and brain structural outcomes within two years (Almeida et al., 2011).
- **Cholesterol:** Whether or not high serum cholesterol causes dementia is not entirely clear. Epidemiological studies suggest that dementia is less likely in those who take statins or have a lower cholesterol level (Rockwood, 2002, Whitmer et al., 2005), but reviews of clinical trials of cholesterol-lowering statins show an overall lack of benefit in treating or preventing dementia (McGuinness et al., 2009, 2010; Sano et al., 2011). While the variable results of clinical trials may be attributable to varying blood-brain barrier permeability to the different statins, or to the stage at which statins were used, it is perhaps more likely that the disparity between epidemiological and interventional evidence lies in the possibility that people of higher socio-economic status, who are less likely to develop dementia, may be more likely to take statins, or that the populations recruited into clinical trials may not be representative.
- **Vascular factors:** The more vascular risk factors someone has, the more likely they are to develop dementia; the effect is additive (Kivipelto et al., 2006). Many of the risk factors associated with the development of dementia overlap with each other: hypertension is more common in those with obesity. A late-life dementia risk index, based on statistically independent contributing risks in a population without known dementia, has been developed (Barnes et al., 2009) and it is instructive to see the elements of this:
  - older age (1-2 points)
  - poor cognitive test performance (2-4 points)
  - body mass index <18.5 (2 points)
  - one or more apolipoprotein E epsilon4 alleles (1 point)
  - cerebral MRI finding of white matter disease (1 point)
  - cerebral MRI finding of ventricular enlargement (1 point)
  - internal carotid artery thickening on ultrasound (1 point)
  - history of bypass surgery (1 point)
  - slow physical performance (time to button up a shirt)(1 point)
  - lack of alcohol consumption (1 point)

Four per cent of subjects with low scores (<4 points) develop dementia over 6 years compared with 23% of subjects with moderate scores and 56% of subjects with high (>7 points) scores. Stroke impairs cognitive function: 10% of patients have dementia before their first stroke, 10% developed new dementia soon after the first stroke, but more than a third had dementia after recurrent stroke (Pendlebury and Rothwell, 2009). It is perhaps not surprising that when AD is also present, the effect of the two pathologies is additive (Esiri et al., 1999). More surprising however, is the observation that stroke may precipitate the development of Alzheimer's pathology and that, although it is known to be a risk for both disorders, ApoE4 does not account for the relation of stroke to dementia (Zhu et al., 2000).

- **Exercise:** The quality of evidence concerning the effect of activity on both physical and cognitive decline in patients with dementia is poor. Overall, what evidence there is suggests that, once the condition has

been diagnosed, there is no benefit on cognitive function which can be attributed to the exercise itself (Littbrand et al., 2011). However, among people with incipient or mild cognitive impairment, a six month programme of regular walking results in a modest improvement in cognitive function over 18 months (Lautenschlager et al., 2008). Similarly, in healthy older adults, aerobic physical activities which improve cardiorespiratory fitness are beneficial for cognitive function (Angevaren et al., 2008). Recent experimental work in small numbers of patients with MCI and normal older people suggests that normal adults who have high levels of exercise are less vulnerable to the effect that an unhealthy diet has on CSF amyloid (Baker et al., 2012). In those with established MCI, the benefit of a healthy diet on A $\beta$  modulation (Bayer-Carter et al., 2011) is greatest when paired with a high level of physical activity. Exercise may thus interact with diet to alter pathological processes that ultimately may be causal in AD.

- **Alcohol:** 'Frequent' use of alcohol in midlife, especially among those who are ApoE4 positive, is associated with a more than three-fold increased risk of dementia in late life (Anttila et al., 2004). 'Frequently' in this context was defined as 'at least several times a month'. While Peters et al. (2008) have suggested that small amounts of alcohol may be protective against AD but not vascular dementia or cognitive decline, a powerful analysis of potential confounders suggested that the association was mediated by IQ (Cooper et al., 2009). Intelligent people drink wine – but it is their intelligence rather than the wine which protects them from decline.
- **Nutritional and dietary factors:** The available evidence does not support a clear role for most of the nutritional and dietary factors that have been examined. The most consistent evidence is available for longer chain omega-3 fatty acids (often measured as fish consumption), with several longitudinal studies showing an association with reduced risk for cognitive decline. For the other factors, the evidence varies from no consistent association (vitamin B, vitamin E, vitamin C, folate, and beta-carotene) to very limited evidence suggesting a possible protective effect (low saturated fat and high vegetable intake) (Davignus et al., 2010). The evidence that high dose B vitamins are useful is restricted to brain imaging, with no convincing effect on cognitive function, except perhaps in those with high levels of homocysteine (de Jager et al., 2011).
- **Head injury:** Although biologically plausible, the association of head injury with the onset of dementia, and the possibility that the ApoE4 allele might influence the strength of the association, remains unproven. It is possible that the association is restricted to severe head injury (Plassman et al., 2000).
- **Social engagement:** Whereas findings on the association of cognitive decline with living alone or being without a partner are inconsistent, a robust association exists between the loss of a spouse and cognitive decline. Limited but inconsistent evidence suggests that increased involvement in cognitive activities in later life may be associated with slower cognitive decline and lower risk for mild cognitive impairment.
- **Cognitive and functional 'reserve':** The term 'cognitive reserve' describes the buffering effect of education, occupational and leisure activities in preventing cognitive decline. Effort is sometimes necessary to retrieve or encode memories. The impact of very early neurodegeneration on effortful thinking has been elegantly demonstrated. In a few families, it is possible to identify individuals who are destined for genetic reasons to develop AD. In these individuals, functional scans show that compensatory increases in brain activity are apparent very early in those without any evidence – either subjective or objective – of problems (Quiroz et al., 2010). Their brains are working harder. This is 'active' cognitive reserve. However, as well as this, the brains of people who are well educated are structurally different – so called 'passive' reserve (Stern, 2009). Furthermore, while education, leisure activities and



occupation all appear to have an effect on verbal semantic fluency, of these, only education is associated with higher cerebral volumes in a population-based study. Grey and white matter volumes in the orbitofrontal and temporoparietal brain areas are strikingly different in those with and without higher educational attainment (Foubert Samier et al., 2012). This suggests that cognitive stimulation in youth results in changes in brain organisation which remain measurable in later life. Academics with a mini-mental state examination (MMSE) score of 24 tend to show greater levels of atrophy on their structural scans than factory workers with a score of 24 (Mortimer et al., 2005); their 'active' reserve compensates. However, a consequence of this 'reserve' is that the trajectory of cognitive decline can be more rapid in those who were effectively compensating than in those who were not. The academic will hold out for longer but then decline more abruptly (Hall et al., 2007).

### Dementia and diagnosis

Over the last 10 years, the terms mild, moderate and severe have come to be used to describe patients with scores on the widely used MMSE of 30-20 (mild), 19-10 (moderate) and 0-9 (severe). However, it is recognised that decline in MMSE is not linear over time and there is not a linear relationship between MMSE score and loss of activities of daily living (ADL) function. In particular, patients with an MMSE of 20 would have a degree of impairment which most lay people would not regard as 'mild'. Few would be capable of independent living with this degree of disability. The experience of Lekeu et al. (2002) illustrates the point: a patient with an MMSE of 21 took 3 months of training for 45 minutes once or twice a week to be able to use a mobile phone. Another with a similar MMSE took 9 weeks to be able to use a prompt card which reminded them how to use the mobile phone without being prompted.

A 'pre-dementia' state, 'mild cognitive impairment' (MCI), describes the situation where there are objective deficits in cognitive function, but these are not of a degree to affect social or occupational function. MCI does not denote a stage that is clearly clinically or patho-physiologically distinct. The concept is one that is defined by exclusion: the patients do not have dementia. Only a third of those with MCI will progress to dementia, and some will revert to a 'normal' state. The boundaries between MCI and 'normal aging' on the one hand and between MCI and 'dementia' are unreliable and unstable (Matthews, 2007). Nevertheless, the presence of MCI has been recently formalised in new diagnostic guidelines (Albert et al., 2011; Sperling et al., 2011).

The 2010 Dementia Strategy 'Living Well with Dementia' (Goodchild, 2009) highlighted the lower than expected rates of diagnosis of dementia in general practice, 31% of the estimated prevalence. There is a government drive to increase this. At the same time, dementia is becoming more medicalised. This is a trend which is being powerfully driven by pharmaceutical companies and by the various societies and charities which promote research and support. A ligand for identifying amyloid deposition on brain scans has recently been licensed in the US for the diagnosis of Alzheimer's. In fact, it only rules out AD. If there is no amyloid, then the patient does not have AD, but if it shows amyloid, that does not indicate AD. These twin pressures and the difficulty in drawing distinctions between 'normal ageing', 'MCI' and 'dementia' will inevitably continue to focus attention on cognitive decline, and pressure to mitigate its effects.

### Falls and dementia: double jeopardy

A number of empirical studies have demonstrated the cross-over between falls and dementia, as people with some forms of the latter run a much higher risk of suffering from the former. Studies have reported



that in non-residential care settings, the risk of falling is 3-5 times higher for those with dementia (Tinetti et al., 1988; Shaw and Kenny, 1998; Milisen et al., 2007). Extensive research into what makes people with dementia more prone to falls has shown that dementia affects tandem gait, stride frequency and length, and also increases the tendency to wander, which also raises the incidence of falls (Shaw and Kenny, 1998; Nakamura et al., 1996). Medication often prescribed to people suffering from dementia (including benzodiazepines, phenothiazines and anti-depressants) can also increase the risk of falls (Buchner and Larson, 1987; Shaw and Kenny, 1998). Certain types of dementia predispose people to falls. Thus Ballard et al. (1998) found 37% of those with Lewy body dementia (LBD) fell more than five times a week, as did 6% of those with AD. Alzheimer's sufferers also find it more difficult to navigate obstacles (Alexander et al., 1995) and the disease also affects motor responses and the sufferer's ability to rely on visual information for balance (Chong et al., 1999; Alexander, 1994). Nakamura et al. (1996) found the severity of the dementia correlated with the number of falls and that those in the advanced stages of the disease were not only more likely to fall, but also to incur serious injury. Shaw and Kenny (1998) found that those with dementia were three times more likely to suffer from a fracture as a result of a fall, while Ramnemark et al. (2000) found that 25% of all people who suffered a fall-related femoral neck fracture suffered from dementia. Some authors argue that people suffering from dementia are not intrinsically more susceptible to injury, but rather that because they are twice as likely to fall the likelihood they will suffer serious harm increases (van Doorn et al. (2003). In terms of recovery post-fracture, those with dementia are five times more likely to be institutionalised (Shaw and Kenny, 1998). Stromberg et al. (1997) found that complications associated with hip fractures, such as infection and fracture dislocation, are common among people with dementia; and Hasegawa et al. (2007) identified dementia as an independent risk factor related to death following a hip fracture.

### 1.3 Falls and dementia in the UK: prevalence and projections

As indicated in section 1.1, as the population ages the prevalence of both dementia and falls is also projected to increase (Knapp et al., 2007a).

#### Prevalence of dementia

In 2010 about 750,000 people in the UK had dementia. AD makes up 62% of this total (416,967 people) and vascular dementia and mixed dementia over a quarter (17% and 10% respectively). DLB accounts for 4% of all dementia patients, fronto-temporal dementia 2%, Parkinson's dementia 2% and other dementias 3% (Alzheimer's Society, 2011a). These different types are distributed differently according to gender; women are more likely to suffer from AD (67% of female dementia sufferers have Alzheimer's, compared with 55% of men), whereas vascular and mixed dementia are more common in men (31% of male cases have vascular or mixed dementia compared with 25% of women) (Knapp et al., 2007b). The incidence of dementia is expected to increase with population ageing as dementia and older age are closely correlated. Less than 1% of people aged under 65 have the condition, whereas incidence is estimated to be far higher among those over 95, with estimates ranging from 30% (Glover, 2008) to 45% (Brayne et al., 2006). Thus as the proportion of the 'oldest' old increases, so too will the prevalence of dementia (Table 1.1). Knapp et al. (2007a) estimate that by 2021 there will be about 940,000 people with dementia in the UK, rising to over 1.7 million people by 2051.

Table 1.1

Projected population and dementia sufferers by age: 2010-2025, England

| Age Group   | Year | Women            |                    |                | Men              |                    |                |
|-------------|------|------------------|--------------------|----------------|------------------|--------------------|----------------|
|             |      | Total Population | Dementia Sufferers | % of age group | Total Population | Dementia Sufferers | % of age group |
| 65 to 69    | 2010 | 1,259,800        | 12,598             | 1.0            | 1,179,700        | 1,7696             | 1.5            |
|             | 2015 | 1,535,700        | 15,357             | 1.0            | 1,432,300        | 2,1485             | 1.5            |
|             | 2020 | 1,404,100        | 14,041             | 1.0            | 1,305,500        | 1,9583             | 1.5            |
|             | 2025 | 1,523,700        | 15,237             | 1.0            | 1,424,100        | 2,1362             | 1.5            |
| 70 to 74    | 2010 | 1,090,100        | 26,162             | 2.4            | 978,600          | 30,337             | 3.1            |
|             | 2015 | 1,187,300        | 28,495             | 2.4            | 1,073,800        | 33,288             | 3.1            |
|             | 2020 | 1,452,000        | 34,848             | 2.4            | 1,311,400        | 40,653             | 3.1            |
|             | 2025 | 1,331,900        | 31,966             | 2.4            | 1,202,800        | 37,287             | 3.1            |
| 75 to 79    | 2010 | 915,400          | 59,501             | 6.5            | 749,700          | 38,235             | 5.1            |
|             | 2015 | 981,700          | 63,811             | 6.5            | 836,100          | 42,641             | 5.1            |
|             | 2020 | 1,079,700        | 70,181             | 6.5            | 931,600          | 47,512             | 5.1            |
|             | 2025 | 1,327,100        | 86,262             | 6.5            | 1,146,000        | 58,446             | 5.1            |
| 80 to 84    | 2010 | 736,300          | 97,928             | 13.3           | 511,200          | 52,142             | 10.2           |
|             | 2015 | 755,500          | 100,482            | 13.3           | 570,900          | 58,232             | 10.2           |
|             | 2020 | 833,000          | 110,789            | 13.3           | 657,900          | 67,106             | 10.2           |
|             | 2025 | 928,600          | 123,504            | 13.3           | 746,800          | 76,174             | 10.2           |
| 85 to 89    | 2010 | 501,766          | 111,392            | 22.2           | 278,991          | 46,591             | 16.7           |
|             | 2015 | 499,219          | 110,827            | 22.2           | 317,513          | 53,025             | 16.7           |
|             | 2020 | 532,141          | 118,135            | 22.2           | 371,448          | 62,032             | 16.7           |
|             | 2025 | 602,208          | 133,690            | 22.2           | 436,193          | 72,844             | 16.7           |
| 90 to 94    | 2010 | 205,773          | 60,909             | 29.6           | 88,472           | 24,330             | 27.5           |
|             | 2015 | 254,244          | 75,256             | 29.6           | 127,210          | 34,983             | 27.5           |
|             | 2020 | 271,807          | 80,455             | 29.6           | 158,239          | 43,516             | 27.5           |
|             | 2025 | 314,306          | 93,035             | 29.6           | 201,992          | 55,548             | 27.5           |
| 95 and over | 2010 | 68,161           | 23,447             | 34.4           | 19,937           | 5,981              | 30.0           |
|             | 2015 | 74,138           | 25,503             | 34.4           | 27,578           | 8,273              | 30.0           |
|             | 2020 | 98,452           | 33,868             | 34.4           | 44,113           | 13,234             | 30.0           |
|             | 2025 | 121,686          | 41,860             | 34.4           | 63,615           | 19,084             | 30.0           |

Source: Mental Health Observatory, 2008.

## Prevalence of falls

Current estimates indicate that 35% of people aged 65 and over suffer from at least one fall a year, rising to 45% among those aged 80 and over (DoH, 2009e). However, it is almost impossible to count the number of falls in the community as only a small percentage is reported. The research standard is to use weekly falls diaries with a researcher making contact each week to collate data; however falls can be forgotten or omitted from these records.

Falls and their consequences are the most common reason a person aged over 65 years attends an accident and emergency (A&E) department, accounting for nearly 50% of all such attendances. They are also the main cause of admission to care homes (Masud and Morris, 2001). Fall related injuries result in as many hospital bed days being occupied as do heart disease, lung disease, diabetes, and stroke combined. Indeed, fall related injuries are the largest single cause of bed occupancy in England (DoH, 2007). It is estimated that 4.6 million bed days in England in 2006/7 were for fractures suffered by people aged over 60 and frailty-related falls for those aged over 75 (Royal College of Physicians, 2011). If we were to rid the world of cancer and vascular disease, most of us would die as the result of fall related accidents in later life. In pre-anaesthetic days, a broken hip was almost invariably fatal.

Of the 35% of fallers over the age of 65, between 10% and 15% are seriously injured and between 2% and 6% suffer from a fracture (Lord et al., 2007). Fractures in older people are generally caused by falls from less than standing height ('low trauma' or 'fragility' fractures). The most common fractures are to the pelvis, wrist, upper arm and hip, with one in every two women and one in six men over the age of 50 suffering a fracture (DoH, 2009e). Osteoporosis is an additional risk factor, more commonly seen in women (the condition affects one in three women and one in twelve men over the age of 50). Every year around 310,000 patients in the UK - the majority aged over 50 - are admitted to hospital with fractures, one in four of whom suffer hip fractures (Oliver, 2009). In England alone, hip fractures affect around 70,000 people per year (British Orthopaedic Association, 2008); 80% are women and their mean age is 80 years (Cummings and Melton, 2002; Oliver, 2009). Of all accident and emergency (A&E) admissions in England, 50% result from fractures of the hip, accounting for 60% of trauma bed-days for those over the age of 75 (British Orthopaedic Association and British Geriatrics Society, 2007; Oliver, 2009). Official (DoH) figures suggest that in a local authority with a population of 300,000 people, around 45,000 would be over the age of 65. Of these, 15,500 will fall each year; 6,700 will fall twice or more; 2,200 will attend A&E or a minor injuries unit; and 1,100 will sustain a fracture (DoH, 2009). A number of authors argue that as the population ages, fragility fractures, in particular hip fractures, will increase significantly (Burge et al., 2001; Cummings and Melton, 2002; Oliver, 2009) and the British Orthopaedic Association and British Geriatrics Society (2007) has shown that between 1999 and 2006 the ageing of the population resulted in a 2% per year rise in the incidence of hip fractures.

Fall-related injuries, a major cause of death in older people, increase exponentially as they age; Osnes et al. (2004) argue there is a 20% mortality rate within a year of sustaining a fracture (see also Eriksson, 2007; Morris et al., 1987; and Van Dijk, 1993). Other studies suggest the figure is as high as 40% (Oliver, 2009) and one study (Scuffham and Chaplin, 2002) reported that falls claim the lives of nearly 14,000 people a year following an osteoporotic hip fracture. Post-operative mortality following a hip fracture at one month is 10%, 20% within four months and 30% at one year (Foss and Kehlet, 2005; DoH, 2009e; Oliver, 2009), with post-operative complications such as chest infections and heart failure the most common causes of death, alongside trauma associated with major surgery (Roche et al., 2005). There is also evidence that the risk of

subsequent fractures more than doubles following a fragility fracture (British Orthopaedic Association and British Geriatrics Society, 2007); other serious injuries include neck fractures, which are often fatal, and head injuries, which may lead to intracranial bleeding. In addition, the fear of falling produced by a fall is said to cause the same degree of physical limitation as the physical injury.

Aside from fractures, falls also injure soft tissue which may lead to disabilities, and those who experience a 'long lie' may suffer increased anxiety. Falls and the fear of falling also lead to loss of function and increased admission to residential care (Oliver, 2009). The 'post fall syndrome' (whereby those who have suffered a fall lose confidence in their ability to walk unaided and as a result become weaker) identified by Murphy and Isaacs (1982) is well documented (Arfken et al., 1994; Shumway-Cook et al., 1997; Vellas et al., 1997; Hadjistavropoulos et al., 2011). This in turn has an impact on mortality. Indeed, Cumming et al. (2000) found that a fear of falling was linked to the incidence of future falls, greatly reduced peoples' ability to perform activities of daily living (ADL) and was related to admission to residential care. Their study also found that decreased physical activity resulted in deterioration not only in physical health, but also in mental wellbeing.

## 1.4 The current and future economic costs of falls and dementia

The growing incidence of falls and dementia described in section 1.3 has major implications for society. They include significant additional costs in the health and social care system, many of which are expected to increase public spending, and the costs which family members providing care for older people affected by these conditions are likely to bear. This section summarises evidence about how these costs are expected to escalate unless steps to manage them differently are taken.

### Costs for the state

In coming years, the population aging already described is expected to increase the demand for costly long-term care, and the rise in falls and dementia features strongly in projections of these future costs. Estimates suggest the number of residential care places will need to expand by around 115% to keep pace with demographic pressures, while the number of hours of home care will need to increase by 103%. Between 2002 and 2041 long-term care expenditure will need to rise by 325% in real terms to stay in line with demographic ageing and over the same period the cost of long-term care is expected to increase from 1.4% to 2.6% of GDP (Wittenberg et al., 2006).

Knapp et al. (2007a) estimated the total cost of dementia to be £17.03 billion p.a. in 2007, claiming this was set to rise. They found the annual cost of the care needed by someone with mild dementia living in the community was £16,689 per year including their health, social and informal care and their accommodation (Knapp et al., 2007a; 2007b). Figures were higher for those with moderate (£25,877) or severe (£37,473) dementia. These authors also showed significant variations in costs, assessing annual expenditure on residential and nursing care (in 2004/05) per head of population aged 65+ at £578 (England), £950 (Northern Ireland), £688 (Scotland) and £572 (Wales). Their study also found that across English local authorities home care expenditure per head of population aged 65+ ranged from £62 to £759 p.a. In their estimates, over one third of the total cost of dementia (36%) was the costs of informal care, with carers of people with dementia estimated to save the state £6 billion p.a. At the same time, an estimated £690 million

of income from employment is lost when family members who care for people with dementia give up work or alter their employment arrangements, leading to a loss of £123 million in tax not paid to the Exchequer (Knapp et al., 2007b).

A subsequent study (Luengo-Fernandez et al., 2010) placed the annual UK costs of dementia even higher, at £23 billion, almost twice the estimated cost of cancer (£12 billion) and three times that of heart disease (£8 billion). This found 1.3% of the UK population (821,884) had a dementia diagnosis and that 37% of this group were living in residential care settings (accounting for £9.1 billion of the £23bn costs). Their study valued the cost of informal care at £12 billion, based on the 1.5 billion hours of care provided by carers, calculating the associated productivity losses at a further £29 million and the health costs of dementia at a further £1.2 billion. Other authors note that between 1996 and 2006 a fall in the number of long-term care places (by one sixth) and (since the mid-1980s) a 65% -70% reduction in the number of old-age psychiatry beds has increased the demands on carers, as the majority of those with dementia now live at home (MacDonald and Cooper, 2007).

