

# Chapter 13

## Design for Agency, Adaptivity and Reciprocity: Reimagining AAL and Telecare Agendas

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It goes without saying that the developed world is facing significant challenges in dealing with the increasing demands of an ageing population, especially around health and care. It is also easy to understand why technology is seen as a key enabler for meeting this challenge. Application areas such as Ambient Assisted Living (AAL) and telecare are receiving increasing governmental, industry and research attention, taking advantage of maturing and increasingly ubiquitous wireless, mobile and sensor-based technologies. However, to date, many of these advances have been largely driven by technology-utopian visions without real understanding for how such technologies come to be situated in everyday life and healthcare practice and what their potential is for enhancing new ways of living into older age. Further, there is limited evidence of their effectiveness to date, and the problems with adoption from the patients' perspectives suggest it is timely to reflect on these experiences and reimagine new ways of approaching AAL/telecare from a broader socio-technical perspective. To this end, we propose AAL/telecare as modular infrastructures for the home that can be adapted and repurposed, starting with personal 'quality of life' and social needs (supporting peer care) and progressing to monitoring, physical and medical needs (supporting formal care) as relevant for

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a person and as needs evolve. This extends the adoption path to supporting healthy ageing, taking notions of agency, adaptivity and social reciprocity as core principles. We illustrate this with some examples and identify some of the associated technical and methodological challenges.

## 13.1 Introduction

The challenge of caring for an ageing population, and an increasing ‘burden’ of care for associated chronic diseases, is now the *de rigueur* mantra (and as we will argue later, in agreement with Mort et al. (2012), a problematic rhetorical turn) to motivate the need for new technology-enabled models of care. As such it is both emblematic of and a model for a consideration of those issues which are discussed elsewhere in this book— notions of social engagement, value sensitivity, user involvement/codesign and so on. The key agenda of such models is to enable people to be looked after in their own homes, thus avoiding the costs and inconveniences of expensive institutionalised care. Such approaches are variously called Ambient Assisted Living (AAL), telecare, telehealth, telemonitoring and so on. Whilst the exact definition of many of these terms is still evolving (Greenhalgh et al. 2012) and the choice of label can depend on the cultural context (e.g. the term AAL is commonly used in Europe but not so much in the United States), we will use AAL/telecare as a placeholder here and focus on the European (EU) perspective.

Among AAL/telecare solutions and service offerings, there is a huge diversity in the different configurations of technologies and in the degree of involvement of healthcare professionals. However, they all tend to encompass some or all of the following features: monitoring of *safety and security*, e.g. to detect water left running, via sensors that operate in isolation and generate alerts when events are detected; monitoring of *activities of daily living (ADL) and lifestyle monitoring* via a network of sensors in the home, again with some alerting function, e.g. for fall detection; and *physiological monitoring*, which usually involves some direct participation of the users, e.g. in taking blood pressure measurements.

At its core then, the vision of AAL/telecare, as a solution for the ‘burden of care for an ageing population’, is based on some form of remote monitoring, exploiting the potential of wireless and sensor-based technologies to track aspects of concern and exploiting the potential of Internet connectivity to provide some form of communication back to a monitoring centre or care provider.

Buying into this vision and the associated rhetoric, there has been a substantial investment of funds and resources into AAL/telecare, both in supporting research programmes and in actual deployments. For example, the AAL Joint Programme of the European Union (EU) was started in 2008 with investments in the order of 600 million Euros. The aim is to specifically encourage cross-national collaboration of small- and medium-sized enterprises (SME), research organisations and user groups ‘to create better condition of life for

older adults and to strengthen the industrial opportunities in Europe through the use of Information and Communication Technology (ICT)'.<sup>1</sup>

Another example is the various initiatives funded by the UK Department of Health around long-term conditions, a recent high profile one being the Whole System Demonstrator (WSD) programme.<sup>2</sup> The cluster randomised control trial (RCT) for the WSD involved over 3,000 patients with diabetes, chronic obstructive pulmonary disease or heart failure, attending 179 general practices from three different areas in England. The expectations of governments for AAL/telecare are reflected in the stated aims of the WSD: 'to show just what telehealth and telecare is capable of, to provide a clear evidence base to support important investment decisions and show how the technology supports people to live independently, take control and be responsible for their own health and care'.<sup>3</sup>