Falls are shown in recent studies to lead to admissions to A&E departments for more than 400,000 older people annually (DoH, 2001c; Scuffham and Chaplin, 2002) and to account for 40% of ambulance call-outs for people aged 65+ (although not all go to hospital) (Snooks et al., 2006; Oliver, 2009). Seven per cent of falls result in A&E department attendance and in people over 65 fall injuries account for around 14% of emergency hospital admissions (Scuffham et al., 2003), while hip fractures and other injuries arising from falls affect mobility and the ability to live independently. Osnes et al. (2004) found (in a sample of 593 older people) that the proportion of those walking without an aid post-fracture declined from 76% to 36%, with 46% unable to go outside without assistance. Over a quarter of the sample lost the ability to prepare food unaided and a significant proportion had to enter residential care (one third of those over the age of 85). Other evidence shows half of those who sustain a hip fracture following a fall become partially dependent and that a third lose all independence (DoH, 2009e). Between 10% and 20% enter residential care following a hip fracture (British Orthopaedic Association and British Geriatrics Society, 2007) and for those who require surgery to repair a fragility fracture the figures are even higher, with 30% requiring residential or nursing care and only 30% returning to full physical functioning (Rosell and Parker, 2003; Oliver, 2009; British Orthopaedic Association, 2007). The cost of care and rehabilitation post-fall is thus substantial. Scuffham et al. (2003) found that falls among people over 60 cost the UK government almost £1 billion annually, most of which was borne by the NHS (59%), the remainder being spent on long-term care by social services departments (c.f. Van Doorn et al., 2003).

Based on the current costs of fragility fractures and projections of population ageing, by 2050 the cost of falls to the NHS is likely to be £2.2 billion per year (British Orthopaedic Association and British Geriatrics Society, 2007). Other studies (Wittenberg et al. 2006; Comas-Herrera et al., 2011) have explored the projected cost of dementia (using older people with cognitive impairment as a proxy), showing that between 2002 and 2031 expenditure on long-term care services for older people with cognitive impairment in England is likely to increase from £5.4 billion to £16.7 billion (from 0.60% to 0.96% of GDP). Using current projections of population ageing and the prevalence of dementia, MacDonald and Cooper (2007) estimate that by 2043 the UK will need to more than double the number of residential care places available just to sustain the current ratio of institutional to community services for those with dementia.

## Costs borne by carers

The economic costs of providing care for an older person extend beyond the state. Care itself can prove costly for family and other carers and for the person requiring care. Glendinning's (1992) study of the cost of care for carers distinguished between the costs that arise directly from the needs of the person requiring care, such as adapted housing and furniture, additional heating, and substitute care, and costs incurred to save time for the carer, for example the use of taxis and cars instead of public transport and of convenience foods. Carers UK (2007a) found that 49% of carers they surveyed subsidised the cost of living for the person they provided care for, as the benefits the sick or disabled person received were inadequate. In addition, one third of the carers surveyed were in debt and one in ten could not afford their rent or mortgage. Savings among carers were also low, with 44% having no savings at all, and 32% savings of less than £1,500 (Carers UK, 2007b).

Knapp et al. (2007b) and Luengo-Fernandez et al. (2010) explore the role of carers and the financial impact of their withdrawal from the labour market in terms of productivity losses and foregone tax revenue for the UK economy. Withdrawing from paid work also has an impact at the individual level. For carers, there is a two-way relationship between employment and caring: employment may be affected by the decision to provide care in terms of income, job progression and hours worked, while at the same time their employment status impacts upon their likelihood of providing care (Evandrou, 1995). Employment and income circumstances affect carers' decisions about combining work and care as each carer needs to consider *'whether she or he was expecting to be in employment in any case, how much they might earn, how easy it is to combine employment and caring, at what cost in terms of hours and rates of pay, as well as how they perceive their alternatives'* (Joshi, 1995: 109). Joshi (1995) argues that the total opportunity cost of combining care and employment depends on three factors: the degree to which caring affects the working hours and salary of the person; whether the carer is able to return to their former level of employment once the caring responsibility has ended; and whether on returning to regular employment, their prospects are diminished by their loss of experience.

Evandrou and Glaser (2003) reported that among women for whom the onset of caring responsibilities occurred between the ages of 45 and 59, one fifth gave up work entirely and another fifth reduced their working hours, diminishing their income. Evandrou (1995) distinguished 'sole', 'joint' and 'peripheral' carers, claiming that 'sole carers' incur the biggest losses of income, although all had lower incomes compared with non-carers. Joshi (1995) demonstrated that men who were carers had average hourly wages 12% lower than those of non-carers, showing that for women the gap was 17%. There was also a penalty for working part time; a woman who moved from full-time to part-time work lost 21% of her hourly rate at age 30 (rising to 28% at age 40, and 29% at age 50). In a separate survey of 1,093 carers, Carers UK (2007b) found that carers lost on average £11,050 in earnings over the course of a year as a result of giving up work, reducing their hours or taking a different position that allowed them to provide care. The same study also found that foregone earnings increased with weekly hours of caring; those caring for 50 hours per week lost £11,986 per year compared to £6,481 for those caring for 20 hours per week. Carers in their late 50s and early 60s tended to suffer the greatest losses as they were more likely to be forced into early retirement at the point when they were higher earners; people aged 55 to 59 lost an average of £12,247 per year, and those aged 60 to 64 lost £13,220. Hutton and Hirst (2001) also found that caring reduced income substantially, primarily



among those who had been caring for four or more years, whose savings and ability to save for retirement were reduced. On average, carers retired eight years early, which also limited the pension contributions they made (Evandrou and Glaser, 2003). From 2010, the 2007 *Pensions Act* introduced changes intended to address this problem: reducing the number of qualifying years required for the basic State Pension from 39 to 30 years for women and from 44 to 30 years for men; and replacing Home Responsibilities Protection with a new system of pension credits for those caring for at least 20 hours per week. Some studies have shown that the impact of caring persists even after caring ends, as many people who reduce their working hours or give up work to care do not revert to full-time employment (Evandrou and Glaser, 2003; Hutton and Hirst, 2001).

## 1.5 The social cost of falls and dementia

For those who experience a fall or develop dementia there are significant consequences both for them and for their families.

### Social costs for people who fall

Falls resulting in a hip fracture significantly reduce quality of life, particularly among the 'oldest old', i.e. those who have already exceeded the average life expectancy (Salkeld et al., 2000). Most people who fracture a hip experience long-term discomfort; for half, their walking ability deteriorates to the degree that they require a walking aid. As mentioned already, 10% to 20% of this group will enter residential care (British Orthopaedic Association and British Geriatrics Society, 2007). Mobility-related activities decline by 15% to 20% after a hip fracture (Rosell and Parker, 2003) and in one study, 80% of women reported that they would 'rather be dead' than suffer the loss of independence associated with a hip fracture (Salkeld et al., 2000). A study which used the American Longitudinal Study of Ageing (LSOA) to explore the longer term effects of a fall in later life (Kiel et al., 1991) found that those who fell, in particular repeatedly, were more likely to report difficulty in carrying out instrumental activities of daily living (IADLs).<sup>2</sup> They were also more likely to enter hospital or residential care and thus to cease to be independent. The fear of further falls has also been found to considerably reduce a person's quality of life (Iglesias et al., 2009) and older people who are afraid of falling were more likely to be depressed (Kressig et al., 2001). Anxiety about future falls also leads to social withdrawal and isolation (Faes, 2010) and, as mentioned above, the fear of falls is also correlated with an increased likelihood of future falls (Kressig et al., 2001).

The impact of dementia on the individual sufferer is relatively under-researched (Midence and Cunliffe, 1996). People in the initial stages of dementia have been found to be concerned about their reduced ability to engage in activities they were used to and enjoyed, as well as more aware of their declining abilities. Midence and Cunliffe (1996) argue that in the face of these difficulties, some dementia sufferers develop coping strategies that include denial, regression and paranoia while others move in the opposite direction and become more friendly and communicative. In more advanced stages of the disease, dementia patients

<sup>2</sup>Activities of Daily Living (ADL) include activities related to self-care such as bathing, dressing and feeding while Instrumental Activities of Daily Living involve the ability of the person to act independently within their own environment such as shopping, using transport and housekeeping (Spector, 1987).

no longer recognise their relatives or their surroundings, and may become panicked and aggressive. Dementia is also linked to depression as abilities decline. Seignourel et al. (2008) explored the incidence of anxiety, an important inhibitor of wellbeing which reduces quality of life, in people with dementia. They found those with vascular dementia experienced more anxiety than those with AD, and that anxiety increased as dementia progressed. These authors also isolated anxiety from depression and found it was independently correlated with lower quality of life and behavioural disturbance. However, research has also linked anxiety in dementia sufferers with depression (Orrell and Bebbington, 1996), highlighting the prevalence of anxiety, which one third of dementia sufferers experienced, and found that those with more social contact were *more* anxious, arguing that constant reassurance served to remind the dementia patients of their dependency and helplessness (Orrell and Bebbington, 1996).

A study by Hulko (2007) (based on a relatively small sample) provides a more nuanced account of the experience of dementia. In her observations, interviews and focus groups with dementia sufferers, Hulko recorded a range of experiences, with dementia described variously as 'not a big deal' to 'a nuisance' and 'hellish'. She also found the experience of dementia was mediated by social location. Caddell and Clare (2010) conducted a systematic review of the literature on the effect of dementia on the self and identity. The literature on this topic is divided between studies which find the sense of self is preserved and those that argue it diminishes 'until nothing is left'. Caddell and Clare suggest the difficulty in defining 'the self' and in measuring its erosion partly accounts for these different views.

### Social costs for carers

For carers, providing care to family members or others who need help can have a detrimental impact on wellbeing. Carers are two to three times more likely to suffer poor (self-reported) health than those without caring responsibilities (Buckner and Yeandle 2006, analysis based on the 2001 Census) and the negative effect of caring on carers' health increases with more weekly hours of care (Table 1.2, based on the General Household Survey 2000/1). Other researchers have noted that '*[f]actors affecting role strain vary, and much depends on what resources people have available to counteract the demands made upon them*' (Phillips and Bernard, 1995: 12). Recent evidence suggests suitable services supporting carers can mitigate negative impacts on health and wellbeing (Yeandle and Wigfield, 2011).

Pinquart and Sörensen (2003) argue that pressures on carers<sup>3</sup> were affected by three aspects of the circumstances of the person cared for: their level of physical disability (which affects their ability to carry out activities of daily living); the extent of their cognitive impairment, such as memory problems; and any behaviour problems, such as those that can characterise dementia. These authors argue that (while the results are not entirely clear) the most significant negative effects for carers arose when there were behavioural changes. For those caring for someone with a physical or cognitive disability, depression was also more strongly correlated with weekly hours of care.

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<sup>3</sup>Throughout this volume, the term 'carer' is used to refer to people who provide their support unpaid, as a family member, neighbour or friend.



Table 1.2

Health symptoms reported by carers by weekly hours of care: 2000 - 01

|                           | Weekly hours of care |       |            | All carers<br>% |
|---------------------------|----------------------|-------|------------|-----------------|
|                           | Less than 20         | 20-49 | 50 or more |                 |
| Feels tired               | 12                   | 34    | 52         | 20              |
| Feels depressed           | 7                    | 27    | 34         | 14              |
| Loss of appetite          | 1                    | 5     | 8          | 3               |
| Disturbed sleep           | 7                    | 24    | 47         | 14              |
| General feeling of strain | 14                   | 35    | 40         | 20              |
| Physical strain           | 3                    | 10    | 24         | 7               |
| Short tempered            | 11                   | 29    | 36         | 17              |
| Had to see own GP         | 2                    | 8     | 17         | 4               |
| Other                     | 2                    | 4     | 2          | 2               |
| Health not affected       | 72                   | 39    | 28         | 61              |

Source: General Household Survey, 2000.

Other studies show that carers of people suffering from dementia face specific challenges. Moise et al. (2004) cite several studies which found caring for someone with dementia was more distressing and had a worse effect on health than caring for someone with a physical disability. Morris et al. (1988) found the incidence of depression to be significantly higher among carers of people with dementia, partly because of the way relationships can change. The factors carers considered most challenging included sleep disturbance, faecal incontinence, lack of mobility and dangerous behaviour, including wandering. For carers of someone with dementia it is challenging behaviour and the 'daily grind' which pose the greatest difficulties (Morris et al., 1988). Moise et al. (2004) reached similar conclusions, pointing out that although physical capabilities may remain intact, cognitive decline means eventually sufferers may be unable to recognise their carer and can develop challenging behaviour: aggression, wandering and personality change. This can lead carers to experience depression and 'anticipatory grief' for the lost close relationship as the health of the person they care for declines and they lose the characteristics that once made them familiar (Morris et al., 1988). Connell et al. (2001) also find evidence of the negative impact of caring for a person with dementia on mental wellbeing persuasive; they report that the prevalence of depression and anxiety is higher for carers of people with dementia than in the general population and also that they use more psychotropic drugs.

Donaldson et al.'s (1997) review of the literature on the impact of caring for someone with dementia highlights social isolation and reduced social activities as key areas of stress. Other studies have found carers experience a higher level of emotional strain in the early stages of dementia due to the adjustment required (Samuelsson et al., 2001). Ory et al. (1999) found that carers of people with dementia experienced more difficulties at work than carers of people with other disabilities, and that they were more likely to move to less demanding employment, take early retirement, decline promotion or give up work entirely. Connell et al. (2001) argue that carers of people with dementia provide more care and support with a greater number and variety of tasks than other carers, which has a greater impact on other areas of their lives such as employment, family life, leisure time and mental and physical health.

Falls too present particular challenges for carers: a fear of falling can follow an incident and this can lead to reduced activity and increased dependence (Cumming et al., 2000; Kressig et al., 2001), as can the actual diminished mobility which results from a fragility fracture. Kuzuya et al. (2006) explored the impact of falls on carers in Japan, finding that carers of someone who had fallen within the past six months were more likely to be depressed than other carers. They claim fear of the older person falling has a negative impact on carers' mental wellbeing and that where dementia was also present the score for carer depression was also higher.

## 1.6 Summary

Dementia and falls are extremely costly, in both financial and social terms, for those who experience them, for their carers and for the state. In providing social and health care, the state's costs arising from dementia and falls amount to around £10.2 billion and £1 billion per annum respectively, costs which do not include the substantial productivity losses that arise from people leaving the labour market to care for family members. For them, the lost or reduced income is also keenly felt and many find returning to employment, or to employment at their previous level, difficult (Evandrou and Glaser, 2003; Hutton and Hirst, 2001; Yeandle et al. 2007). There are also significant social costs both for those who experience these conditions and for their carers, who may become isolated. Both dementia and a susceptibility to falls can also lead to significant loss of independence and entry into residential care.

This chapter has also summarised evidence about population ageing and other demographic changes, including more diversity in family structures and the greater geographical dispersal of family members, because of which caring is increasingly conducted at a distance. The expected increase in the numbers of older people suffering from falls and dementia has been highlighted alongside the declining availability of carers, paid and unpaid.

In later chapters, the focus is on the relevance of technology, and in particular of telecare, as a means of addressing or mitigating some of the negative impacts identified, by reducing costs for the state, providing carers with peace of mind and enabling them to remain in paid employment and allowing people who experience a fall or develop dementia to preserve at least some of their independence for longer.

Chapter 2 thus turns to the literature on ageing and technology, fields which are not usually linked, and in considering these bodies of literature, identifies both gaps in knowledge and areas of convergence.

## Chapter 2

# Understanding telecare: insights from the sociology of technology and ageing

*Chrissy Buse and Emma-Reetta Koivunen*

Despite a burgeoning literature on the 'gender-technology' relation (e.g. Wajcman, 2000), there has been limited dialogue between the sociological literatures on ageing and on technology (Joyce and Loe, 2010) and most research on telecare and assisted living technologies has neglected to engage with critical social perspectives on ageing or technology (Fisk, 2003). Social theories can nevertheless offer valuable concepts for understanding the use of telecare in the context of older people's everyday lives, and why users may engage with, or resist, the use of telecare. This chapter draws out the implications of social perspectives on ageing and technology for understanding telecare, and highlights gaps arising from a lack of engagement between these fields. These are large bodies of literature which it is not possible to cover in their entirety. The chapter focuses on perspectives and concepts which are particularly salient for the AKTIVE project. Exploring mainly sociological approaches, the chapter also considers interdisciplinary perspectives from social and critical gerontology and from science and technology studies (STS), which seek to understand ageing and technology in social context.

## 2.1 Sociological and STS perspectives on technology use

In seeking to understand the use of telecare in social context, it is important to consider how the technology-society relation can be conceptualised. Technological determinism is the view that technology is something separate from society, which 'impacts' upon social relations (Prout, 1996: 201). Technologically deterministic approaches portray technology as having inherent properties and acting in predictable ways (Holloway and Valentine, 2003). As others have observed, deterministic thinking was prevalent in early sociological theories of the 'effects' of technology on social relations (Wajcman, 2000; Sismondo, 2010). While technological determinism has now been widely critiqued, weaker versions of this approach are still present in some social studies (Sismondo, 2010). Technologically deterministic analysis also emerges implicitly in some academic and policy discussions of the potential of technologies for older people and carers (Xie, 2003; Selwyn, 2004; Percival, 2009; Pols and Willems, 2011). Thus it is sometimes assumed that particular technologies are 'inherently useful and desirable' (Selwyn, 2004: 281) and have predictable outcomes in terms of benefits for users, overlooking that users may shape technologies in unpredictable ways (Xie, 2003).

In contrast, social constructionist approaches present technologies as inherently social, and shaped by the interests of designers and users (Wajcman, 2000). The 'social construction of technology' (SCOT) approach suggests that the success of particular technologies is dependent on the response and shared meanings developed within 'relevant social groups' (Pinch and Bijker, 1984). Pinch and Bijker highlight the multi-directional nature of technological development in relation to the differing interests and needs of social groups. The concept of 'interpretive flexibility' developed by SCOT theorists may be particularly useful; this suggests that different social groups understand and use technologies in a variety of ways, which may differ extensively from their intended design (Cockburn and Omrod, 1993; Wajcman, 2000).

While SCOT approaches show that technologies are socially shaped, Tatnall and Lepa (2003) argue that they still separate the technical and the social and are 'socially deterministic'. Actor Network Theory (ANT), by contrast, challenges both social and technological determinism, presenting technology and society as relational and mutually constitutive (Prout, 1996). ANT seeks to deconstruct binary divisions, including those between: social / technical; human / non-human; social / natural; science / technology; subject / object; and structure / agency (Law, 1999; Singleton and Michael, 1993). It examines 'heterogeneous networks' of entities, including both human and non-human actants (Wajcman, 2000). A key concept in ANT is 'translation': *'the process by which entities mutually enrol each other into a combination of some type, claiming to speak for each other, interpreting, configuring and reconfiguring each other'* (Prout, 1996: 202). The properties of entities are not seen as being pre-determined or fixed, but as *'emerging as a consequence of the relations in which they are located'* (Law, 1999: 4). Human entities may include patients / service users, technicians, local businesses and health and social care staff, while non-human entities may include machines and technologies such as computers, modems, or medical appliances (Prout, 1996; Tatnall and Burgess, 2002).

ANT has been viewed as useful because it is able to account for flexibility, diversity and complexity in social practices (Gill and Grint, 1995). The theory also highlights the mutual relationship between technologies and social relations, and the way technologies may be shaped by, as well as shape, social contexts and relationships (Holloway and Valentine, 2003). The approach has been used by feminist researchers to explore how gender identities and technologies are mutually constituted (Wajcman, 2000) and could be similarly applied to understanding the construction of age identities in relation to technology. It also brings into focus the broad and complex networks around technologies (Tatnall and Lepa, 2003).

However, ANT approaches initially focused on networks of designers rather than of users, which meant that groups who have been historically marginalised from the design of technologies, such as women, were excluded (Gill and Grint, 1995). One solution has been conducting research which widens actor networks to include users, and people in lower paid job roles (Singleton and Michael, 1993). Tatnall and Lepa (2003) took the methodological approach of 'following the actor', and used initial focus group discussions with older Internet users to define the framework of participants in their research. Nevertheless, another fundamental problem with ANT is that it has difficulty accounting for historical social divisions and relations of power which pre-exist interactions (Singleton, 1995). This has been problematic for feminist theorists seeking to locate technology use within gendered power relations (Gill and Grint, 1995), and is also problematic for understanding the use of telecare in the context of historical relations and divisions around age.

There has been relatively little research applying insights from social constructionist and ANT perspectives on technology to understanding telecare. However, research drawing on these approaches is growing, and illustrates how telecare can be reconfigured by users in unexpected ways (Blythe et al., 2005; Reed, 2009; Milligan et al., 2010; 2011; Pols and Willems, 2011; Milligan et al., 2011). For instance, Reed (2009) found that one participant refused to use a pendant alarm, but instead carried her cordless phone with her at all times as a way of contacting help in case of an emergency. Blythe et al. (2005) reported finding older people using a system designed for emergency contacts to communicate with one another on a regular basis. Milligan et al.'s (2010) research has also illustrated the implications of telecare for extending and introducing new actors into 'networks of care'.

## 2.2 The 'domestication' of technologies within everyday lives and contexts

'Domestication' provides a potentially important conceptual framework for understanding technology use within everyday contexts, such as the home. Rather than discuss the 'effects' of technology, this theory explores what users do with technologies once in the home (Haddon, 2006). The focus is on the context of use, and the location of technologies within temporalities, spatialities and relationships in social settings. 'Domestication' has been described as the process of 'taming the wild' (Haddon, 2006) and making new or alien technologies into an everyday part of domestic space (Ward, 2006). It follows the biographies of technologies as they are brought into households (Silverstone et al., 1992) and integrated (or rejected) into this space, involving four key stages, outlined in Box 2.1.

These four stages are not distinct but overlap or intersect in the process of integrating and using technologies in households (Holloway and Valentine, 2003). For instance, spatial location and ownership are interconnected and the location of technologies in households can be part of marking out personal space in the home (Holloway and Valentine, 2003; Bakardjieva, 2005). This focuses on households, although the concept of 'conversion' situates the use of technologies within wider social networks 'beyond the home' (Holloway and Valentine, 2003).

### Box 2.1

#### Stages of Domestication

Four main stages in the process of domestication are outlined by Silverstone et al. (1992):

##### **Appropriation**

The initial purchase of technologies and their subsequent 'possession and ownership' within the household. This also includes the ongoing purchase of software, and subscription to services. Appropriation also refers to the way the meanings of technologies are reconstructed in relation to the identities, biographies, and experiences of household members.

##### **Objectification**

The spatial location and display of technologies within the home, and their relation to spatial meanings and divisions.

##### **Incorporation**

The integration of technology into temporal routines within households, and the way technologies may shape temporalities.

##### **Conversion**

The discussion of technologies with others outside the home, and their use to convey taste or status.

This approach offers a framework which has been practically applied to researching how different social groups integrate and use different technologies within the context of the home. Applications of domestication of technology have highlighted the point of view of users of technology and their active role in developing the technology (e.g. Hynes, 2009). For instance, studies using this approach have explored: teenagers' use of the Internet at home and school (Holloway and Valentine, 2003); ICT use among single

parents (Haddon and Silverstone, 1995) and older people (Haddon and Silverstone, 1996; Lim and Tan, 2005); home workers' use of computers and the Internet (Haddon and Silverstone, 1993; Ward, 2006); and the integration of computers and the Internet into different family households (Habib and Cornford, 2002; Bakardjieva, 2005; Hynes et al., 2008). By studying everyday contexts, the approach reveals how gendered and generational divisions and barriers to technology use may be constructed on a micro-scale between household members (Lim and Tan, 2005). For instance, anxieties about using a technology can be reinforced through reliance on another household member to use them, or the exclusion of technologies in a separate space (Brabazon, 2008). Different household members may also have to compete for access to shared ICTs (Holloway and Valentine, 2003).

The domestication framework can also be applied to understanding telecare use in everyday contexts, and recent research has begun to draw on this approach. For instance, Pols and Willems (2011) explored the use of webcams in a rehabilitation clinic, and found that, as a new technology, this form of telecare needed to be 'tamed' or 'domesticated' and affected practices of care in unpredictable ways. There have also been several recent studies exploring the use of telecare in the home and the domestication of these technologies (e.g. Lopez and Sanchez-Criado, 2009; Lindegaard and Broderson, 2010; Milligan et al., 2010). These studies illustrate the implications of telecare for meanings of home, and boundaries of public / private, and suggest that while some aspects of telecare improved quality of life, others did not become 'domesticated' into the home and disrupted the sense of 'homeliness' (Lindegaard and Broderson, 2010).

## 2.3 The social construction and context of ageing and 'old age'

In exploring telecare use among 'older people', it is important to consider what constitutes an 'older person' and the meanings of ageing. Harper (2006a) points out that the theoretical concepts of age and ageing are limited and based on biological ageing. She notes that, like race and gender, age and ageing should be explored socially, culturally and historically. She also highlights the key concepts of generation and cohort, which link the 'individual life course and the social changes that occur during the historical time of that life course' (Harper, 2006a, p.77). Social constructionist, life course, and anthropological approaches argue that age categories are socially constructed, and illustrate how meanings of ageing and 'old age' vary across cultural and historical context (Laz, 1998; Blaikie, 1999; Hockey and James, 2003; Vincent, 2003; Gilleard and Higgs, 2005). One obvious example is the clear distinction of life-stages such as 'childhood', 'adolescence', 'adulthood' and 'old age' developed during Western modernization in the 19<sup>th</sup> century (Hockey and James, 2003). Particular social norms and expectations are associated with these age categories, as well as institutional and bureaucratic regulations which govern access to work, education and care (Bytheway, 1997). The establishment of pensions and a fixed retirement age is central to the modern category of 'old age', as is the definition of an older person as someone aged 60 or 65 and over (Vincent, 2003). Images and representations associated with the modern category of 'old age' have historically been negative, focusing on dependency, frailty, and mental and physical decline (Kaufman, 1986; Featherstone and Hepworth, 1991).

However, some writers claim that fixed life-course stages are now becoming more flexible in postmodern society, with changing patterns in family, employment, and consumption (Featherstone and Hepworth, 1993; Featherstone, 1995; Blaikie, 1999; Hockey and James, 2003; Gilleard and Higgs, 2005). The distinctions between education, work and retirement are becoming increasingly blurred, with an increasing number of people retiring early, or returning to education or employment post-retirement (Blaikie, 1999). Greater

affluence among older people in Western society means they have greater economic power as a consumer group (Vincent, 2003; Gilleard and Higgs, 2005). This has led to more positive images of later life, depicting older people as healthy, active, and independent consumers (Featherstone and Hepworth, 1993; Katz, 2001; Katz and Marshall, 2003). Nonetheless, these images are only available to those with the material resources to access them, and structural inequalities continue to shape the lives of many older people, reflecting earlier patterns of inequality according to class and gender (Vincent, 2003, 2006). Furthermore, the 'oldest old', including those suffering from ill-health, are becoming increasingly marginalized (Hockey and James, 1993).

Various cultural constructions of 'old age' are drawn on in discussions and images of technology use in later life, in both popular and academic sources. For instance, research on the use of the Internet and computers in later life has illustrated how 'old age' and new technologies are often positioned in opposition to one another, with new technologies being constructed in terms of youthfulness, modern values and speed (Jaeger, 2005). Richardson et al. (2005) have argued that the discourse of 'ageing as a problem' is often pervasive in policy discussion of the information society and Internet use in later life, even though this occurs alongside the more positive discourse of 'active ageing'. Much computer design and other literature in this area has drawn on negative depictions of older people in terms of mental and physical decline, loneliness, and dependency (Östlund, 2002; Jaeger, 2005). While there has been less examination of the relation of telecare to cultural constructions of ageing, Fisk (2003) has argued that representations of older people in advertisements for 'social alarms' have on the one hand presented messages of activity and independence, but on the other frequently focus on images of the frailest older people, reinforcing representations of decline and frailty. However, older people are increasingly involved in the design of technologies, and as illustrated in Chapter 3, design literature now more frequently presents positive and critical accounts of later life (e.g. Czaja and Lee, 2008; Reed, 2009).

Cultural constructions of 'old age' and their relation to particular technologies are important as they shape user engagement (or disengagement). For instance, in the case of Internet and computer use, the Oxford Internet Survey in 2007 found that retirees were more likely than younger people to say they did not use the Internet because it was 'not for people their age' (Dutton and Helsper, 2007). In survey and qualitative research on Internet use among older age groups, users have frequently cited 'feeling too old' as a reason for not using these technologies (e.g. Selwyn et al., 2003; Selwyn, 2004; Dickinson and Hill, 2007; Turner et al., 2007). There are also indications that representations of old age may shape engagement with telecare; for instance, researchers have previously found that users were reluctant to use technologies such as pendant alarms due to their association with dependency and frailty (Peeters, 2000; Lindegaard and Brodersen, 2010; Rodeschini, 2011).

## 2.4 An everyday life approach to understanding experiences of 'old age'

Although macro perspectives are important for highlighting the social context of 'old age', to understand how ageing and 'old age' are experienced a 'micro-level' or 'everyday life' approach is needed (Gubrium and Holstein, 2000; Hockey and James, 2003). This includes exploring how older people themselves experience and construct meanings around 'old age', and the location of these experiences within everyday contexts and mundane aspects of daily living. Such an approach is important to avoid defining 'old age' in overly positive or negative terms and for exploring the reality of older people's daily lives. This includes examining



how age identities are constructed within micro-interactions and settings (Blaikie, 1999; Lin et al., 2004) and may vary according to different contexts (Kaufman, 1986). However, some authors claim these interactions also need to be located within wider cultural representations and structures which may shape and constrain them (Laz, 1998; Laliberte-Rudman, 2006).

This approach to theorising later life can be brought together with an everyday life or 'domestication' approach to understanding technology use. Studies have shown that ICT use is situated within various aspects of older people's everyday lives, including the transition to retirement, social networks and relationships, and hobbies and activities (e.g. Selwyn et al., 2003; Buse, 2009). In Selwyn's (2004) research, a lack of engagement with computers and the Internet among older people was most often due to a perceived lack of relevance to their everyday lives and interests. Previous studies have highlighted the role of television in shaping routines following retirement, due to the loss of time structures traditionally associated with paid work (Haddon and Silverstone, 1996; Morley, 2000). However, as retirement becomes more flexible and fluid, technologies may also contribute to the blurring of boundaries between home and work, and between education, work and retirement (Buse, 2009).

Examining the construction of age categories in everyday contexts and discussions presents a more complex picture of how users may draw and negotiate representations of ageing and technology. For instance, older Internet users have been found to draw on various constructions of old age, both positive and negative, in online and offline discussions (Blit-Cohen and Litwin, 2005; Lin et al., 2004; Richardson et al., 2005). Reed (2009) explored how age categories were constructed during teleconferences as part of a telephone befriending service, finding that age categories were sometimes parodied in humorous ways, although in other instances ageing was referred to more negatively, focusing on health issues and physical complaints.

Everyday life approaches also highlight the 'situational' nature of experiences and constructions of age and the importance of place in shaping meanings and constructions of age divisions (Laws, 1997). Research has shown that in later life, home becomes increasingly important to older people for maintaining a sense of independence and continuity in social identity (Kontos, 2000; Percival, 2002; Valentine, 2001), as has also been recognised in recent national policies (see Chapter 4). Experiences of home may become more problematic in later life, however, with the onset of illness or disability (Featherstone and Hepworth, 1991, 1993; Featherstone, 1995; Hockey and James, 2003; Bhatti, 2006), which can limit activities and the use of space at home (Percival, 2002). Although home care can help older people remain at home, it can also impinge on the sense of privacy associated with this space (Martin-Matthews, 2007), even though this is generally seen as preferable to moving into a residential or 'old person's home' (Chapman and Hockey, 1999; Martin-Matthews, 2007).

Such understandings of place and particularly of 'home' are important for understanding how the use of telecare is situated within and may shape the meanings of 'home' and ageing. This is illustrated by recent studies, including one by Laviolette and Hanson (2007) who conducted a case study of heart failure sufferers and examined changing perceptions of users as they appropriated telecare. They found that these technologies sometimes had negative implications for older people's sense of independence and 'continuity of self'. On the other hand, telecare facilitated continuity by enabling users to remain in their family home. Similarly, Milligan et al. (2010) found that monitors and sensors could disrupt a sense of privacy or feeling 'at home', but that wearable devices increased the users' sense of ontological security and independence.



## 2.5 Locating later life in context: biographies, life-course and generations

As well as locating experiences of old age within the context of everyday life, biographical, life-course and critical sociological and gerontological approaches have argued that experiences of old age need be located within the broader context of experiences throughout the life-course (Kaufman, 1986; Blaikie, 1999; Gubrium and Holstein, 2000; Hockey and James, 2003). Biographical approaches are crucial for situating experiences in later life within change and continuity over time (Hockey and James, 2003). The resources and experiences which are available for people to draw on in later life reflect social conditions and experiences throughout the life-course (Jeffreys, 1997). Biography is also important for understanding how changing age identities are constructed and experienced over time, drawing on narratives of past, present, and future (Hockey and James, 2003).

In exploring the use of technology in later life, biographical approaches are important for avoiding depictions of 'old age' as a static and isolated stage, and taking into account the influence of skills, experiences and attitudes toward technology, which people develop throughout their lives (Mollenkopf and Kasper, 2005). Several studies have illustrated how biographical experiences shape ICT use in later life and may shape engagement and uptake of technologies (e.g. Haddon and Silverstone, 1996; Mollenkopf and Kasper, 2005; Buse, 2010). For instance, Mollenkopf and Kasper (2005) found that biographical experience with older technologies was an important predictor of Internet use in later life, and that women were more likely to report avoiding technologies through their lives, which influenced the likelihood of using the Internet and computers later on. Research by Buse (2010) illustrated how people's embodied biographical experiences of using technologies, such as the typewriter, shaped their later use of computers and the Internet in retirement.

Biographies reflect the interplay of personal accounts of ageing with historical and social context (Blaikie, 1999). This is captured in the concept of 'social generations', which refers to a cohort of people born at the same time and subject to shared historical experiences (Mannheim, 1952; Hareven, 1994; Pilcher, 1994; Edmunds and Turner, 2002). Some claim such experiences produce a shared generational consciousness or identity (Hardy and Waite, 1997). Mannheim also argued that 'formative experiences' are particularly significant in shaping the experiences and values of a generation, and that later experiences '*receive their meaning from this original set*' (Mannheim, 1952: 298).

Drawing on these theories, different 'media generations' or 'technology generations' are said to have shared experiences of using particular technologies within their 'formative period' which then shape experiences of technology use throughout their lives (Bolin and Westlund, 2009). This approach has been applied to understanding media preferences (Volkmer, 2006), the use of mobile phones (Bolin and Westlund 2009) and the use of the Internet (Gilleard and Higgs, 2008, Rama et al., 2001). These studies support the argument that differences in using these technologies is generational rather than a result of the physiological and material conditions of later life. For instance, experimental research by Rama et al. (2001) examined performances in using software-style interfaces, and found a generational effect in the number of errors participants made. Those born after 1960 (the software generation) made fewer mistakes than those born prior to 1960 (the electro-mechanical generation). Gilleard and Higgs (2008) attempted to untangle the effects of ageing from those of generation in shaping digital divisions in Internet use in the UK. They found

that health and frailty variables did not explain age divisions, but divisions disappeared once the use of ICTs and participation in cultural activities was controlled for. They argued that this suggests a generational difference in engagement with consumer culture, rather than the effects of ageing.

Qualitative research also illustrates the significance of generational experiences for shaping technology use in later life. By bringing domestication approaches together with biographical, generational, and life-course theories, such research illustrates how older people's biographies shape their everyday experiences of technology use within the home. For instance, the restriction of television viewing to the evening has been linked to the strong work ethic among older generations (Haddon and Silverstone, 1996; Gauntlett and Hill, 1999; Buse, 2009). Research by Haddon and Silverstone (1996) found that although the purchase of technologies was shaped by changes during the life-course, it also reflected earlier generational experiences of poverty which led to more cautious attitudes toward spending. Similarly, research has found that technologies which participants 'grew up with' (such as the radio) were used more naturally, and were more highly integrated into everyday lives and routines (Lim and Tan, 2005; Buse, 2010).

Understanding the influence of biographical and generational experiences may therefore be important in understanding the use of, and barriers to using, telecare among older people and their carers. It has been noted that the characteristics of users and carers have a significant role to play in how successfully telecare is taken up (see section 6.2). However, there has been little exploration of the extent to which users' biographies and generational experiences play a role in shaping engagement with telecare. One exception is Reed (2009) who found that initial concerns expressed by some participants about using a teleconference befriending service were overcome by relating this service to earlier technologies such as the television or radio. In addition, Hanson et al. (2008a) found variable levels of engagement with telecare among older people, which related to their biographical experiences and attitudes toward using technology.

Biographical approaches may also be significant for understanding experiences of using telecare among people with dementia. Taking a biographical approach is important for challenging the reduction of people with dementia to their condition, and bringing back into focus other elements of their social identities and biographies which constitute personhood (Hockey and James, 1993). Furthermore, a growing body of research illustrates how, among people with Alzheimer's Disease, 'embodied' memories and tacit pre-reflective knowledge involved in gestural communications, interactions, and activities such as dance, music, and painting, can be retained (Kontos, 2003, 2004; Nettleton et al., 2011). It has been argued that technology use similarly involves tacit, embodied knowledge acquired through embodied biographical experiences of using technologies through the life course (Buse, 2010).

## 2.6 Summary

This chapter has drawn together insights from sociological perspectives on ageing and old age, and social approaches to understanding technology use. Sociological and STS perspectives on technology use are important for theorising the use of telecare in everyday life, and exploring what users do with these technologies once in the home, rather than discussing their effects in a deterministic fashion. Domestication approaches provide a framework for understanding how technologies are adopted and integrated into

domestic space, and their fit into the temporalities, spaces and relationships in this setting, as well as their situation within broader social relationships. Bringing these perspectives together with sociological theories of ageing enables a more complete and critical understanding of the use of these technologies within the context of older people's everyday lives. This includes the social and material conditions of later life, as well as constructions and experiences of 'old age' within everyday interactions. Sociological approaches focusing on the life course, biographies and generations also highlight the importance of understanding experiences in later life within the broader context of lifetime experiences, and the shared experiences of particular generations. These issues have implications for understanding how technologies are used, and the challenges and barriers in using particular technologies, which can be applied to conceptualising telecare use in later life.

## Chapter 3

# Technology, ageing and design

*Rama Gheerawo and Peter Buckle<sup>4</sup>*

Whereas Chapter 2 explored the importance of integrating sociological approaches to technology and ageing and of advocating a focus on the micro-level to gain deep, contextualised insights, this chapter takes a design-focused perspective. However, as will become clear, similar conclusions have been drawn in the field of design in terms of the importance of involving user perspectives, not only in the research process, but also at the design stage. A number of different approaches are explored in the chapter, which considers both inclusive design and design ethnography. Although these methods have the same focus as the sociological approaches already described (on how technology is used and experienced by older people) and are indeed influenced by methods such as ethnography, they originate from a design perspective. Thus their aim is to utilise the knowledge of users and users' experience to create better designed and therefore more desirable technologies. Due to the practicalities of designing products, these studies rarely involve extended timescales, the aim being to generate creative insights as opposed to in-depth understanding. The chapter also explores the system design approach which situates products within systems of actors, in particular in the field of healthcare, to explore risks. Mapping these systems and the risks associated with them is seen as central to the design process. The chapter also includes a discussion of patient safety research. Just as it is important to include the needs of users and systems in designing technology, so it is vital to learn from instances where poor design has led to errors or accidents. Prospective Hazard Analysis can be utilised to map potential risks during the design process, and the final part of this chapter outlines recent practice using this approach in terms of assisted living technologies.

## 3.1 Technology, design and ageing

Technology, as used here, refers to information technology (IT), in particular those technologies that provide communication, personal support, information and entertainment. These areas of IT are becoming less bespoke, more convergent and more pervasive in both personal and professional lives (Woods, 2003). They represent a rich research area for design.

The physical results of getting older involve multiple, minor impairments affecting eyesight, hearing, dexterity, mobility and memory (Haigh, 1993). IT that is hard to use, or difficult to access will not satisfy the needs of older people and this has significant implications for design that is mismatched to functional ability (Laslett, 1998). This perceived tension between technology and its users is widely described as 'technology-push, user-pull'. The terms 'push' and 'pull' originated in logistics and supply chain management (Hinkelman and Putzi, 2005), but have become widely used in business and marketing. In an IT

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context, they articulate the difference between technology driving the ideation process and the market demanding it. In the 1960s, strategists realised that 'demand pull' would effectively support programmes biased towards a 'technology push' (Roberts and Gadberry, 1968).

In the mid-70s, 'demand pull' began to be seen as an equal route towards innovation (Lewis, 1975) while a decade later, researchers into the stimuli of the innovation process reported that the number of innovations stimulated by 'need pull' substantially exceeded those stimulated by 'technology push' (Voss, 1984). In critical areas of design such as medical equipment empirical studies concluded that 'understanding user need' was a discriminating factor between commercially successful industrial product and process innovations, and those that failed (Shaw, 1985).

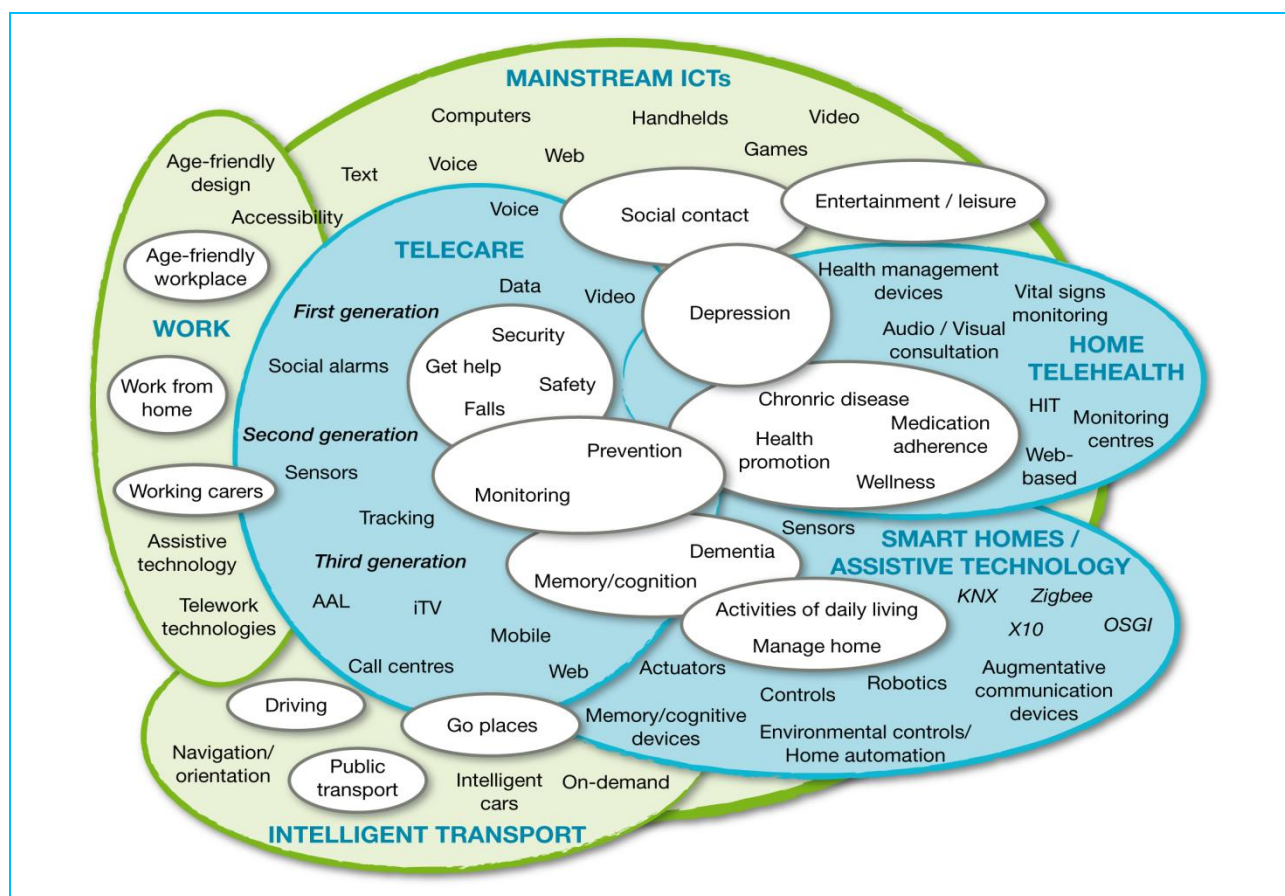
The 1990s saw technology developing rapidly. Fourth and Fifth Generation models of innovation responded to this increasing pace and innovation in this sector was no longer sequential; it became parallel and even complex (Rothwell, 1994). Working with communities can establish focus not just on commercial products but also (as highlighted in Chapter 2) new understanding of the uses of technology (Hofmeester and de Charon de Saint Germain, 1995). This becomes important in moving the designer's view beyond the artefact or the technology and on to the rich area of designing to support communication, lifestyle and information exchange for the users.

Although a considerable range of promising devices and systems for telecare and telehealth has emerged from design, development and research efforts in Europe over the last decade, wider mainstreaming of IT-enabled solutions within real world service settings has yet to occur. Some of the underlying reasons identified by the EU Commission's action plan include insufficient understanding of user needs, an underdeveloped marketplace and lack of visibility of relevant solutions to potential deployer organisations and end users, as well as technical, infrastructural and regulatory barriers. *The ICT & Ageing: European Study on Users, Markets and Technologies* report, written by the European Commission's ICT for Inclusion Unit, analyses the market situation in 16 countries and benchmarks good-practice case studies (Kubitschke and Cullen, 2010).