However, evidence for the success or otherwise of such AAL/telecare systems is decidedly mixed and points to the 'current gap between policy enthusiasm for tele-monitoring and its more limited uptake and impact in practice' (Greenhalgh et al. 2012). Mort et al. (2012) also draw critical attention to the negative rhetorics around AAL/telecare, i.e. of 'threats', 'burden', 'age time bomb', 'silver tsunami' and so on, the 'stigmatising and ageist rhetoric forms' used to motivate the move to AAL/telecare.

The main focus of this paper is to argue for a different rhetorical and practical view of AAL/telecare as being socially embedded and practically situated in the everyday homes and lives of the people for whom they are intended and where the experiences to date with such systems suggest it is timely to reconsider the conceptualisation and design of AAL/telecare systems from a broader socio-technical perspective. A more detailed motivation for this shift is presented in the next section where we review reported experiences to date.

## 13.2 Mixed Outcomes from AAL/Telecare Experiences to Date

The outcomes reported from various studies paint a mixed picture of the evidence base for AAL/telecare (see, e.g. Barlow et al. 2007; Brownsell et al. 2011; DelliFrance and Dansky 2008; Hardisty et al. 2011; Steventon et al. 2012).

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<sup>1</sup><http://www.aal-europe.eu/about/objectives/>

<sup>2</sup>[http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Healthcare/Longtermconditions/wholesystemdemonstrators/DH\\_084255](http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Healthcare/Longtermconditions/wholesystemdemonstrators/DH_084255)

<sup>3</sup><https://www.gov.uk/government/publications/whole-system-demonstrator-programme-headline-findings-december-2011>

As will be seen below, studies of deployments of AAL/telecare solutions are most often based on smaller-scale pilot projects and tend to follow the medical model of randomised control trials (RCTs), relying on quantifiable measures; as such they tend to focus on aspects of efficiency and effectiveness, where evidence for the success or otherwise is usually reported in terms of health and cost outcomes oriented towards the medical system, such as the use of care services (admissions to the hospital, length of stay, etc.), patient compliance, etc. More recently, some qualitative studies are also starting to appear but are still relatively rare.

Across the various studies, there are some reports of positive outcomes. A 2012 report on the WSD trial indicated a reduction in mortality rates, admissions and patient bed days (Steventon et al. 2012). (Others have also critiqued the design of the WSD RCT studies, e.g. because the unit of randomisation was the general practice and no comparable interventions were offered (McCartney 2012), thus raising question marks about possible bias and how much the positive results really stand.) A systematic review by DelliFrance and Dansky (2008) reported an overall 'moderate, positive and significant effect' on clinical outcomes such as fewer visits to the emergency room, fewer admissions, etc., especially for heart disease and psychiatric conditions but not, for example, for diabetes. A different systematic review by Barlow et al. (2007) concluded that the most effective interventions were automated 'vital signs' monitoring and telephone follow-up by nurses, both resulting in reduced use of healthcare services, but there was insufficient evidence, for example, around effects of safety and security monitoring or about the effects of telecare for asthma, dementia and depression. Neither review found sufficient evidence to suggest cost advantages to date, and a recent report on the WSD project even found that the costs of the telehealth intervention were higher and thus not cost effective compared to 'usual care' (Daugaard 2013, Personal communication with Henning Daugaard, Director of Social, Health and Employment affairs, Frederiksberg Municipality 2013–07–15; Frederiksberg Municipality 2013, p. 82), especially as patients reported similar quality outcomes in both conditions (Henderson et al. 2013). In summary then, there are some positive effects to be found, but it is hard to compare such reviews and outcomes because of the range of different interventions and diseases included. Further, clinical outcomes do not always translate into cost savings.