The technological focus of this review is mainly on applications that have particular relevance for the services that can support independent living and home care for older people. Although needs of older people in this domain are very heterogeneous, they can be grouped in a manner that maps to the three main 'market' segments that typically structure the service delivery landscape in Europe; social care, health care and housing (Figure 3.1). A new, cross-cutting element that is, at least in principle, enabled by technological developments concerns provision of services and supports on a mobile basis.

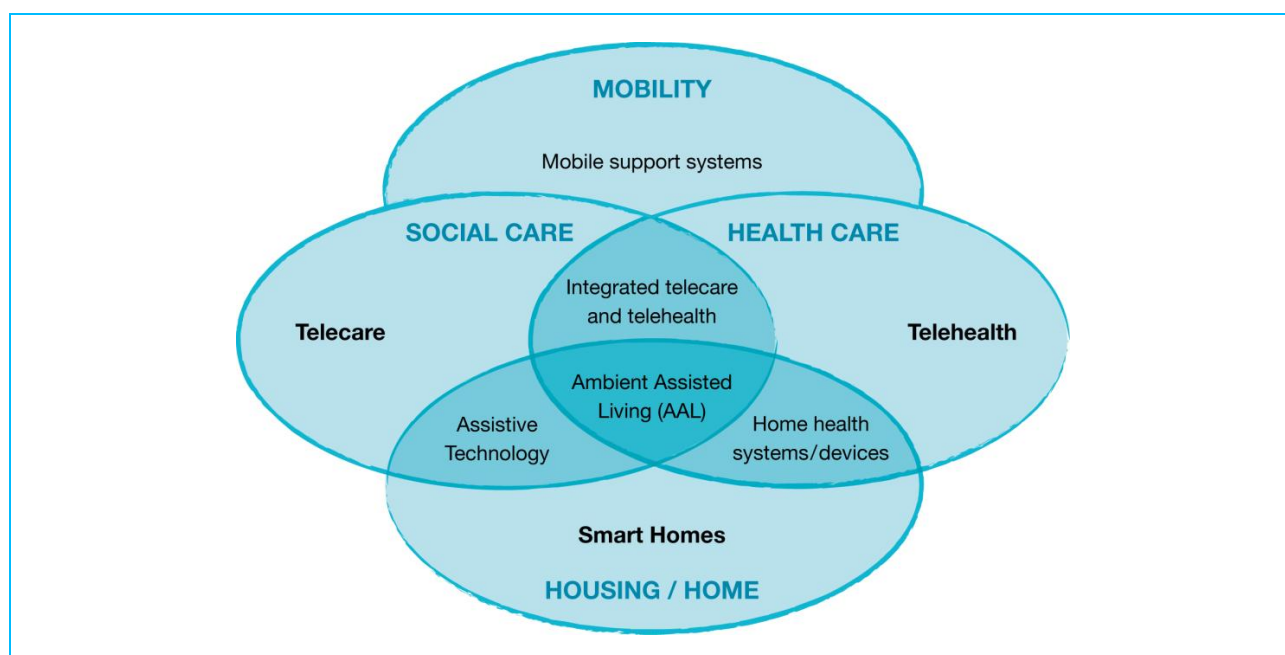
The technological space can be organised in terms of three main clusters; telecare, home telehealth and smart homes. As illustrated in Figure 3.2, these map respectively and fairly well to the three core service domains; social care, health care and housing. These three technology domains provide a useful organising frame for research and analysis.

Figure 3.1  
The service delivery landscape in Europe



Source: Kubitschke, L. and Cullen, K. (2010).

Figure 3.2  
IT mapped on to service domains



Source: Kubitschke, L. and Cullen, K. (2010).



## Inclusive Design

Inclusive design has been recognised by the UK government as a potentially important driver of change; it is described as '*a process whereby designers ensure that their products and services address the needs of the widest possible audience*' (DTI, 2000). Inclusive design has traditionally dealt with physical design and differences in age and ability. However, as technology becomes more pervasive, the new barriers to inclusivity are increasingly digital. Centring design around people can increase competitiveness and value, especially in fast-moving technology markets, however design for older people should go beyond physical requirements to also address personal aspiration and emotional connection, something that people continue to value as they get older (Audit Commission, 2000). This is very much aligned to the thinking contained within inclusive design, defined as comprehensive, integrated design that encompasses consumers of diverse age and capability in a wide range of contexts (British Standards Institute, 2005). As designers instinctively focus on designing for people who have similar capabilities to their own (Keates and Clarkson, 2003), the people-centred methods employed in inclusive design can allow empathy to grow between a designer and a person who might be 50 or 60 years older than they are (Gheerawo and Myerson, 2006)

Design is more than just an aesthetic process. Papanek (1972) stated that design must become more responsive to true needs and more research orientated, but it is only over the last decade that these ideas have become more mainstream. When designer Patricia Moore conducted an immersive experiment between 1979 and 1982, dressing up as an older woman to understand attitudes to older people, her efforts were not recognised as 'design' (Moore and Conn, 1985), though her findings contributed much to understanding how design and ageing are interrelated.

The emerging field of design ethnography (Clarke, 2010) formalises the tools, methods and techniques of a people-centred approach, showing how the ethnographer's methods of observation, interview, diary entries and fieldwork can benefit designers. Many designers who have engaged in ethnography have also re-imagined it. The design group IDEO created a set of 51 methods cards for design teams to use in empathic research and human-centred design (IDEO, 2003). The cards are classified into four suits – *Ask, Watch, Learn* and *Try*. The Norwegian Design Council simplified tools by presenting nine key methods (Eikhaug and Gheerawo, 2010) divided into three categories of *Low, Medium* and *High* Contact.

Although people-centred design borrows much from ethnography, the designer cannot benefit by simply co-opting techniques without adapting them to a specific purpose. The longer studies that ethnography favours do not always work in the shorter time frames that designers have. The search is for creative insights rather than an expansive understanding of every aspect of a user's life. Design ethnography is still developing as a discipline but draws from existing tools and techniques as well as developing new ones. Some of the most recent definitions of people-centred inclusive design approaches are published online. A few are listed below:

- [www.inclusivedesigntoolkit.com](http://www.inclusivedesigntoolkit.com) Created by the University of Cambridge and BT: this site uses the British Standards Institute definition of inclusive design from 2005, quoting that it is '*The design of mainstream products and/or services that are accessible to, and usable by, as many people as reasonably possible ...*

*without the need for special adaptation or specialised design*'. By meeting the needs of those who are excluded from product use, inclusive design improves product experience across a broad range of users. Put simply, inclusive design is better design.

- [www.designingwithpeople.org](http://www.designingwithpeople.org) Produced by the Helen Hamlyn Centre for Design: the approach of [www.designingwithpeople.org](http://www.designingwithpeople.org) has been derived from conversations with designers working in inclusive design or social innovation practice. Most of those interviewed articulated a belief that knowing how to find and work with real people was becoming more difficult. Therefore, this web tool aims to act as a first-step learning tool for designers to explore their own ways to design with people. It draws its definition of inclusive design from the UK Government which described it as '*a process whereby designers ensure that their products and services address the needs of the widest possible audience*'.
- [www.inclusivedesign.no](http://www.inclusivedesign.no) Created by the Norwegian Design Council: this is a design-driven, business-facing resource that describes inclusive design as a people-centred strategy for innovation. Inclusive Design can enable designers to have a more effective and creative role in the development process. Involving users can help to define issues and set direction as well as validate ideas at the end. In the business setting, Inclusive Design is a powerful strategy for innovation. The greatest potential is where Social Interests and Commercial Interests overlap. Inclusive Design does not need to be limited to the design process but can become a philosophy for the entire company – from employment policy to customer service.

There are new relationships in design research that are now being explored as we move from designing for people to designing with people and in some cases designing by people, seeing users as active participants in the research process rather than just passive recipients (Fulton-Suri, 2007).

### 3.2 The Systems Design approach: systems engineering and ergonomics

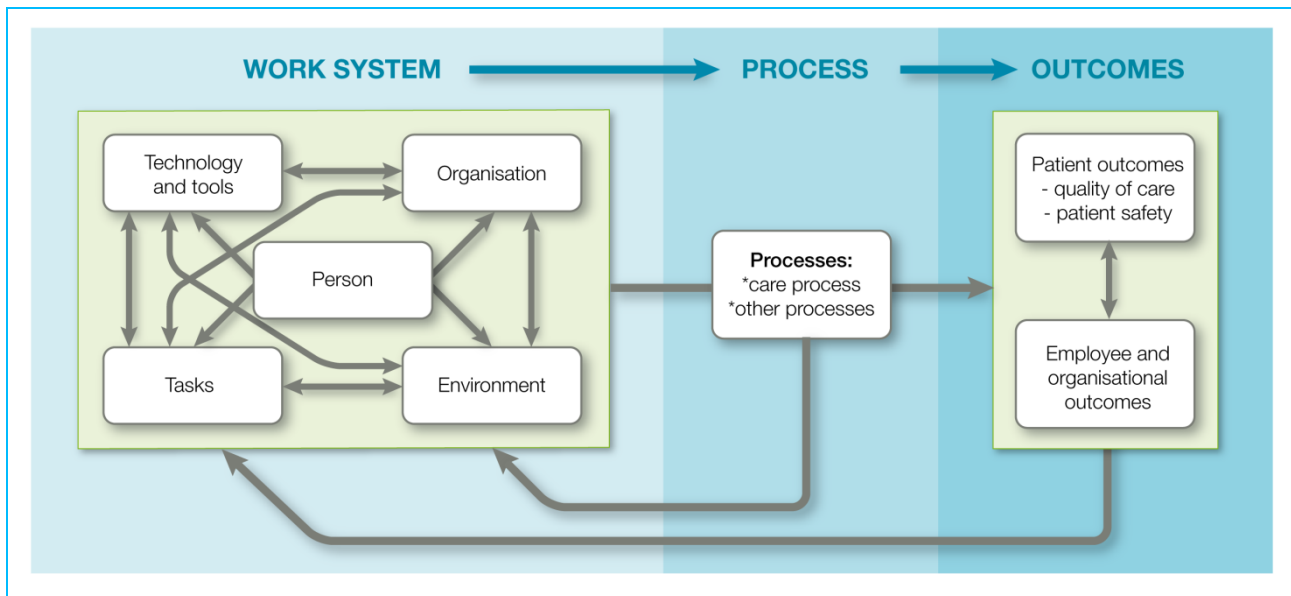
Design is a structured process for identifying problems and developing, testing and evaluating user focused solutions. Application of the design process to healthcare and social care could generate products, services, processes and environments that are intuitive, simpler, safer to work within, easier to understand and more efficient to use. By contrast, design that does not follow such a structured approach is likely to be confusing, less effective and potentially dangerous to medical staff or patients. Achieving an appropriate level of understanding of complex systems is an essential first step if risk is to be reduced.

Ergonomists and systems engineers have long since recognised that enhancing performance and reducing risk in complex socio-technical environments requires an emphasis on design (or re-design) at a systems level. In typical work systems this includes a consideration of people / users, equipment, jobs, tasks and the socio-technical context of the work. Those involved with such design have traditionally examined the system goals, the allocation of functions and tasks (e.g. to teams, people, equipment, IT), the equipment design, the interactions between sets of equipment and groups of people, the work organisation and the job design. These factors are identified in the model in Figure 3.3.



Figure 3.3

Conceptual model for ergonomics in the health and social care industry

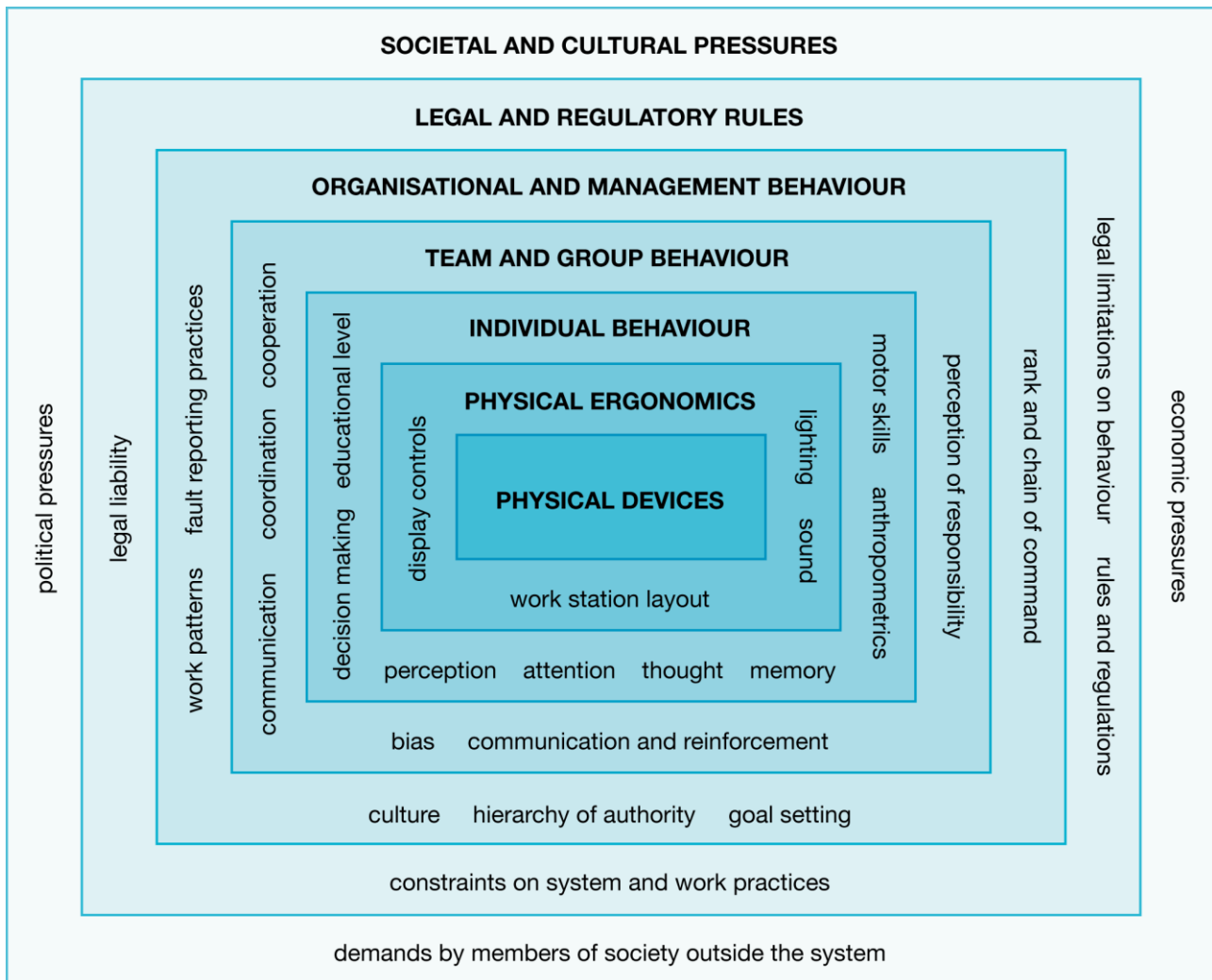


Source: Carayon et al. (2006).

An alternative model (Moray, 2000; see Figure 3.4) enables the levels of the system to be more closely conceptualised for the purpose of understanding, interpreting, evaluating, information collection and design. This model provides a high level view of the system that considers how an individual is one component in a system that includes the physical environment in which tasks take place and the physical design of equipment or other artefacts that are used. Thus the behaviour of a technology user will be affected by the physical environment, for example lighting and noise levels. Other factors in the system affecting behaviour will be team or group influences (for example peer pressure to conform, shared use) and organisational and management factors that can affect how and when tasks are done. Most care professionals work within some kind of team, and so a consideration of factors such as communication, supervision and responsibility is required. Absence of, or poor, communication between and within teams is likely to produce errors. Traditionally, information flows vertically through a hierarchy and orders are sent from the top down with the expectation that lower levels will implement them. Adverse events can occur because individuals of lower status experience difficulties challenging decisions of a person of higher status.

Inevitably with a technology such as telecare that is linked to health and social care, there are influences that arise from legal and regulatory bodies (for example the Medicines and Healthcare Products Regulatory Authority [MHRA]). Finally, social and political pressures arise from our expectations surrounding an ageing population and health / social care that have further influences on the behaviour of individuals within the system. The behavioural options available to those working in a system may be tightly constrained by regulatory rules (Moray, 1994) and only certain changes or interventions may be administered or procedures undertaken. As systems become more complex, the task of regulating becomes ever more difficult. For example, how do regulators cope with the issues that arise when multiple pieces of equipment are used conjointly or when 'intelligent' software is embedded within care systems, thereby blurring the boundaries between equipment design and clinical decision-making? Each of these elements is considered within the model (Figure 3.4), with exemplars of the individual factors that need to be considered.

Figure 3.4  
Ergonomics systems



Source: Moray, 2000.

The relevant information (Moray, 1994) needed to reduce error in the design of equipment to be used by humans is readily available. Each level of the system can then be considered with respect to risk or error. Such an approach is detailed in Box 3.1 where exemplar risks (e.g. those leading to errors or failures) have been identified for each level of the system shown in Figure 3.4. The examples are drawn from the research literature surrounding concerns over patient safety. Many of these have strong parallels with the social care context that is encountered with those with long term conditions being cared for in their own homes.

We need to ensure that the 'big systems picture' understanding (that has been so often missing in the care sector) is central to any risk assessment (e.g. prospective hazard analysis). This user-centric (ergonomics or human factors) approach emphasises the need for risk assessment to include the intended user. Mapping the 'system' is a central focus for complex and intricate systems (Buckle et al., 2006; 2010). As the interfaces between stakeholder groups become apparent, so too does the potential for error. Such mapping exercises have led to the development of a model (Figure 3.4) to serve as a template for future systems design and are at the core of the design thinking for risk analysis of current and planned systems, such as the Prospective Hazard Analysis (PHA) toolbox (see Cambridge, Surrey and RCA, 2003).

### Box 3.1

#### Ergonomics of risk and error in socio-technical systems

**Physical devices:** In the model (Moray, 2000), at the centre of the system, is the physical device or tool being used. There are many illustrations and examples of errors and difficulties associated with the use of equipment (e.g. Obradovich and Woods, 1996) and telecare equipment initiatives need to be considered in light of this and assessed from the user perspective as well as from a technical stance.

**Factors affecting the person:** Omissions (i.e. the failure to carry out some of the actions required to achieve a desired goal (Reason, 1990) are often identified as a common type of error (Poster and Pelletier, 1988). The role of such errors is likely to be of importance in other care settings and when technology is being relied upon. Understanding why omissions occur may lead to improved design of products, communication and organisation that reduce the probability of such errors occurring.

**Physical environment:** The physical environment, (e.g. lighting, noise) can play a significant role in affecting the integrity of a system. Where telecare and telehealth are concerned, these aspects of the environment may be important in any part of the system, from the end users' home environment to the monitoring centre. Given the increased likelihood that the service user may have additional sensory impairments (e.g. limited visions, hearing difficulties), then this factor becomes of even greater significance.

**Team and group behaviour:** Care professionals generally work within a team structure, and so a consideration of factors such as communication, supervision and responsibility is required. Absence of, or poor, communication between and within teams is known to contribute to errors (Dean et al., 2002). In some instances supervision is seen as inadequate and other issues, for example, overlapping responsibilities between teams, are also recognised as contributing to errors (Dean et al., 2002). Traditionally, information flows vertically through a hierarchy and orders are sent from the top down with the expectation that lower levels will implement them (West, 2000). Adverse events can occur because people of lower status experience difficulties challenging decisions of a person of higher status. For example, Sexton et al. (2000), who compare healthcare with aviation, suggest that poor communication is the equivalent of poor threat and error management.

**Organisational and management behaviour:** Although factors affecting people have been highlighted there is limited value in focusing on individual activity, as this tends to perpetuate a blame culture. The focus needs to widen to include systems issues underlying the problems that are present in any complex work environment (Anderson and Webster, 2001). System failures are sometimes difficult for 'front line' staff to recognise because the decisions underpinning these systems may have been made in the past by those at a higher level of the organisation (Leape et al., 1995). System changes to reduce errors suggested include adjusted work schedules simplifying work systems and enlisting the help of frontline personnel.

**Legal and social pressures:** The behavioural options available to those working in a system may be tightly constrained by regulatory rules (Moray, 1994); for example, only certain changes or interventions may be administered or procedures undertaken. As systems become more complex, the task of regulating becomes ever more difficult. For example, it is problematic for regulators to deal with the issues that arise when multiple pieces of equipment are used conjointly or when "intelligent" software is embedded within care systems. Such complex interactions between technology and people blurs the boundaries between equipment design and clinical/care decision-making.

Source: Modified from Ward et al., (2010b).

### 3.3 Lessons from patient safety research for technology, design and ageing

The importance of effective design thinking in care has gained increasing recognition following major reports into failures in healthcare settings (e.g. Bristol Royal Infirmary Inquiry, 2001; DoH, 2001a). Equally important have been recent studies, expert panels and government statements which have shown that just as poor design has in the past precipitated accidents and errors, so the effective use of design has the potential to deliver a significant reduction in risk of error in health and social care settings.

However, the extent of problems and the limited resources available for research has often been reflected in studies and projects that do not truly represent a systems approach. Thus, there is evidence of an over-reliance on the idea of technological 'solutions' that, subsequently, are found not to meet user needs, or only to meet the needs of some of the essential user groups. Similarly, 'behavioural' solutions are frequently advanced, such as team training, but these rarely consider what else in the system might need to be re-designed to enable effective and sustained improvements.

Much of the research over the past decade has helped develop an improved knowledge base that should be helpful in the design of systems for care and health. However, the complexity of the challenges, the difficulty of implementing and sustaining interventions and the current economic climate continue to stretch the ability of researchers to deliver better systems and provide evidence of improved practice. The publication of Design for Patient Safety (Cambridge, Surrey and RCA, 2003) marked a huge step forward, enabling systems ergonomics thinking to be incorporated into the development of safer healthcare and care systems. The report, written by the University of Surrey jointly with the Engineering Design Centre at Cambridge University and the Royal College of Art, demonstrated how design can be used to cut the risk of medical errors and accidents, making hospitals safer for patients and improving environments for healthcare workers. The report found that the NHS was 'seriously out of step with modern thinking and practice' on design, leading to avoidable risk and error. It also found that design practice and understanding is less advanced in the NHS than in other safety-critical industries and that not only did the design of individual devices and products need to be improved, but also the way the NHS views the potential of design thinking and methods to help organisations as a whole. It also demonstrated that any design initiative needed to be seen in the light of the 'big picture' of the healthcare system (e.g. Carayon et al., 2006, see Figure 3.3) and how it relates to patients. The model serves as an excellent starting point for helping those who design physical or organisational contributions or those who procure or commission such artefacts to understand the role of design. It provides a simple representation of how and where knowledge can be used to better inform the design process. It also enables rapid assessment of how and where existing systems in health care may be prone to failure.

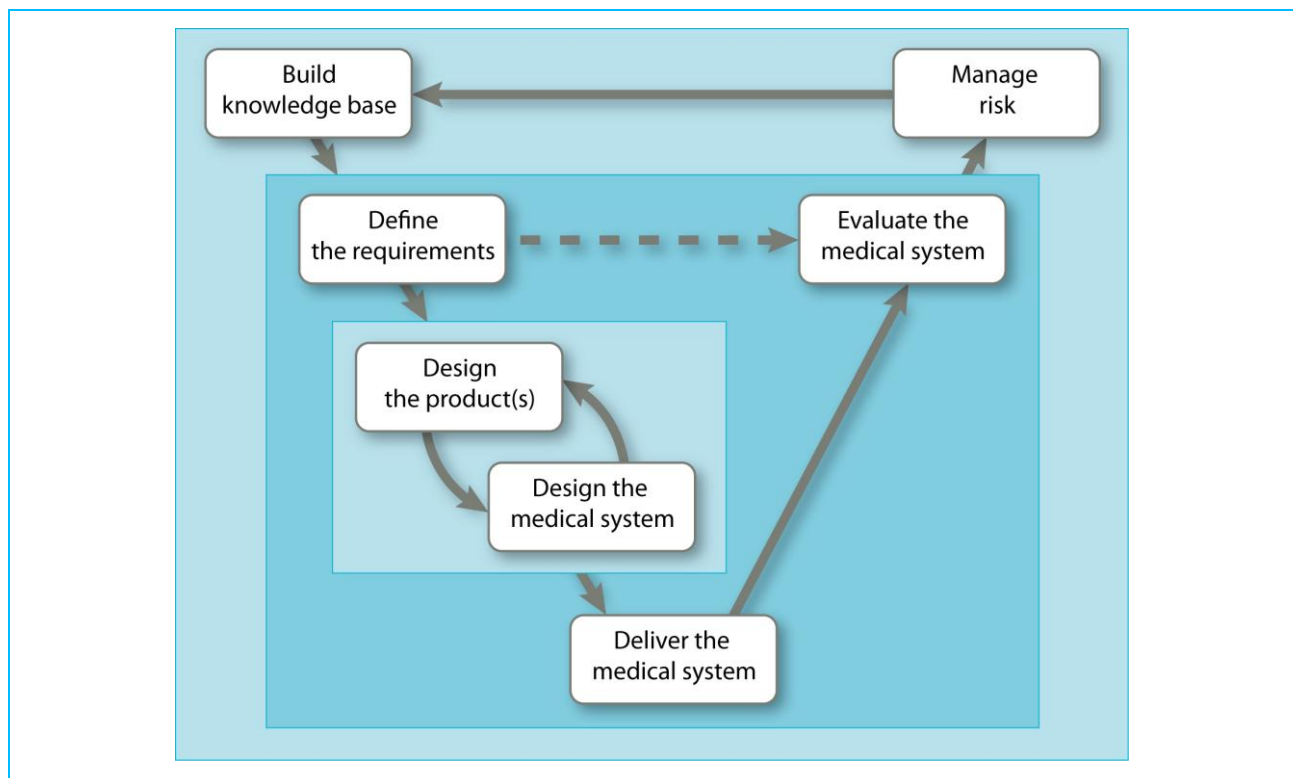
In most health care systems, there has been an emphasis on designing products in isolation from the full operational system. In effect, the product is delivered into the existing system without fully understanding how that system will then behave. For example, the introduction of a new model of infusion pump, perhaps with enhanced functions, may run into difficulties if appropriate training is not available for all those who may have need of it. Similarly, procurement based on purchase cost alone may produce problems of maintenance or servicing, resulting in hidden costs or failed services. Both of these, either directly or

indirectly, may compromise patient safety and quality. The need for a systematic approach that includes an understanding of human factors / ergonomics impact is evident.

A vital starting point for improving the design of systems is the evaluation of the existing systems. Appropriate evaluation can generate a vastly improved knowledge base on which design requirements can be more clearly specified. Indeed, one criterion that might to be used is that any innovation should not violate the performance of other systems. To ensure this would require a significant effort to ensure that risk assessment was undertaken at the earliest stages of innovation.

Figure 3.5

### Design for patient safety



Source: Adapted from Cambridge, Surrey and RCA, 2003.

One recent research study (Ward et al., 2010b) has provided some simple tools to enable the health care industry to better assess risk in existing systems or in innovation (i.e. the trigger). Following this, the steps involved are:

- **Articulate:** where the objective is to provide a description of the purpose of the assessment.
- **Define:** this step leads to a description of requirements for the assessment.
- **Describe:** leading to a description of the system to be assessed.
- **Identify:** this is a complex stage that requires the identification of system hazards.
- **Assess:** the undertaking of a structured review to evaluate system risks.
- **Propose:** this requires a detailed evaluation of the risks and the generation of proposed actions.

The assessment of risk then provides designers with a clear *description* of potential risks within a system. It also enables an *assessment* of the resultant risk associated with the hazards and their defences and a *representation* of the results of the risk assessment. These data then become an integral part of the knowledge base upon which improved design criteria can be based. This approach has now been used in a number of case studies (Ward et al., 2010a; Anderson et al., 2012a, 2012b), leading to improved design requirements. For the design of healthcare systems to be scientific, evidence-based and sustained, there will need to be many more such examples.

### 3.4 Human factors approach to prevention of errors: risk assessment

The strongest and most robust approach to completing the step identified in section 3.2, i.e. the undertaking of a structured review to evaluate system risks, appears to be the use of Prospective Hazard Analysis (PHA) approaches. These are widely used in many high risk industries, such as nuclear and chemical. It is particularly helpful as it moves away from a risk culture that is largely reactive to past errors and becomes instead proactive and predictive. However this approach may also require organisations to adopt a different culture and a process that may be seen as new.

PHA comprises a range of tools that form a process which is best described as systematic and structured (Ward et al., 2010b) (Box 3.2). These processes when appropriately constructed can enable the identification of hazards and the potential consequences of these hazards. This, in turn, enables an estimation of risk to be established. PHA methods require existing system performance data and, importantly, subjective sources of risk information.

#### Box 3.2

##### Description of Prospective Hazard Analysis

|                     |   |
|---------------------|---|
| <b>Systemic</b>     | That the approach takes account of the interaction of the part of the system being examined and the wider system within which it sits.                          |
| <b>Systematic</b>   | It has specific aims and scope, and is methodical.  |
| <b>Structured</b>   | There is a logical approach, which is followed consistently, and which supports consistency and repeatability.  |
| <b>Documentable</b> | The approach allows detailed records to be kept, not only of the hazards and risks that have been identified but also of the reasoning behind their evaluation. |
| <b>Informative</b>  | The output can be used to support improvement and redesign processes.   |

Source: Ward et al. (2010 b).

PHA methods can be applied both to existing systems and to novel systems (i.e. ones where there are no available operating performance data). Because they consider hazard and risk prospectively they are of value in assessing both existing systems and planned changes to existing systems. The basic elements, or stages, of PHA are shown in Box 3.3 (Ward et al., 2010b).

### Box 3.2

#### Stages of Prospective Hazard Analysis

|                                       |   |
|---------------------------------------|---|
| <b>Identification of the need</b>     | The definition of the objectives and scope of the assessment.   |
| <b>Description of the process</b>     | The development of an agreed description of the socio-technical system and the relevant processes within it.  |
| <b>Identification of hazards</b>      | The determination of how the system could fail using the process description for systemic and systematic guidance.  |
| <b>Identification of consequences</b> | The determination of how those failures could affect vulnerable groups and the assessment of the likelihood of those consequences being realised.   |
| <b>Clarification of the risk</b>      | The assessment of the acceptability of the level of risk and the identification of the manner in which the risk could be reduced, whether by lowering the likelihood of occurrence or the magnitude of the consequence. |
| <b>Communication of the results</b>   | The provision of a means to communicate the results of the assessment.  |

Source: Ward et al. (2010b).

## 3.5 Design in practice

Design and technology are fast-moving industries. Section 3.4 looks at current practice drawn from recent conferences and design symposia.

### Assistive technologies, independence and design

- In 2009, the Design Council and Technology Strategy Board worked together on a project called 'Independence Matters' to 'seek new ways to help older people with long-term conditions stay independent for as long as possible' (Hewer et al., 2011). Ethnographic research showed how 'objects, technology and services that are designed to allow people to be independent can also stigmatise if they are perceived as being objects of frailty and difference'.
- Corriea de Barros et al. carried out a survey of the design of daily living aids to understand why they attract stigma (Corriea de Barros et al., 2011a). They proposed the involvement of stroke patients and



their carers in the creation of solutions to counter the stigmatising effect (Corriea de Barros et al., 2011b).

- Interface design holds many possibilities for assistive technology (AT). Developments in Natural User Interface (NUI) such as the potential for computers to 'lip read', understand audio commands or interpret emotions could greatly improve understanding of an older person's wellbeing, either through active communication or passive monitoring (<http://research.microsoft.com/en-us/about/feature/nui.aspx>). FaceOSC is a new tool for prototyping face-based interaction that works on an open-source basis that allows developers to create their own interaction and is typical of developments in this space (<http://hacklab.recyclism.com/workshops/faceosc/>).

### Assistive technologies for social interaction

Research into technology for people with dementia who are living at home suggests that designers should expand their focus from securing the safety of patients to supporting social interaction (Naumann et al., 2011). Technology can be used to assist older people with social activities such as reflecting, recording and sharing their personal histories with friends, family and carers in order to help maintain their sense of identity. The users themselves can be involved through a co-creation process to develop their own design concepts (Lim et al., 2011).

Non face-to-face communication needs to have a convincing context to aid understanding. Older people with mild cognitive impairment may lose the ability to retain facts but can still interpret implicit information where available (Hoshi et al., 2011). AGNES, a 'User-sensitive Home-based Systems for Successful Ageing in a Networked Society', is a '*context-sensitive home-based interactive system*' that aims to improve communication between older people and their family, friends and carers through use of its '*Blended Reality Space*'. Collaboration between the University of Dundee and Microsoft Research also looked at future possibilities for digital technology in social interactions between students and their grandparents. The result was design concepts that were more sensitive to the needs of older people (Pullin et al., 2011).

### Some current practice

- *Babybot*, by Netown Corporation in Taiwan, is a system that has been implemented in several hospitals. Using Babybot equipment in the home, the older person can check vital signs and submit the data in advance of hospital appointments, and communicate with healthcare professionals via a webcam. Unusual measurements trigger an immediate response. *Babybot* has also been adapted for testing multiple people in community centres.  
  
(<http://www.intel.com/content/dam/www/public/us/en/documents/case-studies/healthcare-core-vpro-netown-study.pdf>).
- Dutch company *Zorg* provide an internet-based service that delivers healthcare to the patient in his or her own home. This includes the ability to co-browse the online health information, and for one person to take over the controls of both terminals in order to explain or demonstrate ([www.zorg-online.nl](http://www.zorg-online.nl)).



- *Verklizan* uses video and sound communication to link carers or healthcare providers with older patients. This service allows remote measuring of several vital statistics, and displays health and medication information on the person's television ([www.verklizan.org](http://www.verklizan.org)).
- TOPS (Technologies to support Older adults: Personal and Social interaction) is an ongoing research project which aims to provide health information via digital technology while providing an element of social interaction. It is being carried out by the Centre for Rural Health and aims to deliver healthcare support to sufferers of chronic pain in rural areas, who may have low or no access to specialist services. The support would be delivered through the familiar technology of telephone or television (<http://www.dotrural.ac.uk/tops/>).

### Activity monitoring

- Willems studied the use of activity monitoring in care for persons with dementia, developing ambient technology that allows the caregiver to monitor the activities of a person with dementia without disturbing them (Willems, 2010). Other systems involved caregivers in the design process of an activity monitoring system. Barriers to involvement include a technology vocabulary gap between caregivers and developers, and translation of 'needs' into 'functional requirements'. A workshop with caregivers led to categorisation of functional requirements (FRs) and non-functional requirements (NFRs) (Veld et al., 2010).
- Neyens et al. (2010) developed and evaluated a system for monitoring physical indicators for older people living in a community. This on-going study worked with older people to develop the monitoring system and feedback. The system gives the person or caregiver feedback about changes in indicators and long-term developments, in order to adjust care to the person's needs.
- Laviolette and Hanson (2007) studied a group of chronic heart failure sufferers aged over 60 undergoing a trial of a home-based health monitoring system. They used interviews to focus on the patients' own perception of their needs, and their relationship with both the technology and the healthcare provider and how this affected their satisfaction with the system.

## 3.5 Summary

This chapter has addressed ageing and technology from a design perspective, examining various methodologies which have been used to produce more user-appropriate products. The involvement of users and systems of users has become a key approach in design, producing technology which is more attuned to the user's needs and preferences and is therefore more desirable. In addition, lessons have been learned from previous errors in design within the field of patient safety research, which in turn has progressed towards designing with potential risks and errors in mind using a Prospective Hazard Analysis approach.

The chapter concluded with some recent examples of telecare from a design perspective. Chapter 4 narrows the focus to address the policy context with regard to telecare and telecare.

## Chapter 4

# Assisted living technology and telecare: the policy and practice context

Alan Roulstone, Barbara Harrington, Gary Fry and Chrissy Buse

This chapter explores the policy context around telecare and some of the evidence base used in commissioning telecare, giving examples from local authorities. It also discusses the role of 'personalisation' as an additional driver behind the telecare agenda. First, however, the way telecare and assistive technology (AT) are defined within policy discourse is discussed.

## 4.1 Background to the telecare policy agenda

A number of key factors have converged to add major impetus to the increased use of telecare applications in the last 15 years. Broadly stated these are developments in technology, demographic and social care challenges, and the growing aspirations of disabled people and those with long-term conditions, especially in older age (see Woolham, 2006). In the UK, the growth and influence of the disabled peoples' movement since the 1980s has helped ensure that community-based independence is part of the rights agenda. A key feature of the independence agenda is the role of AT in helping disabled people gain greater control over their social environment. There are 10.6 million disabled adults in Britain, and disability prevalence rates rise with advancing age (DWP, 2010). As outlined in Chapter 1, demographic changes will ensure that more people live beyond age 70 (ONS, 2010). Younger disabled adults' expectations are that their lives will be based in the community. The likelihood is that more people will 'age in place' and remain at home throughout their lives (Chapin and Dobbs-Kepper, 2001; Sixsmith and Sixsmith, 2008). There is substantial evidence that the need for assistive devices increases with age. The importance of assistive devices in facilitating greater access to and control over domestic space cannot therefore be overstated. The Department of Health (DoH) made clear the weight of challenges and opportunities in their report Building Telecare in England:

*It is not realistic to plan to deliver care and support services in the way we do at present. We must embrace new ways of working both to meet the diverse needs and aspirations of people using services and to take full advantage of new and developing technologies. Telecare offers choice and flexibility of service provision, from familiar community alarm services that provide an emergency response and sensors that monitor and support daily living, through to more sophisticated solutions capable of monitoring vital signs and enabling individuals with long-term health conditions to remain at home.*

(DoH, 2005a: 3-4)

## 4.2 Definitions: assisted living technology and telecare

In the policy discourse, an influential definition of 'telecare', and one that captures the breadth of devices, is that offered by the Royal Commission on Long-Term Care in an early appraisal of telecare benefits:

*....an umbrella term for any device or system that allows an individual to perform a task they would otherwise be unable to do, or increase the ease and safety with which the task can be performed.*

(1999: p. 1)

A complementary definition is given in the appendices to the Commission's report, where the aims of AT are seen as:

*to allow older people to maintain their autonomy and dignity, to enable pursuit of self fulfilment, to allow an independent life and valued membership of the community.*

(1999:p. 326)

Assistive devices which are electronic and complex sometimes attract specific terms such as Electronic Assistive Technology (Audit Commission, 2004), while technology specifically aimed at older service users has attracted the term 'gerontechnology'. However since the mid-2000s the term 'telecare' has been the pervasive term in use to sum up information and communication technologies that can be used to aid independence and greater home-based living options for those historically at risk of institutionalisation. For example, the Royal College of Nursing adopts the following definition:

*Telecare uses a combination of alarms, sensors and other equipment, usually in the home environment, to help people live more independently by monitoring for changes and warning the people themselves or raising an alert at a control centre. Examples of telecare devices include personal alarms, fall detectors, temperature extremes sensors, carbon monoxide detectors, flood detectors and gas detectors.*

(RCN, 2011)

The Social Care Institute for Excellence, perhaps the key social care guidance and evidence resource, adopts the DoH definition of telecare as follows:

*Equipment provided to support the individual in their home and tailored to meet their needs. It can be as simple as the basic community alarm service, able to respond in an emergency and provide regular contact by telephone.*

(DoH, 2005a: 8)

The Scottish Government Joint Investment Team adopted the following definition:

*The remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes, using information and communication technology to trigger human responses, or shut down equipment to prevent hazards.*

The Joint Investment Team also makes the distinction between first, second and third generation telecare. The first refers to community alarm schemes which are activated by the user, are connected to a call centre and result in a response, primarily from a neighbour, relative or friend allocated as 'key holders'. The second generation refers to telecare which grew out of this first level of community alarms to include additional sensors for hazards such as smoke, flood and carbon monoxide. The Joint Investment Team argues this presents a more comprehensive way of addressing risk and maintaining independence. Finally the third level expands telecare to include the adaption of broadband, wireless and audio-visual technology to include a care element, for example the use of technology to provide real-time consultations with medical professionals (Scottish Government Joint Investment Team, 2009b).

### 4.3 Self-directed support and personalisation: a key driver in telecare?

A key impetus for greater telecare take-up is the shift to greater self-direction and personalised adult social care in the UK. Although benefiting adults of working age more than older disabled people and people with long-term conditions (LTCs), direct payments and latterly personal budgets are making possible greater choices and new forms of purchasing by service users and their representatives, which have major implications for social care commissioners and providers. The shift to personalised social support was somewhat ironically the result of the limitations of the first wave of self-direction. The limited take up of direct payments ten years after their arrival in 1996 had meant that only 5% of eligible people were in receipt of direct payments some ten years after the 1996 *Community Care (Direct Payments) Act* was passed (Davey et al., 2006). Limited take-up, views that independent living had not taken strong root in adult social care, and the growing demographic cost implications of an ageing population have led to redoubled efforts to 'modernise' adult social care and the recent emphasis on the compulsory offering of direct payments for those deemed eligible (DoH, 2009a). Self-directed developments became more ambitious and contained strong rights-based ideas.

Two key policy documents have been built within these contexts, the Green Paper *Independence, Wellbeing and Choice* (DoH, 2005b) and the White Paper *Our Health, Our Care, Our Say* (DoH, 2006b). These policy documents along with the earlier personalisation features of *Valuing People* (DoH, 2001b) began to solidify the spirit of previous changes in adult social care by fostering personalised choices and the requirement for professionals to connect their work while placing disabled people at the centre of the decision-making process on social support (DoH, 2006b).

Things have not progressed in a linear and unproblematic manner however in terms of independent living ideas translating into telecare and telecare use. In 2009, the DoH was tempering its ambitions somewhat, with growing evidence that commissioning patterns were continuing to be episode (crisis intervention) based and of a risk aversion to 'upstream interventions through enhanced primary and community care-based alternatives; and focusing on 'self-care' (Goodwin and Clark, 2009: 20). The authors of this DoH-funded report point to the reluctance of social care / health commissioners to invest in telecare. This has led to sporadic, localised activity and a propensity for 'pilot' projects rather than full-blown long term investments

in this area. The authors point to a number of misapprehensions in this approach: firstly that among the sometimes conflicting or limited evidence there are clear examples of case studies or test sites where efficacy and financial savings are both evident. They note: '*Areas such as dementia, falls programmes, intermediate care and re-ablement have proven fertile ground for new innovations*' (Clark and Goodwin, 2010: 8). The Preventive Technology Grant has been important here in funding investment beyond pilots. The implications are that policy, research and adult social care department staff need to be working with the available evidence in commissioning appropriate telecare infrastructures. The inclusion of telecare (and telehealth) in Joint Strategic Needs Assessments and joint commissioning plans is a way of ensuring that longer term commissioning patterns become proactive and systematic rather than piecemeal and responsive (Department of Health Care Networks, 2009).

## 4.4 The policy context and evidence base

### Individual users

AT in general and telecare in particular are now key features of UK and wider policy discussion. An early clue of the value being placed on AT and telecare was outlined in the NHS report of 1998, *An Information Strategy for the Modern NHS 1998-2005*. Although a much wider evaluation of ICTs and a modern health service, it noted:

*Telecare technology will be used to provide a reliable but unobtrusive supervision of vulnerable people who want to sustain an independent life in their own home'.*

(NHS Executive, 1998: 15)

This period of course saw the rolling out of community care policies following the publication of the Griffiths report in 1988. Determination to modernise social care and make community care a reality had become very tangible by the late 1990s (DoH, 1998). Health and social care agendas were (at least) being exhorted to enter a much greater dialogue in joining up service delivery. Following the 1999 *Royal Commission on Long-Term Care* (Sutherland, 1999), AT has become a key policy and practice preoccupation, albeit with primary reference to housing as opposed to social care and health providers. As noted earlier in this report, an ageing population, a changing profile and prevalence of age-related disability and the growing fiscal crises of many advanced economies have led to growing concerns about the potential of telecare use. In concrete terms, the closure of many long-stay institutions, the growth of personalisation and emphasis upon independence into later life all add to the impetus for greater telecare and AT adoption. This is particularly the case for information and communications technologies (ICTs), given the cost-benefit ratios seen to be attached to some of these telecare devices. The 1999 report reflected on the domestic potential for AT and telecare; however these developments have a longer heritage in England and Wales, and their use goes back to the 1960s and 1970s in council-run sheltered housing (Fisk, 2003).

The 1999 Commission was followed by the Audit Commission's 2004 report *Independence and Wellbeing* which noted the British Department of Health target of getting greater telecare presence into domestic contexts by 2010. In July of the same year, as part of the 2004 Spending Review, the Chancellor announced

£80 million of funding for a social services' Preventative Technologies Grant over two years from April 2006 (DoH, 2006a). This was designed to extend the benefits of new technology community alarms (telecare), with the aim of reducing the number of avoidable admissions to residential care and to hospital and supporting local authorities in developing telecare initiatives, in partnership with the housing, health, voluntary and independent sectors. The money was invested on a spend-to-save principle (National Audit Office, 2002), with an expectation of improvements in quality of life and efficiency gains in both the health and social care systems, including reducing the need for residential and nursing care; increasing choice and independence for service users; reducing the burden placed on carers and providing them with more personal freedom; and providing care and support for people with long term health conditions (DoH, 2005: 6). The grant and wider policy were laid out in the key policy document (DoH, 2005a), which aimed to offer guidance for local authorities on implementing greater telecare options in their social care policies and practices. It is thus within the past six years that the telecare agenda has been accelerated in England (Yeandle and Fry, 2010) with the announcement of this grant and the publication of the 2005 policy document *Building Telecare in England*.

*Building Telecare in England* also set out guidelines for the infrastructure needed by local authorities to implement telecare services successfully, including: training; equipment; 24 hour contact and response services; joined up working between different sectors; information and advice for service users, carers and professionals; and governance systems and procedures (DoH, 2005a). This document emphasised the role of telecare in enabling people to live independently for longer and providing service users with flexibility, choice and control. It described the aims of the Preventative Technology grant to increase the provision of telecare support by at least 160,000 older people nationwide, provide service users with greater independence, reduce the need for residential care, reduce carer burden, and enable carers to have more freedom (DoH, 2005a: 6). This was a clear policy commitment to telecare and new modes of care delivery into the 21<sup>st</sup> century. Although routed through social service departments, joint social and health planning and delivery of telecare policy and practice was assumed in allocating monies.

Key developments associated with the launch of *Building Telecare in England* included the NHS Purchasing and Supply Agency (NHS PASA), which supported the development of a telecare infrastructure and launched a four-year contract for telecare products and services (Yeandle, 2009). An additional development was the establishment of a Telecare LIN (learning and improvement network) as a '*national network supporting local service redesign through the application of telecare and telehealth to aid the delivery of housing, health, social care and support services for older and vulnerable people*' ([www.telecarelin.org.uk](http://www.telecarelin.org.uk)). This network continues to gather and disseminate evidence evaluating the effectiveness of telecare initiatives, including the implications of these initiatives for carers and care workers<sup>5</sup> (Yeandle, 2009).

A Telecare Policy Collaborative was also established in 2004 to ensure policy and practice sharing insights and included DoH, local authority, PCTs and NHS Trusts, care providers and telecare industry representatives. Telecare and related health technologies were seen by the Collaborative to have potential in contributing to a number of important agendas such as:

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<sup>5</sup>Throughout this volume, the term 'care worker' is used to refer to those who provide care and support for older people in a paid capacity, for example as a homecare worker employed by a care provider or as a paid personal assistant.

- Admission avoidance and timely discharge.
- Falls prevention strategies.
- Saving lives through more reliable fire and smoke detection for older people.
- Timely information to inform people's care package reviews.
- Improving quality of life and reducing care costs for people with long term conditions and with strokes.
- Better monitoring of people with chronic obstructive pulmonary disease (COPD) and diabetes which can alert to changes in condition and significantly reduce out-patient attendances.

Despite the challenges of joined-up health and social care working (Harris and Roulstone, 2011) by 2004 there were a number of very successful partnerships around joint AT policy and practice. An early example, established before the disbursement of the Preventative Technologies Grant, was the *Getting Started with Telecare* (South East Region) project. This ran from September 2003 to March 2004 and aimed to reduce delayed discharge and offer community solutions using telecare. The South East Change Agent Team, in partnership with the National Integrated Community Equipment Service (ICES) Team, established joint protocols and objectives and a project manager was appointed to work with three designated control sites within South East England. The project aimed to raise the profile of telecare and to support the evidence already in existence of the benefits of telecare to help improve bed capacity. Three projects were to be set up and if possible evaluated during the timescale agreed. The three areas were to tackle different initiatives:

- Medway: supporting people at home / admission avoidance if possible.
- Eastbourne: hospital discharge.
- Isle of Wight: people who have fallen or are at risk of falling.

The project established that while funding boundaries remained a challenge, it was possible to work jointly and to raise public awareness of the potential of telecare (Thorp, 2004).

Evidence of the effectiveness of telecare was beginning to emerge with the *Wanless Review of Social Care, 'Securing Good Care for Older People'*, which drew together the lessons from a range of pilot studies (Wanless, 2006). Although cost assessments were still limited, Wanless concluded that:

*However, enough lessons have been learned from pilot studies that the emphasis should now shift to moving telecare into the mainstream.*

(Wanless, 2006: 153).

Poole (2006) provided a later summary of case study evidence of the benefits and potential of telecare that has served as an annexe to the Wanless Review. Stronger evidence of cost-benefit savings and wider multipliers in the social care arena for telecare was provided in a Cochrane Review of published evidence on both telecare and telehealth (Currell et al., 2000). Further evidence of the benefits accruing in telecare are made clear in Barlow et al. (2007) who undertook a systematic review of the evidence for the Care Services Improvement and Telecare Policy Collaborative. Barlow found circa 100 studies meeting robust trial measures that make findings reliable.



Continuing these developments, the Whole Systems Demonstrator (WSD) Sites project was launched in 2008, comprising a two year project funded by the Department of Health, which aimed to provide robust evidence for the implications of telecare and telehealth (DoH, 2009f). There was concern that even good practice in telecare provision was fragmented and not embedded in wider systemic practice by the late 2000s and thus the programme intended to place telecare and telehealth into a context of integrated social and health care sites to benefit 6,000 service users and 660 carers (DoH, 2008). The demonstrator aimed, inter alia, to:

- Promote peoples' long term well-being and independence.
- Improve peoples' and their carers' quality of life.
- Improve the working lives of staff.
- Be cost effective.
- Be clinically effective.

This project represented the 'largest randomised control trial of telehealth and telecare in the world, involving 6,191 patients and 238 GP practices across three sites, Newham, Kent and Cornwall' (DoH, 2011: 2). The aims of the Whole Systems Demonstrator Sites included assessing the impact of telecare on carers' quality of life, and one of the key strands of the evaluation involved assessing the implications of telecare for providing carers with support and reassurance (DoH, 2005a).

At the time of writing the WSD has passed to the Kings Fund and the full evaluation results are awaited. However barriers to implementation and roll-out are now in the public domain (Kings Fund, 2011). A key factor in establishing the efficacy of telecare in supporting older disabled people is that of equity. Users of adult social care are disproportionately concentrated in the lower socio-economic groups and thus an evaluation of efficiency also needs to comprehend any effects on equity of provision wrought by telecare use (Knapp, 2011). The above discussion has focused on England, however Scotland, although later in starting telecare work, has arguably been more active in progressing telecare at a policy level. Mention is made in the following key documents: 'Managing Long Term Conditions' (Scottish Executive, 2007a), 'Better Health, Better Care: Action Plan' (Scottish Executive, 2007b), and 'Seizing the Opportunity: Telecare Strategy 2009-2010' (Scottish Government, 2008). Scotland has arguably been better placed to roll out telecare as social and health care are both free at the point of use (Skills for Care, 2011). The publication of 'Implementing Telecare – An Action Guide 2009' (Scottish Government, 2009a) helped in the establishment of a Joint Improvement Team (JIT) to take forward telecare inter-professionally.

References to telecare have increasingly featured in more specific policy developments, for example it is mentioned as important in the national dementia strategy 'Living Well with Dementia'. Telecare also features strongly in 'Transforming Adult Social Care' and in the Social Care Green Paper (DoH, 2009b, 2009c, 2009d). The extension of potential to people with dementia is an important development, as even recent commentaries were at best agnostic as to the value of telecare in dementia (Woolham and Frisby, 2002). Most recently, 'Building the National Care Service' (DoH, 2010) suggested a growing view that telecare should be central to future social care policy.

In terms of more recent 'best practice' examples of telecare implementation, Lambeth Council (AT lead) and the South London and Maudsley NHS Foundation Trust (OT Consultant) are working closely to implement



and monitor the impact of telecare on dementia care. This project aims to support service users with dementia and their care networks in reducing falls, accidents and mishaps for people with a range of dementia presentations (Lambeth Council and South London and Maudsley NHS, 2009). Southampton City Council and Southampton NHS Community Healthcare Trust have also joined forces to link telecare and telehealth; they have established a joint demonstrator and joint project manager. SCC and SCHAT jointly employ an installer of telecare and telehealth equipment and are signed up for Skills for Health links with their local university (Southampton Community Healthcare Trust, 2011).

## Carers

Telecare is part of the government's vision for a new social care system, which provides increased choice and independence for service users and their carers, and more integrated health and social care services (Yeandle, 2009). However, telecare initiatives have been in place in England since the 1990s (Yeandle, 2009) and the implications of telecare for carers and service users were recognised early on in policies such as the first *National Strategy for Carers* (HM Government, 1999). This document described the potential of telecare for improving support to carers, and the role of ICTs in enhancing the provision of information for carers. It also highlighted the challenge of making these technologies 'people friendly', and integrating them alongside other health and social care services. A range of government policies have highlighted the importance of telecare for supporting service users and carers. For instance, policy documents such as the Green Paper *Shaping the Future of Care Together* (HM Government, 2009) and *Putting People First* (HM Government, 2007) have described the role of telecare in providing increased choice, control, flexibility and personalised support to service users. These policy documents highlight the potential of telecare for enabling people to remain independent in their own homes, and providing services tailored to their individual needs (HM Government, 2009). The role of telecare in providing personalised support to people with dementia and their carers in the community is also emphasised in the National Strategy for Dementia (DoH, 2009b).

The potential of telecare for providing support to carers has been re-emphasised in revised versions of the *National Strategy for Carers*. The revised strategy, launched in July 2008, described the possibilities of telecare for providing carers with greater peace of mind, and improving their ability to make time and space for themselves, in the knowledge that the person they care for is being looked after (HM Government, 2008). The updated version of this strategy published in 2010 reiterated the potential of telecare for supporting carers as part of its priority areas (HM Government, 2010). For instance, Priority Area 2 'Realising and Releasing Potential' pointed to the possibilities of telecare for helping carers to fulfil their employment potential, and balance paid work and care. Telecare is also recognised as important for achieving the aims of Priority Area 3 'Life Outside Caring', in providing the reassurance which enables carers to take time away from the person they care for.

## 4.5 Telecare use in dementia / falls care: ethical considerations

Aside from considerations around the costs and benefits of telecare, the ethical implications of its use should also be considered, and this area is included in the policy discourse and guidance (CSIP, 2005; DoH, 2007). This review has explored some of the emerging empirical evidence used to validate telecare policy,

and provides broader examples of research into telecare use in Chapter 5. It is evident however, that although telecare has the potential to make a significant contribution to the health and social well-being of older people, particularly those suffering from dementia or who experience falls, for these groups there are significant ethical issues to be considered encompassing complex questions concerning the implementation of suitable systems. The cost-benefit approach to telecare implementation must consider not only the person but also the wider networks involved in the implementation of telecare, including commissioners, health and social care professionals and carers. This point is emphasised in a recent report by the Alzheimer's Society (2011b) focusing on the importance of avoiding the social exclusion and stigmatisation of people with dementia-related conditions. This report recommends that the implementation of telecare should not provide one-sided solutions to care needs, nor be at the expense of promoting strengths of patients. This cost-benefit approach, and the tensions it elicits, is reflected in commentary by other researchers. Savenstedt et al. (2006) discuss a 'duality' in the attitudes of many carers, whereby telecare is perceived as a promoter of both 'inhumane' and 'humane' care. Carers reported that the same aspects of telecare that could promote humane care could also result in dehumanised care. This attitude makes carers defensive and resistant to change. Similarly, in a study of service users' attitudes to telecare, Niemeijer et al. (2011) identified six categories ranging from the need for a sensitive balance between freedom and security; to being beneficial and appropriately tailored to the patient; the importance of clearly defined procedures for all equipment users; active monitoring throughout the implementation; and clear normative guidance. As in the previous study, the authors acknowledge an inherent duality in the views on using surveillance technology, and one rooted in a moral conflict between safety and freedom.

Zwijssen et al. (2011) also acknowledge the lack of debate about ethical considerations involved in the use of telecare in care for older people living at home. They claim that what little discussion exists relies on concepts discussed above, such as autonomy and obtrusiveness. However, the authors claim that this approach often complicates the debate rather than clarifying it, largely because it contains many ambiguous underlying concepts and assumptions. For instance, in the authors' opinion, most ethical objections arise from the view that people are, or should be, independent and self-determinant. However, they question whether this is the correct view and whether it is helpful in the debate on telecare use in care for older people. In conclusion, the authors claim that other ethical approaches which view people as in relationships which are social and reciprocal might be more applicable, placing the debate on the use of telecare in the care of older people on a different footing.

For Woolham et al. (2006), additional ethical considerations include: fear of telecare replacing social care and increasing service user isolation; inadequate consultation with service users before implementation of telecare systems; and a lack of knowledge about telecare among health and social care professionals. The authors advocate using a common manufacturer and installer to prevent different groups from blaming each other in the event of problems.

It is clear that no ethical consensus has yet been reached in the use of telecare, as Niemeijer et al. (2010) note. This underlines the need for clear(er) policies. Some commentators claim that telecare manufacturers have a duty to provide information about the 'ethical side-effects' associated with the use of particular devices, and that the process of providing a client with an appropriate system should include a checklist of questions designed to enable decision makers to work through any ethical issues raised (Ganyo et al., 2011).

For others, such as Bowes et al. (2012), everyone involved in the implementation of telecare equipment has a role to play in taking appropriate ethical considerations into account when providing clients with telecare.

The Social Care Institute for Excellence (SCIE) has developed ethical guidelines for commissioners and health care professionals involved in the implementation of telecare services, including older people and sufferers of dementia. SCIE's report (Perry et al., 2010) explores some of the complex ethical issues involved in using telecare to enhance health and social well-being among these groups. It covers pre- and post-installation issues and includes the following guidance for professionals, including that they should:

- Acquire informed consent from people with cognitive impairments; this will require effective presentation of information.
- Avoid the imposition of telecare on clients.
- Achieve the right balance between quality of life and independence / safety.
- Embed telecare in wider care planning involving joined up working between relevant agencies.
- Monitor telecare after installation to avoid emergent problems.
- Consider data emerging from telecare systems (e.g. clarity over its purpose and storage).
- Appreciate the limitations of telecare (e.g. telecare cannot monitor changes in well-being as sensitively as a trained healthcare professional can).
- Ensure access to telecare in a fair and equitable way.

## 4.6 Summary

This chapter has focused on the impetus behind the inclusion of telecare in social care policy, examining the literature on personalisation as well as some of the evidence on telecare use and examples from local authorities. It has addressed the policy context with regard to telecare for both service users and their carers. The chapter has also discussed the ethical dilemmas which telecare commissioning faces. In focusing on the policy context, the chapter has referenced the empirical evidence commissioned or presented by national governments with regard to telecare; Chapter 5 widens the emphasis to include the broader academic literature on telecare use by both individual users and their carers (both paid and unpaid).

## Chapter 5

# The benefits of telecare for service users and carers: existing empirical evidence

*Gary Fry and Chrissy Buse*

While Chapter 4 considered policy on telecare and the issue of cost-effectiveness, this chapter focuses on the benefits of telecare reported in studies of service users who suffer from dementia and / or a susceptibility to falls, their carers and care workers. Over the last decade, the use of telecare equipment in the care of older people with these conditions has attracted much attention from academic researchers, policymakers, and organisations evaluating their own telecare services. The evidence examined in this chapter illustrates the benefits for people with dementia or who suffer falls, such as increased independence, safety, and security. It also discusses a range of benefits for carers including: increased independence; greater peace of mind; improved health and well-being; reduced carer 'burden'; and improvements in relationships with the person/s they look after. Additionally, benefits for care workers are identified, although it is shown that research in this area is still at an early stage and warrants further development.

## 5.1 The experiences of telecare service users

The experiences of telecare service users have been explored in much research, with an emphasis on exploring the outcomes of telecare programmes and products. In a review of pilot studies of telecare implementation in 150 local authorities in England, Clark (2008) found that 48 referred to dementia in their strategic plans for the provision of social care, and 22 included dementia as a key condition to address in their plans for future development. Clark's provisional findings (based on information provided by project managers and feedback from service users, carers and care workers) indicated that when used with dementia sufferers, telecare can:

- Reduce the need for residential care, mainly through delayed admissions.
- Offer increased choice and independence for service users.
- Reduce pressures on carers and give them more personal freedom.
- Reduce the potential for accidents and falls in the home.
- Contribute to the development of a range of preventative services.

Some telecare systems have been the focus of impact assessments carried out by independent researchers. The *Just Checking* service, used by many English local authorities, is designed to monitor the movements of older people with dementia in their own homes and is one of the few telecare systems to have been subjected to repeated evaluations which include the perspectives of users and of paid and unpaid carers. Findings from studies of this service are presented in Box 5.1.

Other empirical studies have also examined the use of telecare in the care of older people with dementia. In a study of telemonitoring devices with 35 older people based in Surrey, Horton (2008a) found many

reported that the system gave them a greater sense of security and enabled them to remain in their homes. Others, however, found the devices intrusive and felt they could not always control when the call centre was alerted. This affected their willingness to use the devices. Results from a county-wide pilot study in Kent also identified both advantages and difficulties in the use of telecare. Frontline staff felt telecare was helpful in caring for people with dementia, giving confidence to both dementia sufferers and their carers; however, the authors of this study also noted concerns about additional pressure on carers when response staff did not perform their function well (Alaszewski and Capello, 2006).

### Box 5.1

#### Evaluations of *Just Checking*: a telecare service designed to support older people with dementia

In Warwickshire, *Just Checking* (JC) was installed in the homes of six service users and was used by four care managers, two nurses and eleven family carers. Interviews (including one with a person with early stage dementia) revealed many positive impacts, with prevention or delayed patient admission to residential care, and carers and care workers gaining better insight into how the condition affected the person being cared for (e.g. daily and nightly activity). This led to better planning of care support packages, with care workers visiting at key points during the day. Carers gained confidence by overcoming unnecessary worries, as the behaviour of the person cared for was often different from what carers imagined it to be when they were not there.

(Warwickshire County Council, 2006)

In Leeds, occupational therapists evaluated the use of JC with 55 service users over a year, finding that JC was an effective assessment tool for people with dementia living alone in their own homes, improving the quality of assessment and leading to suitable care packages for service users. People with dementia were able to manage at home better than their carers expected, and interventions could concentrate on the capabilities of the patient, giving them 'a voice' in decisions about their care. Support workers felt the system provided a clearer picture of daily activity, which was helpful in scheduling care visits, identifying risks, understanding behaviour (particularly restless nights and sleep patterns) and eliminating the necessity of multiple 'checking' visits by carers and care workers.

(Roworth-Gaunt et al., 2009)

In Nottinghamshire, 21 people (13 key workers and 8 family carers) were interviewed about their use of 30 JC installations. In some cases, especially where a service user lived alone, JC was found to support unpaid carers and assist care workers in planning formal care inputs. This led to greater confidence and more sustainable care packages. Some carers used JC to monitor relatives' activities, feeling that it provided reassurance by helping them respond quickly to a crisis. Several carers lived abroad and were able to check data on their relatives whenever they needed to. Although there was a risk of relying on JC data and excluding other, potentially valuable sources of information, JC was found to be greatly reassuring to distant family carers. Some carers who had struggled to cope for some time (before JC was recommended) felt that having the system installed at an earlier stage would have been helpful. One felt her father's admission to hospital could have been avoided if the JC system had been in place earlier; JC had revealed that his lethargy during the day was due to not sleeping rather than to an underlying medical condition.

(Schneider et al., 2010)

Cash (2004) used interviews and surveys with 28 service users with dementia, their carers and care workers. This study found that:

- Early introduction of telecare was essential; if it was implemented too late it was not effective.
- Dementia presents with a range of symptoms. Equipment that worked for one person did not necessarily work for all, so it was important for assessment of needs to be conducted carefully.
- There was sometimes a danger of misinterpreting 'symptoms'. Getting up at night might denote disorientation, for example, but it would be inappropriate to respond to this with telecare if adjusting medication would be more effective.

Cash argues that simple solutions should be explored first, a recommendation also made by the Alzheimer's Society (2011b) in its report on using telecare in the care of older people with dementia. The latter report suggests that strategies such as using 'post-it' notes or simple lighting devices can be as effective as telecare and it claims that only about 30% of problems can be solved by telecare. Similarly, Bewernitz et al.'s (2009) study of 11 service users reported that smart technology ('prompting' devices for everyday tasks, rather than telecare packages) could help people suffering from dementia with 'light' tasks (e.g. drinking water, brushing teeth, and assisting in upper body dressing) 86% of the time, but that more demanding issues (e.g. overcoming a susceptibility to falls) required more complex care support, including telecare systems (e.g. a falls detector).

Some research has found that introducing telecare can have unanticipated outcomes for older people. In a study of 52 older people living in community housing, Brownsell et al. (2008) found that some telecare trials aimed at reducing fear of falling in older people were unsuccessful but had other positive effects, including increasing service users' confidence in public places and at night and reducing their fear of crime.

## 5.2 The experiences of carers and care workers

The vision for telecare set out in national policy (Chapter 4, section 4.4) emphasises its potential benefits in supporting carers, and in improving the delivery of health and social care services. Policy documents emphasise the need for further robust evidence evaluating the potential benefits and the implications of these technologies for carers (HM Government, 2010), particularly in light of the rapidly changing nature of telecare and the need to evaluate new innovations (DoH, 2009f). This chapter considers empirical evidence examining carers' and care workers' experiences of using telecare, the benefits they have identified, and the challenges and barriers experienced. This literature is growing, but much research is still based on pilot projects or exploratory studies and findings are often tentative or preliminary (Percival, 2009; Yeandle and Fry, 2010).

### Perceived benefits of telecare for carers

Several studies of different telecare interventions have reported very positive experiences of telecare for carers (Alaszewski and Cappello, 2006; Marziali et al., 2006; Marziali and Donahue, 2006; Jarrold and Yeandle, 2009). Jarrold and Yeandle (2009) found that all carers who took part in their exploratory research reported a positive experience of using telecare. Carers frequently describe increased 'peace of mind' as one of the key benefits of telecare (Alaszewski and Cappello, 2006; Jarrold and Yeandle, 2009; Keogh and Delaney, 2009). Jarrold and Yeandle (2009) also found that by reducing the stress carers experience telecare

can enhance their relationships with family or close friends. Carers interviewed in a study of telecare conducted by Kent County Council felt reassured that if 'anything happened', help would be available quickly through the alarm system and (even if they were not present) their relative would have the security of alerts triggered automatically and a '24 hour backup system' (Alaszewski and Cappello, 2006). Jarrold and Yeandle (2009) also found that the carers they studied in Scotland felt confident of the efficiency and reliability of the telecare response service in the case of an emergency.

By increasing peace of mind, telecare may improve carers' health and well-being. As noted in section 1.5, a large body of evidence shows that caring for a long period impacts negatively on health and well-being (Carers UK, 2004; PRTC, 2011; NHS Information Centre, 2010). The reassurance provided by telecare has enabled carers in several studies to report reduced stress and anxiety (Strawn et al., 1998; Alaszewski and Cappello, 2006; Woolham, 2006; Rahimpour et al., 2008; Keogh and Delaney, 2009). In Jarrold and Yeandle's (2009) research, carers reported feeling 'less tired', 'less anxious', and 'less stressed' and in this and other studies, carers described improved sleep patterns when telecare was in place (Keogh and Delaney, 2009).

In a range of studies, carers have reported that telecare gives them more independence (Alaszewski and Cappello, 2006; Rahimpour et al., 2008; Keogh and Delaney, 2009). Telecare allowed them sometimes to leave the person cared for unattended to take a break from their caring role, appreciating this even if it merely involved a short trip to the shops (Jarrold and Yeandle, 2009) or to carry out activities in other rooms in the home (Alaszewski and Cappello, 2006). Jarrold and Yeandle (2009) also report that some carers found having telecare in place enabled them to remain in, or gain, paid work. Carers who were also in paid work reported that, with telecare in place, they felt less tired and less worried about the person they looked after, and less conscious of being 'constantly on call' (p. 28).

One study found that some carers who did not live with the person they cared for visited them less frequently when telecare was in place and reduced their 'surveillance' or 'monitoring' of the older person (Alaszewski and Cappello, 2006). Telecare is also claimed to facilitate 'caring at a distance', and to increase flexibility in the caring role (Powell et al., 2010) or reduce the pressure or 'burden' on carers (Strawn et al., 1998; Jarrold and Yeandle, 2009).

In several studies, carers described feeling better supported in their role when telecare was in place (Alaszewski and Cappello, 2006; Jarrold and Yeandle, 2009). Carers studied in an evaluation of the 'ACTiON project' in Sweden (which provided information, education and support to carers and care workers through ICTs) described an improved ability to care and to sustain the caring role (Magnusson et al., 2005). Studies have also found that 'networked ICT interventions' can help carers develop social networks and social support, reducing isolation (Magnusson et al., 2005; Torp et al., 2008; Percival, 2009; Yeandle and Fry, 2010). A further benefit of telecare described in some studies is carers' improved relationship with the person they support (Jarrold and Yeandle, 2009). Some carers report that telecare benefits the person they care for, with Pilotto et al. (2011) finding (in a survey of 223 carers) that most carers consider telecare systems improve service users' lives with regard to: quality of life (66%); care (56%); safety (87%); monitoring bed rest and night-time movements (81%); medication use (87%); ambient environmental conditions (85%); and emergency communication (83%).

Carers of people with dementia are particularly vulnerable to mental ill-health, depression, guilt and mental distress (Luengo-Fernandez et al., 2010) (section 1.5). Several studies suggest that telecare can improve the mental well-being of these carers. Strawn et al. (1998) found a significant reduction in stress levels and stress-related responses among carers of people with dementia following a telecare intervention. A review



of fifteen studies of telecare and telehealth interventions found moderate positive effects on anxiety and depression among carers of people with dementia, although the results varied with carer characteristics (Powell, 2008 cited in Ekeland et al., 2010). However, a review of North American studies using randomised control trials (Powell, 2009) demonstrated mixed results in the impact of telecare interventions on carers' psychological well-being, with some studies indicating no difference in measures of depression, anxiety, carer strain or health behaviour. Similarly, in research conducted in Norway by Torp et al. (2008), there was no improvement in quantitative measures of carer stress and mental ill-health as a result of telecare interventions.

A key area of concern for carers of people with dementia is wandering, which raises ethical questions about monitoring of older people (see section 4.5). In a study of telecare used to monitor wandering among older people, Robinson et al. (2007) interviewed ten health and social care professionals, three carers and six service users in focus groups. They found that in choosing to use this equipment, health and social care professionals were most likely to focus on clients' safety over their rights to privacy. Carers felt health and social care professionals tended to be overprotective, as they viewed strategies carers thought acceptable as too risky (perhaps fearful of possible litigation). The carers in this study focused on the quality of life of the person they cared for and did not feel that 'tagging' devices for older people with dementia reduced their dignity. Rather, they valued the 'peace of mind' it gave them as carers and felt more concerned about the costs and technical aspects of the equipment. Service users in this study, by contrast, were mainly concerned about what they saw as the 'social embarrassment' that could arise with monitoring devices (such as machines beeping in public) or about becoming the victim of crime (through theft of the equipment).

The studies discussed above show that concerns about the implementation of telecare vary according to the perspective of the people involved. However, differences have also been found within groups. Focus group interviews with carers conducted by Landau et al. (2010a) found that carers were more concerned about the safety of older people with dementia than any lack of privacy they might experience. However, when the person cared for was supported by other caregivers (such as care workers) carers prioritised the older person's autonomy over their safety. Another study by the same authors involved interviews with 42 cognitively intact older people about using GPS tracking devices with people with dementia. Participants differentiated between themselves and people with dementia, supporting the use of telecare equipment when dementia was formally diagnosed or evident, valuing the safety of people with dementia over preserving their autonomy, and noting that the acceptability of specific equipment depended on its weight, size and ease of use (Landau et al., 2010b).

In other studies, carers have differed widely in their attitudes to the use of telecare in the care of older people with dementia. In a French study of 270 families of patients with Alzheimer's disease or related disorders, Rialle et al. (2008) identified two opposite groups: carers who favoured a substantial use of technology, and those who were hostile to it. This distribution of attitudes was U-shaped, with most either for or against the use of technology. In the supporting group, female carers were more willing than male carers to wish to use a tracking device for the quick recovery of wandering patients.

Carers in Rialle's study also felt telecare systems were more useful for dementia patients aged 75-84 than for those aged under 75 or over 85 years, and for patients with moderate rather than mild or severe dementia. In a study of 233 Italian, Spanish and Greek carers of people with Alzheimer's disease, Pilotto et al. (2011) found that carers aged over 50 who had low levels of education thought technological-based



solutions to service users' needs were more useful than carers of the same age with higher levels of education.

Some research has explored variations in carers' attitudes to the use of telecare in the case of dementia. Astell et al. (2009) report that engaging carers with technology is difficult if the carer is older and / or feels ill-prepared to learn new skills. Others have reported that telecare can have unexpected effects on carers. In a study of 76 American carers, Czaja and Rubert (2002) report that using telecommunications technology to assist with the care of older people with dementia helped carers benefit from improved knowledge of operating such equipment, which enabled them to access new sources of support (e.g. online forums).

In a study involving interviews with 34 carers, Powell et al. (2010) found that although experience of telecare was often limited, many carers felt it was certain to be used more widely in dementia care in the future. This study also found that many carers considered themselves too old to develop new skills. They expressed a general enthusiasm for the benefits of telecare, although not usually for themselves. Consistent with Astell et al.'s (2009) research, Powell et al. identified several key challenges, including:

- Establishing an appropriate balance between privacy and autonomy, as well as maximising safety.
- Ensuring that a telecare solution to health and social care needs did not result in a loss of valued personal contact.
- Establishing responsibility for and ownership of the equipment, as well as who bears the costs.
- Preventing telecare from being used as a substitute for alternative services rather than as a complementary solution.

Powell et al.'s report concludes by claiming that to fully support carers and dementia sufferers, the use of equipment should be accompanied by a comprehensive debate by stakeholders on key issues.

### Perceived benefits of telecare for care workers

There is little research on perceptions of telecare among care workers, particularly in a UK context, and the available studies often report mixed responses. For instance, qualitative research involving interviews and observations with 30 care professionals in Finland found that attitudes varied according to the particular context, profession, and telecare / telehealth application (Vuononvirta et al., 2009). Findings of studies in the UK (Mair et al., 2005; Yeandle and Fry, 2010) and Sweden (Savenstedt et al., 2006) suggest staff may be more ambivalent toward telecare than carers or service users. Nonetheless, in some studies, staff have been extremely positive about the benefits of telecare for the people they support and their families (Magnusson et al., 2005; Alaszewski and Cappello, 2006; Horton, 2008a), although in one study care workers emphasised that service users needed a great deal of initial reassurance and care workers were sometimes disappointed by the low take-up of certain technologies (Hanson et al., 2008a). Another study which explored the impact of telecare on care workers' job roles and on service delivery found that telecare had little impact on their work and was easily integrated into routine activities (Hanson, et al., 2008a). Elsewhere, social care staff reported that having telecare in place improved their ability to carry out their role effectively, providing them with another tool to assist service users and improving system responsiveness (Alaszewski and Cappello, 2006). Care workers in this study also saw telecare as helping service commissioners to secure 'cost-effective' support and enabling people to remain independent. Some care workers felt telecare services offered them opportunities to develop new professional skills, and a small minority said their workloads were lower when telecare was used. Telecare and networked technologies have also been found

to save time and reduce the number of client visits needed, as well as to reduce travelling time for staff. One study found that installing home care monitoring equipment reduced the time nurses spent travelling to patients' homes in rural areas (Nesbitt et al., 2006), while care workers in Magnusson et al.'s (2005) research emphasised the advantages of telecare for developing contacts with other health and social care professionals, and enabling them to conduct meetings without physical proximity.

### 5.3 Telecare as a tool supporting needs assessment

As shown in Box 5.1, telecare can be used by health and social care professionals as an aid in needs assessment for people with dementia and / or who suffer falls. Schmidt et al. (2011) found that staff delivering the *Just Checking* (JC) scheme felt that the onset of the condition was usually the critical period for incorporating telecare monitoring data into assessment, but noted that at this stage many carers feel reluctant to engage with equipment (fearing it may be intrusive). Yet when care needs escalate, sometimes to crisis point, it can be too late to use telecare-derived data to help in needs assessment. Evidence from JC suggests that carers are gradually becoming less resistant to the use of telecare in this way, and are more likely to support its use at the outset of a relative's difficulties.

Schmidt et al. (2011) also reports that while JC is good at detecting absences from home and unusual patterns of movement in the home, carers and care workers do not always feel confident about interpreting data, which they sometimes consider ambiguous. Making sense of regular movements made by people suffering cognitive impairments who are particularly active was a particular problem. Researchers in a range of studies stress that telecare should be used as only one part of a care needs assessment strategy, with other tools (such as diaries and interviews) also used (Bailey et al., 2011; Doughty and Cameron, 1998). Robinson et al. (2007) found that most carers believe a person-centred approach is best, with qualitative data supplemented by observational information. Health and social care professionals in their study also emphasised the importance of getting to know the patient first, so that decisions about care could be based on personal knowledge.

### 5.4 Summary

This chapter has focused on the implications of telecare for individual service users, care workers and carers. Recent policy statements have highlighted the potential of telecare to provide support, reassurance and peace of mind to both people with disabilities and carers, helping the former to maintain their independence and the latter to sustain their caring and other roles. The available empirical evidence from studies of service users and their carers lends considerable support to this view, although researchers note that data have often been collected by service providers or are based on small studies whose findings cannot be generalised to wider populations of telecare users. A key theme in the literature is that telecare provides a sense of security and confidence for service users, particularly those with dementia, as well as for their carers. Carers in a range of studies have reported benefits in using telecare, including: increased independence; greater peace of mind; improved health and well-being; reduced pressure on carers; and improvements in their relationship with the person they look after. Research on care workers is limited and presents a less clear picture. Some studies have reported that using telecare enables care workers to carry out their job roles more effectively, while others highlight challenges in using these technologies among service users, carers and care workers, as explored in more detail in Chapter 6.

## Chapter 6

# Limits and barriers to the take-up and adoption of telecare

Alan Roulstone, Barbara Harrington, Chrissy Buse and Gary Fry

There are a number of barriers to the take-up and adoption of telecare. Wielandt and Strong (2000) reviewed literature about compliance with prescribed adaptive equipment and found medical, client, equipment, assessment and training related factors. Miskelly's (2001) review of conceptual models for AT outcomes points to the requirement to understand the interplay between diverse technologies, population diversity, mental capacity, cost and sensory impairment. Some barriers are practical, concerning poor design or types of property. Clark and McGee-Lennon (2011) highlight a range of potential barriers to take up, with design features, lack of stakeholder knowledge, personalised solutions, levels of obtrusiveness, control features and continued support all being important. Major barriers to (and therefore risk factors for) the take-up of telecare also include psycho-social factors relevant to older and disabled people and how these interact with telecare. The latter are considered in section 6.1 and the barriers carers and care workers face are explored in section 6.6.

## 6.1 Psycho-social barriers

Dewsbury (2001) highlights the danger of seeing IT from the '*scientific community's dispassionate stance*' of offering untold benefits. Isolation, for example, can be a major problem for older and disabled people and this is a problem that reliance on technology may not solve and may even compound (Marshall, 2000; Orton, 2010). Dewsbury argues that telecare packages should meet needs in a range of areas, notably social, psychological, physical and emotional needs, and is concerned that there may be a 'technologisation of needs'. The danger identified is that the technology may allow people to '*function in society, rather than actively participate in it*' (Dewsbury and Edge, 2000: 11). Psychosocial and cultural issues are important for adapting to technology (Pape et al., 2002). Pape references Mann et al. (1997) who found in a study of visually impaired people that maximising independence and employing healthy or unhealthy coping strategies were key to the adoption of telecare, and Nochajski et al. (1996) who found AT user rates were lower in those with cognitive limitations. For Pape, AT adoption depended on independence, a sense of control and cost savings (Pape et al., 2002). The introduction of the technology needed to be part of an effective strategy for coping, one that preserved the preferred self-image and / or gave people independence if that was what they wanted. For others the speed of change to telecare, especially with movement from institutionalised care, was critical, with a need to introduce telecare options in a timely way to avoid rejection (Bayer et al., 2007). Heywood also stresses that AT should fully reflect human needs. She points out that people sometimes find it hard to accept and adapt because this means coming to terms with their condition or disability (Heywood, 2004). Some people do not like to feel they are too dependent, and telecare can exacerbate this feeling. There are also individual values (for example cleanliness or taste) which may affect take-up of AT. However one study suggested that it is important not to view older people as technophobes, as some may want more rather than less technology (Brownsell et al., 2000).

What then can we establish as prerequisites for higher uptake? Lansley et al. (2004a and 2004b) used four perspectives of user acceptability in their study of housing adaptations for older people:

- Independence.
- Successful ageing.
- The meaning of home.
- The social model of disability.

Respondents in their study took pride in their homes but were also very keen to have mobility aids such as stair lifts or bathing aids. There were different responses to other aids such as pendant or smoke alarms. The researchers concluded that older people adopted AT when it addressed a felt need. This is echoed in McCreadie et al.'s (2002) study of the acceptability of AT for older people, which established a complex model of acceptability *'in which a "felt need" for assistance combines with "product quality"'* (2002: 91). It was important for users to have some control over the decision of whether to accept AT. Adoption of telecare depended on perceived need, the usefulness of the technology and whether it supported a person's sense of personal identity (see also Sixsmith and Sixsmith, 2000; Wielandt and Strong, 2000). McCreadie cites Brickfield (1984) who suggested that older people's acceptance of technology is related to their problem-solving skills rather than their age. Older people are also more likely to want AT if they perceive it as contributing to health and well-being rather than as a mark of dependency (McCreadie, citing Lebbon and Boess, 1998). Bertera et al. (2007) noted the importance of telecare in strengthening links with a person's health care providers. Recent WSDAN (Whole System Demonstrator Action Network, see section 4.4) projects (for example in Croydon) and 'innovation houses' in West Bromwich offer older people insights into what telecare involves ahead of any commitment (Clark and Goodwin, 2010).

Wielandt and Strong (2000: 70) found several client-related factors for not adopting AT which included degree of genuine choice, an embarrassment factor, individual preferences for types of equipment, lack of motivation, psychosocial problems and preference for human assistance. People had their own reasons for not viewing equipment as of benefit or value, and could have disagreements about these with their therapist or adviser. In a later study, Pols and Moser (2009) looked at how people adapted to three different forms of telecare – a robot dog, an Icat (a robot that provided information), and a health buddy (a machine for taking physical measurements and reminding people to take medicine). With telecare there can be a fear of replacing human interaction with machines. However, technologies can help in human interaction, such as with the increasing use of mobile phones. Pols and Moser found that affective values and the way people involved the machines in their social lives had an important influence on use. Thus, the robot dog, which was an aid to making a person more active, worked because it was programmed to be spontaneous so that exercise was more like play than a chore. The cat worked less well because it was purely a source of information. The health buddy worked because the machine was linked to a nurse and so there was a sense of contact with the nurse.

A large study (Taylor and Agamanolis, 2010) of 1,324 service users in North East Scotland who used a personal alarm found that these were not always worn. The sample was mainly of women aged over 79 years among whom wearing a pendant might prevent some harm if they fell. Sixty-nine per cent used the pendant some or all of the time but nearly a third only wore it some of the time. People were most likely to remove it at night even though this is the time when falls are most likely to occur. The reasons people gave for not wearing the pendant included:

- Concern that they might press the button by accident.
- That the pendant did not work outside the home.
- That the pendant was too bulky and/or conspicuous.

Wearers did not want added applications like a watch or music-player, or in a range of styles or colours, although younger generations who reach older age may well desire such adaptations (Buse, 2009). It is interesting that among practical issues, there was again a psycho-social issue about seeing the pendant as 'a badge of vulnerability' and displaying this to other people. The emphasis of many papers is thus on involving users in design and implementation (see also Chapters 2 and 3). This is reflected in López and Domenech's (2008) phenomenological study of pendant alarm use. Distinguishing between 'fragile' and 'vigorous' bodies, wearing a pendant for some of the older people studied symbolised a 'fragile body' and needing other people's help / being dependent. That is why some of them on occasion resisted wearing the pendant, as a way of asserting the autonomy of what they regarded as their 'vigorous body'. McCreadie et al. (2002), seeing users not as a problem to be solved but taking note of needs and tastes, note that treating older people as active evaluators would be a more appropriate approach. Another study notes the importance of good information on telecare ahead of prescription and implementation (McCreadie et al., 2006). A major cross-national review of telecare identifies user friendliness, information and support systems as all being important (Magnusson et al., 2004). Some researchers have suggested models for helping to ensure better acceptability of AT. Some (Tinker and Lansley, 2004; McCreadie and Tinker, 2005) try to combine the importance of elements such as felt need with the quality of AT and good processes for information.

## 6.2 Telecare and impairment diversity

While there is necessarily concern to offer greater autonomy for older and disabled people as a whole, researchers have noted differences in the take-up and adoption of telecare by different groups of older and disabled people. Those with congenital disabilities have been found to have a higher rate of successful integration with AT (Pape et al., 2002), regarding it as a way of gaining increased independence. Those with progressive disabilities want to use AT to enable participation in activities and control symptoms. However, for some people there is a social stigma attached to devices which can signify being closer to death and / or a loss of independence, so there might be changes in values and goals in relation to AT. The study found more generally that providers need to fully understand the meanings assigned by end users, and that their expectations, anticipated social costs and personal self-perceptions of disability are all important (see also Percival and Hanson, 2006). Mann et al. (2002) established that people with musculoskeletal and neurological conditions owned and used the most telecare devices and that redundancy levels were lowest in this group, while those with hearing impairments were least satisfied and had the lowest mean telecare use. Perceived need and fit with a person's impairment were both key factors in use and redundancy. Hanson et al. (2008b) note the importance of service users' pre-existing views of the purpose of community care – ranging from preventive to crisis / reactive approaches – in shaping views and in readiness to embrace AT and telecare.

Wielandt and Strong's (2000) major literature review found that certain medical diagnoses were related to greater use. Those with diagnoses of rheumatoid arthritis and polio were more likely to use telecare. Clients with joint degeneration disease were more likely to use equipment than those with a spinal cord injury, and

clients with acute orthopaedic diagnosis were more likely to use it than those with chronic diagnosis. Those with osteo-arthritis of the hip plus other orthopaedic or medical problems continued to use AT longer than those who only had osteo-arthritis of the hip. Frail older people are less likely to tolerate the process of needs assessment and consequently less likely to accept AT (Dickinson et al., 2003).

Short-term memory loss (age-related cognitive change) can also make learning about new AT difficult for frail older people, who are also less used to learning while doing. This group are likely to need the support of a teacher / tutor / adviser at home, and are unlikely to have access to help from friends and family of a similar age. The younger generation due to become old might be better equipped to learn while doing, and to cope with new wireless technology (Tinker et al., 2004). Pro-technology users and 'early adopters' were more likely to take up and adopt major packages of telecare, particularly Smart Homes (Spence et al., 2000). A study with a control group showed that older frail people exposed to different forms of ICT over a period of time adapted more quickly to the use of telecare in their health and social care needs and were more likely to recommend it to others (Finkelstein et al., 2011). Older people in another study (Mahoney et al., 2001) who were quick to adapt to telecare tended to be significantly older, more highly educated, and to report a greater sense of management of the situation than 'non-adopters'. Adopters were much more likely than non-adopters to have been rated as highly proficient by the trainer following the technology training session. Other studies have shown that in the case of dementia, new technology is no more likely to cause difficulties than familiar equipment and that careful attention should be given to training, not only during implementation but also continually through the use of telecare (Nygard and Starkhammer, 2007).

### 6.3 Providers and commissioners

Funding issues are important in the take up of new technology and funding issues have been identified as one of the factors for not benefitting from AT (Cowan and Turner-Smith, 1999). A later study identified delays (caused by lack of funding) for lighting for those with visual impairment, which subsequently led to higher costs as falls increased (Heywood and Turner, 2007). Although introducing computers and the internet to older people was partly successful because computers were provided (Osman et al., 2005), Heywood and Turner's report (2007) points out that housing interventions tend to result in improved mental health (increasing feelings of safety and improving general mental health), and that since there is increased risk of hip fractures for older women who are depressed, timely funding of interventions is important. In some cases the number of agencies involved in the process of assessing and supplying telecare has caused difficulties, with misunderstandings arising, particularly between engineers and health services (Dewsbury et al., 2002a), or providers and assessors not taking an holistic view and installations being made to address a particular health problem (Tinker et al., 2004). As 88% of people with a severe disability also have additional disabilities (Waller et al., 2010) it is important that account is taken of the complete health picture. Studies of inter-professional working in other countries report that where 'professional seamlessness' is achieved, telecare prescribing is more effective and telecare less likely to be 'redundant' (Verza et al., 2006). Lewin (2010) notes the following as combined barriers to joint working 'and greater take-up of telecare: no large-scale controlled trials to convince medical opinion formers, limited expertise in the caring profession and few training courses, limited financial incentives for introducing telecare into state-funded services and a lack of integrated health and social care.



Alaszewski and Cappello (2006) studied Kent County Council's telecare strategy and noted a lack of congruence between care managers and operational staff, recommending that, to avoid increasing burdens on carers when alarms are set off accidentally, telecare monitoring centre practices should be standardised. A study of telecare implementation in Scottish authorities found 'cultural barriers' to greater adoption; some social care staff were suspicious about motives for introducing telecare and concerned about surveillance (Beale et al., 2009; see also Crump, 2005). Another Scottish study noted the following barriers could hamper implementation of a telecare strategy:

- Lack of clarity about key local outcomes.
- Limited, inconsistent or poor project management.
- Lacklustre sponsorship / engagement by senior decision makers.
- Lack of buy-in from key stakeholders.
- Limited understanding and skills to implement service redesign.
- Fear of the consequences of 'getting it wrong'.

(Scottish Government Joint Investment Team, 2010)

Some UK authorities have responded by making improvements in how they co-ordinate and roll out telecare; for example, Worcestershire County Council introduced telecare 'champions' to promote the value of telecare within the authority (Worcestershire County Council, 2007). Some commentators see the continued financial pressures on local authority budgets, alongside resistant professional cultures, as serving as a serious barrier to wider telecare adoption (Goodwin, 2011). Cost savings from AT result when they substitute some form of formal care (Agree and Freedman, 2000, 2004; Hoenig et al., 2003; Agree et al., 2005) and the biggest yields are made where property is easy to adapt and people have disabilities requiring a lot of formal care (Goodacre et al., 2008). However housing authorities have little motivation to make the adaptations since the staff savings are made in health and social services (Goodacre et al., 2007). Completion of spend-to-save studies alongside careful mapping of population needs is important in telecare planning (Audit Commission, no date). Some seasoned commentators question whether a robust evidence base exists in cost-benefit terms, however, as traditional costs are rarely collected in a consistent way, while the benefits of telecare may take some time to reach a point at which a true benefit tally can be established (Hendy and Barlow, 2008).

Reducing costs or taking them outside the remit of Fair Access to Care Services (FACS) assessments is a clear way of promoting greater telecare use (Cheshire Council, 2010; CSIP, 2007). A London-wide Joint Improvement Partnership pilot led to the identification of key barriers and solutions to telecare take-up in a range of London boroughs. Barriers included: installation delays and problems, lack of staff resources, clients not being clearly identified, lack of staff awareness and training and insufficient local funding. Solutions identified to maximise telecare included: amending eligibility criteria to include preventative use of technology, clear local funding arrangements to assist with planning, better integrated commissioning, and joint working between agencies. Increased and ongoing training for staff, greater promotion of telecare nationally and locally and improved ownership and leadership were also seen as important (London Joint Improvement Programme, 2009). Indeed, in the 'Aztec' project based in Croydon, a variety of telecare products were used to monitor wandering and to assist with cooking. Based on case studies and interviews with service users, carers and care workers, the researchers reported that successful implementation of telecare requires a committed effort by carers and care workers to ensure it is properly commissioned. The



equipment can lead to many benefits for service users and their carers, but only if carefully monitored. For instance, human errors (e.g. misuse of equipment) may need to be tackled (Dunk and Doughty, 2006).

At the opposite extreme to risk aversion are risks that telecare may be seen as a panacea for a broad range of adult social care challenges. While much of the literature celebrates the growing range and sophistication of assistive devices, it also warns that assistive devices cannot solve all problems for disabled adults. As Lansley puts it:

*...despite the promise of assistive technology, the design of packages of telecare to suit the specific and expected future needs of individuals, their incorporation into the home and their effective use are not straightforward... The cost of installation, issues of who should pay, the disruption caused ... For many moving from the theory of assistive technology ... to the realities in practice will not be easy.*

(2001: 440)

Heywood (2001) points out the value of low technology solutions by stating 'users value the independence given to them by showers, stair lifts and downstairs toilets' (p. 31). Clearly the cost of technology is a consideration in weighing up the benefits against risks of social isolation and financial outlay. This approach is especially important in considering Smart Home options.

*Smart homes can be useful; enhancing the quality of life for people whose life is limited by their domestic environment. However, technology for technology's sake can be debilitating and disempowering.*

(Dewsbury et al., 2002b: 2)

Poulson and colleagues (2002) found that the attitudes towards new technology and Smart House technology of wider stakeholders (for example family and care workers) was a factor in shaping how well these technologies and environmental adaptations were accepted. Care workers were seen to occupy a particularly powerful position in shaping this process of acceptance or rejection of AT. Although perhaps geared to older disabled people, the point McCreadie and Tinker (2005) emphasise is the importance of the perception of the potential assistive device, its 'fit' with the person's wider sense of belonging and familiarity with and acceptance of their environment. According to them, the acceptability of technology depends on a complex interplay between: felt need, based on perception of self and 'fit' with product quality as perceived by potential user efficiency, reliability, simplicity, safety of technology availability and cost of device. The perceived value of an item of technology may even vary during the course of a day, as McCreadie and Tinker note in discussing use of pendant alarms; some users would wear their alarm all the time, others only when they were feeling 'off colour'. Dewsbury et al. (2002b) used 'cultural probes' to explore potential assistive device users' views; these included using cameras, diaries, maps, photo albums and postcards to build a picture of users' self-perceptions and their likely fit with a particular assistive device.

## 6.4 Design and maintenance

Poor design, poor manufacture and poor reliability have contributed to poor take-up of AT (Wielandt and Strong, 2000; Lansley et al., 2005). Sometimes equipment did not fit with what the client needed, was too difficult to use, was unsafe, did not work properly, or was not delivered on time (Wielandt and Strong, 2000), all of which affected compliance. For example, a medication regime where users in an old people's

home had devices to remind and record taking of medication failed to work effectively because staff could not tell whether patients had actually taken medication (Cheverst et al., 2003). This resulted in accidental overdosing, and one deliberate overdosing. Users were worried about medication and fell back on relying on staff to remind them to take medication. Technology that does not function for people with cognitive disabilities can be particularly distressing (Dewsbury, 2001). Because building of new public housing has slowed, even as far back as 2004, 50% of the current stock was over 50 years old; older housing is less easy to adapt (Tinker et al., 2003; 2004). New developments tend to have smaller living spaces which again make it more difficult to install grab rails or for rooms to be big enough for wheelchairs. Lansley et al. (2004b) found that ground floor flats and bungalows in their study of 82 dwellings represented the greatest potential for AT use in adapted settings.

## 6.5 Training and how telecare is used

Providing telecare users with training was also judged important (Cowan and Turner-Smith, 1999). Daniels et al. (2010), citing Mann et al. (1999) and Tomita et al. (2007), found that success in using telecare with older people could be achieved if the equipment was adapted to needs and if intensive instruction was given. In a study evaluating the introduction of computers and the Internet to older people, group training was found not to be effective (Osman et al., 2005). Adequate instruction in use was important, and some researchers advise that instruction should preferably be given at home and include family and carers (see section 6.6) (Wielandt and Strong, 2000).

Pols and Willems (2011) highlight the difficulty of predicting how technology will be used. Telecare may not be 'tamed' by users but rather 'unleashed' on those given the devices. If this happens, the promise of the technology will not be achieved, as putting equipment into people's homes is no guarantee it will be used. In some pilots, devices have been abandoned after trials stop, and as Heywood and Turner (2007) found, there is limited knowledge about outcomes, and the causes of these, when technology is used. In an earlier study, Cowan and Turner-Smith (1999) found that many providers of AT did little or no follow-up after installation, to identify any changes users might require and others have found that as a diagnosis or user's physical status can change, technology can easily become redundant if this happens (Wielandt and Strong, 2000).

## 6.6 Barriers, issues and challenges for carers and care workers

Although many carers and care workers report positive experiences of telecare, studies also highlight some barriers and challenges. As also noted in Chapter 5, resistance among care workers and professionals can present a barrier to the successful implementation of these technologies (Savenstedt et al., 2006). In a review of the literature on the use of telecare among carers of people with dementia, it emerged that carers' willingness and ability to use telecare are key factors in whether it is successfully taken up (Siotia and Simpson, 2008). Both carers and care workers have expressed uncertainty and anxiety about the use of telecare (Wallace et al., 2001; Magnusson et al., 2005; Alaszewski and Cappello, 2006; Horton, 2006), and concerns about not having the necessary skills (Powell et al., 2010). This relates to a lack of knowledge and training in how to use these technologies (Magnusson et al., 2005; Alaszewski and Cappello, 2006; Horton, 2008; Yeandle and Fry, 2010). Such fears are particularly prominent among older carers using Internet based

technologies (Powell et al., 2010). Training courses for both carers and care workers could be important in reducing anxieties about using these technologies, and addressing barriers concerning a lack of knowledge and understanding of how to use them (Brownsell, 2009; Doughty, 2009; Powell et al., 2010; Yeandle and Fry, 2010). Providing carers with support and advice on how to use telecare at the point of installation is also important for ensuring that they are able to use these technologies confidently (Jarrold and Yeandle, 2009). Designing technologies which map on to people's earlier skills and competencies can also be useful for encouraging engagement and overcoming anxieties (Buse, 2010), as suggested in Chapter 2. For instance, recent telecare applications based around the television draw on technological skills which are more familiar to older generations, and have received positive responses from carers (Wallace et al., 2001). As discussed in Chapter 2, there is a growing body of research exploring how the biographies and experiences of older users may shape telecare use. However, there is little research examining how the personal characteristics of carers and care workers, including those relating to age / generation, gender, and biography may shape their engagement with, or resistance to, these technologies.

Another barrier to the successful uptake of telecare by carers concerns a lack of information and awareness (Jarrold and Yeandle, 2009), as carers and care workers are often unaware of the range of telecare services available or how to access them. To address this, it is argued more needs to be done to raise awareness of telecare in local areas. Sometimes carers described a lack of additional carer support alongside telecare services (Alaszewski and Cappello, 2006), and both staff and carers have emphasised the need for integrating telecare with effective face-to-face services and support (Alaszewski and Cappello, 2006; Botsis and Harvigsen, 2008; Powell et al., 2010). This includes effective assessment of the needs of the carer and person cared for, and a co-ordinated response (Alaszewski and Cappello, 2006). Assessing telecare needs as part of a carer's assessment may be a way of moving towards more integrated support (DoH, 2005b; Jarrold and Yeandle, 2009).

In previous studies, a small minority of carers and care workers have also expressed anxieties about the implications of telecare for privacy and surveillance (Alaszewski and Cappello, 2006; Powell et al., 2010). Carers in one study also expressed initial fears that telecare might be intrusive, although these concerns were overcome with time (Jarrold and Yeandle, 2009). In several studies, carers and care workers have described fears that technology may replace face-to-face provision of care, or diminish the quality of care (Magnusson et al., 2005; Alaszewski and Cappello, 2006; Savenstedt et al., 2006; Hanson et al., 2008a; Powell et al., 2010). In one study, care workers also expressed concerns that these technologies may lead to a lack of continuity with previous care provision (May et al., 2011). However, initial concerns generally diminished over time with the realisation that telecare did not drastically alter care provision (Hanson et al., 2008a).

Carers of people with dementia face specific challenges and barriers in using telecare effectively in their role. Telecare can assist with the specific issues involved in looking after someone with dementia, including: time orientation; night / day confusion; falls at night; leaving cookers and other appliances on; and wandering (Jones, 2004; Ganyo et al., 2011). However, these specific needs can also raise particular problems. One carer in the ENABLE project felt the night and day calendar created tensions, as it reminded the person they care for of their memory problems (Jones, 2004). It has also been suggested that telecare may increase the pressure on carers of people with dementia due to repeated call-outs and false alarms (Alaszewski and Cappello, 2006). In seeking to overcome any increased pressure or burden on carers, one way forward is to adjust the key contacts so that the carer is not always the first point of contact. In one study, carers also expressed concerns that deterioration in the condition of the person they care for would

lead to increased monitoring and intrusion of privacy (Powell et al., 2010). It is claimed that to clarify the benefits of telecare for people with dementia and their carers, use of technology needs to be explored over a longer period of time (Keogh and Delaney, 2009) to capture how it may change with the changing needs of people with dementia (Jones, 2004).

Health and social care staff also report structural and organisational barriers to using telecare effectively in their roles. For instance, research reported by the Telecare LIN found that restrictions on homecare workers' roles limited the extent to which they could assist users with telecare (Yeandle, 2009). A further challenge concerned the lack of co-ordination across health and social care sectors, which led to difficulties for healthcare professionals, and uncertainty about the responsibility for telecare (May et al., 2011). Social care staff in Alaszewski and Cappello's (2006) research described communication problems between the monitoring centre and social services, which made implementing telecare services more difficult. Other studies report that health and social care organisations do not always have the resources to roll out these services evenly to all staff (May et al., 2011; Yeandle and Fry, 2010). Some recent work has emphasised the need for both on and off-the-job training for care sector staff, preferably mandatory, (Wigfield et al., 2012: v), with a survey of 254 staff in social care reporting in 2012 that current training opportunities regarding use of AT was 'average to poor' (Wigfield and Wright, 2012: viii).

For care workers, the research findings have been mixed, with some attributing positive effects while others highlight that in many cases there are initial reservations about the use of telecare. Engstrom et al. (2009) report two main issues: fear of losing control and struggling with the technical aspects of systems. However, both can change after engagement with telecare, which commonly results in improved confidence with equipment. A report by the Dementia Services Development Centre (DSDC, 2010) acknowledges that when telecare is first introduced, care workers may have concerns about job security and be fearful of being replaced by technology. However, the introduction of telecare may open up possibilities for new roles and should not reduce contact time with people with dementia. Instead, the report claims, routine check visits can be replaced by equipment, freeing up staff time for more worthwhile social interaction.

While many health and social care staff have emphasised the benefits of telecare for the people they support, they sometimes felt there was a mismatch between technologies and the needs of services users (May et al., 2011). Managing the differing needs of care workers, carers and the people they care for can also be challenging (Keogh and Delaney, 2009; Wigg, 2010). To address this, Alaszewski and Cappello (2006) recommend that telecare should be personalised to meet the specific needs of clients / carers.

In one study, staff described problems with the usability of technology, and technical difficulties (Horton, 2008b), although this was not the case in all research (Alaszewski and Cappello, 2006). The DSDC report (2010) also emphasises the importance of more than one carer or care worker being familiar with telecare. There should be someone available at all times who is familiar with how each piece of equipment works. Call centre staff need to be aware that the person they are responding to has dementia and should understand the appropriate care arrangements, drawing on an individual response protocol established at the time of installation. Discussing this plan at regular team meetings will help care workers deal with emergent issues. This is especially important in organisations where there is a high staff turnover or regular use of agency staff. Recent research by Skills for Care points to the fragmentary nature of skills and qualifications being applied to telecare in the social care workforce (Skills for Care, 2011). In the light of the WSD project, there is a clear need to review the workforce skills and knowledge base in a way that can be reflected fully in the Qualifications and Credit Framework (QCF) established in England. The majority of

carers in Alaszewski and Cappello's (2006) study found telecare devices easy to use, although a small minority experienced difficulties, particularly in the early stages. Jones (2004) also found that carers reported technical problems with some devices, although this may reflect the focus of their study on telecare prototypes. Another practical issue described by some care workers was the difficulty of finding suitable location(s) for AT in the home (Magnusson et al., 2005).

Kaye (2008) reports that to improve the benefits of telecare for the care of people with dementia, future developments need to be more sensitive to changes in the person's condition over time. This will help alert health and social care professionals and carers to the importance of modifying care packages to suit the needs of the person cared for. Robinson et al. (2009) report that future devices should be integrated easily into service users' daily routines and that areas targeted for improvement should include facilitating two-way communications, flexibility of systems as illnesses progress, and equipment that can help to guide people with dementia home when out walking. The author reports that attention should also be focused on minimising the size, weight and visibility of devices to reduce stigmatisation.

## 6.7 Summary

This chapter has explored a variety of barriers to the adoption of telecare for service users and their carers. Individual service users may be reluctant to use telecare for a variety of reasons, including the perceived association with decline, reliability, a lack of provision in their local authority, and inadequate information and training. Studies also highlight challenges in using these technologies among carers and care workers, including: anxiety about using telecare; a lack of skills or knowledge; practical and technical difficulties; and concerns about the implications of telecare for privacy. Carers of people with dementia face particular challenges in using telecare in their caring role. Possible ways forward to address these issues have been outlined, including providing training and support for carers and care workers. Despite the growing body of research in this area, there remains a lack of understanding of how the social and personal characteristics of people, carers and care workers may shape their use of telecare. Research is still at an early stage and findings are often inconclusive, indicating the need for further studies on the implications of telecare for carers and care workers (Yeandle and Fry, 2010). This is particularly important in the context of rapid technological developments, and the need to evaluate new innovations in the telecare market (DoH, 2009b).

## Conclusions

*Kate Hamblin and Sue Yeandle*

This volume of the AKTIVE Research Report has drawn on evidence and theories discussed in the literature which are relevant to the focus of the AKTIVE project. It has also been informed by the professional experience of AKTIVE consortium members. The aim of this work, undertaken as the AKTIVE project began, was to capture key insights and knowledge and to highlight gaps and weaknesses in past understandings. The literature consulted was drawn from various disciplines relevant to how older people living at home with the frailties associated with dementia or a heightened risk of falling might be affected by having telecare available. It also considered the possible impact of telecare on the paid workers and family members, neighbours or friends who may play a part in caring for older people.

The literature review was an important preparatory step and paved the way for the AKTIVE project's new empirical study of households in which older people with the conditions mentioned have telecare in place. That study got under way in late 2012 once initial consultations with stakeholders, a preliminary set of interviews to capture the perspectives of carers and care workers and research ethics approval processes had been completed. The study employs a method called 'everyday life analysis'; the study findings and details of this methodological approach will be published in Volumes 2 and 3 of the AKTIVE Research Report in 2014.

The literature review represents the combined work of various members of the AKTIVE Consortium and their associates. The review team drew on expertise and published work in a number of different disciplines: sociology and social policy; design, technology and ergonomics; gerontology, demography and social psychology; and two medical specialisms (dementia and falls). The chapters of the review were written by Peter Buckle, Chrissy Buse, Adam Darowski, Gary Fry, Rama Gheerawo, Kate Hamblin, Barbara Harrington, Rupert McShane and Alan Roulstone. Editorial work was undertaken by Gary Fry, Kate Hamblin, Emma-Reetta Koivunen and Sue Yeandle.

In the literature review, the salience of the now well-established evidence showing that the population of the UK is ageing has been emphasised. The review has highlighted key contributions to the literature on this topic, showing that while in the future population ageing will undoubtedly mean an increase in the numbers of people needing care, the number of people available to provide the support frail older people need will be falling. Evidence about the likely prevalence of falls and dementia among the older population has also been presented in the review. This showed that, unless new ways of managing and responding to them are identified, the financial and social costs of responding to these conditions are expected to rise significantly. Evidence drawn from clinical practice and from the medical and gerontology literature also considered what these conditions mean for those who experience them and for their families and summarised how the conditions arise and are currently treated. The review found that only limited use is currently made of telecare in the support available to older people with these conditions. In several of the chapters authors suggest that there could be future benefits for some sufferers or their carers in using technology to help them manage their condition and their everyday life, although the review makes it clear that these benefits (and the conditions in which they can be achieved) are not yet fully understood.

In the review chapter focused on the literature on the sociology of ageing and on the sociology of technology, the authors highlighted the importance of context and of individual biographies in shaping people's experiences of growing older and of using, or being encouraged to use, technological innovations.



They suggest that insights and theories developed in these bodies of literature may nevertheless be useful to researchers, as they may help them develop understandings of how telecare is used in practice in peoples' everyday lives. This is likely to be valuable in helping to identify the different factors which may lead to telecare being rejected by some users or, in other cases, used effectively.

The authors found little evidence in previous research on telecare and telehealth of researchers integrating existing social theories on ageing or technology or critically engaging with these approaches. For example, most past studies had not used insights from social constructionist perspectives, and Actor Network Theory had only rarely been applied to the analysis of the role of telecare in supporting older people. A few newer studies had adopted these approaches, however, showing that telecare can be reconfigured by users in unexpected ways. The review has also indicated that theories of the 'domestication' of technology may be helpful in understanding how technology is used in everyday contexts such as in the home, and that this approach may offer an important conceptual framework. These theories may be helpful in helping researchers explore what users actually do with telecare rather than simply focus on identifying the 'effects' of technology.

Contributors to the review indicate that some aspects of the sociological literature on ageing have implications for understanding how technology is used. This literature shows, for example, that age categories are socially constructed, and that the images, expectations, and regulations associated with 'old age' vary across time and culture. Thus social constructions of ageing can shape engagement with technologies and people may resist using telecare or be unwilling to accept it if it is negatively associated with dependency and frailty. Biographical approaches, which took the way older people's skills, experiences and attitudes to technology had developed throughout their lives into account, rather than depicting 'old age' as a static and isolated stage, were also shown to be important.

Since the 1980s, understanding users' needs and the contexts in which technology is situated have been key themes in the literature on (and practice of) design and technology. 'Inclusive design' involves product users in the design process which benefits users (because the technology produced is better attuned to their needs) as well as designers and manufacturers (who gain through increased value and competitiveness). Inclusive design supports appropriate technology solutions and uses people-centred methods which enable empathy to develop between designers and older people, whose understandings of appropriate assistive technology may differ. The review showed that design ethnography, in which methods such as observation, interviews and diary entries are used, and systems design, which takes actors' wider networks into account and examines how technology works within them, can be important. It also explored the applicability of Patient Safety Research, drawing on the literature on identifying hazards in the design process, and Prospective Hazard Analysis, which models potential risks.

In the chapter which explored the policy literature on the development and implementation of telecare contributors showed how telecare has emerged as a feature of UK policy, identifying it as a response to growing awareness of the needs of an ageing population. The authors explored the rationale and key features of the main programmes of investment in telecare introduced by governments in the UK, and the growing body of research on telecare, some of which has been sponsored by government and gathered together in official databases. Some of the studies undertaken had investigated the impact of telecare on users of this technology, highlighting in particular its role in maintaining users' independence and in reducing their anxiety; some also found a range of positive effects for carers. The contributors noted that there was much less evidence available on how telecare affects care workers and that the findings of these



studies were mixed. Some evidence was nevertheless identified which suggests that telecare can, in certain circumstances, play a positive role in the support given to older people by workers who attend them at home in a professional capacity.

In a variety of past studies, the review found evidence of barriers to the use and uptake of telecare. The findings of these studies had included evidence of psycho-social barriers and of variability in individual capabilities and familiarity with technology. Some had reported that practical constraints in using telecare were significant, and that these included the costs involved in developing and implementing programmes of telecare support. Resource allocation to support the development of telecare use at home had been variable across the UK and this had been a cause of the uneven implementation of telecare services. There was also evidence in the literature that uptake of these technologies had sometimes been hampered by a lack of information and awareness about telecare among carers and care workers.

The literature review thus offered many clues to the AKTIVE project on how its own new empirical work should be focused and developed. Insights about the conditions respondents have and about the salience of design features and past experience of technology have been used by the team in developing its approach to understanding how telecare fits into the everyday lives of older people. This has sharpened the focus on understanding why, and in what circumstances, the technology may be valued, tolerated or rejected, and how it might be adapted or introduced to deliver more benefits to older people who have memory problems and/or dementia or who are prone to falls. The review has allowed the AKTIVE team to build on existing knowledge and to seek in its own work to address gaps in understandings. This is being approached mainly through the everyday life analysis method, in which older people who have telecare in place are followed over a period of time and receive repeated research visits at home, during which their use of telecare and other aspects of their care and support are identified. The method also allows the research team to explore how the technology affects the various people in their networks of support (family members, friends, neighbours or workers employed to assist them in their homes). When the study of older people in households is completed, it will enable the AKTIVE research team to draw on the multi-disciplinary expertise within the AKTIVE Consortium to make detailed policy recommendations about the future role telecare could play in providing valued and effective support to help older people with the frailties studied to live active and independent lives in their own communities.

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