On the other hand, there are also many other reports and systematic reviews that are less positive, pointing to a lack of supporting evidence and highlighting more complex issues that go beyond the technology to the broader clinical, organisational, legal and support structures and processes into which telecare needs to be embedded. For example, a systematic review of what the authors termed 'lifestyle monitoring technologies', i.e. called AAL/telecare here, concluded that in fact the 'evidence base for lifestyle monitoring is relatively weak, even though there are significant numbers of commercial installations around the world' (Brownsell et al. 2011). Hardisty et al. (2011) also point to broader issues with the implementation of AAL/telecare (using the language of 'telemonitoring'), concluding that 'attempts to use telemonitoring [...] over the last two decades have so far failed to lead to systems that are embedded in routine clinical practice' (p. 734).

Some of the reasons for the lack of embedding into actual practice might be found in Fitzsimmons et al. (2011) who report from their experience of trying to set up an RCT of a preventative telehealth service for chronic obstructive pulmonary disease (COPD) that ‘whilst the need to improve care delivery modalities [ . . . ] is recognized, in reality, the shift to the primary sector is proving more difficult to enact than initially anticipated’. Their experiences highlight the complex service delivery issues entailed in telecare, that can challenge traditional boundaries between local authorities and healthcare providers and that can require significant changes to established roles and responsibilities, working patterns, data flows and so on.

However, even though one of the critical issues around AAL/telecare solutions is adoption from the seniors’ perspectives, this tends to receive much less attention in evaluation studies and reviews. The studies included in the reports above, as previously stated, tend to frame the evaluation in terms of clinical and cost outcome measures and in doing so prioritise the perspective of the service delivery/medical system. It is also to be noted that these outcome studies, by definition, only involve patients who have agreed to use the system. Where ‘patient’ perspectives are included in evaluations, they are often noted in terms of some overall statement about usability and user acceptance, often based on survey data. Qualitative studies on actual user experiences are relatively rare.

It is these more qualitative studies though, foregrounding the processes and experiences of people actually using AAL/telecare or not, that we use as motivators to argue for a shift on our conceptualisation of AAL/telecare. Gale and Sultan (2013), for example, draw attention to the ways in which such technologies ‘can modify emotional and bodily experiences’ for the COPD patients they interviewed, who reported ‘peace of mind’, in part due to the way that telehealth legitimised contact with their health professionals and gave them increased confidence. Aarhus and Ballegaard (2010) conduct a more in-depth ethnographic work across a number of technologies and conditions for supporting care at home and unpack what they call the ‘elaborate boundary work’ that people engage in ‘to maintain the order of the home when managing disease and adopting new healthcare technology’. Müller et al. (2010), in a study of the use of location monitoring for people with Alzheimer’s disease, identify dilemmas between awareness vs. privacy and safety vs. autonomy. All these studies therefore point to the adoption of AAL/telecare into everyday life as a highly complex negotiated process, involving modifications, negotiations, integrations and segregations as people both deal with the disease issue and work out how to get on with life.

Studies of people who do not take up AAL/telecare are also instructive about what is important from patients’ perspectives. Sanders et al. (2012), for example, also studied the WSD project but focused on people who rejected participation or who agreed to participate but later withdrew from the trial (i.e. unlike some of the people in Gale and Sultan’s (2013) study, they did not experience ‘peace of mind’). In a qualitative analysis of interviews with these people, the authors identified a number of barriers to the participation and adoption of telehealth and telecare from the patients’ perspective. These

included (1) concerns about *technical competence* and the need for special skills to operate the equipment, (2) concerns about ‘threats to *identity* associated with positive ageing and self-reliance’ and to independence by undermining ‘self-care and coping’ and (3) concerns about *disruptions* to existing services that they valued (an interesting concern against Gale and Sultan (2013), pointing out that the same technology can be experienced very differently by different people).

Other barriers identified in the literature around adoption of AAL/telecare are a lack of perceived usefulness (Huang 2011), lack of face-to-face contact with caregivers, poor usability, lack of trust, increased professional responsibility, lack of organisational willingness to change and financial barriers like the absence of reimbursement arrangements (Reginatto 2012). There is also a concern that ‘monitoring [. . .] may also increase the amount of information which flows from users to carers, which can result in a form of function-creep that actually undermines independence [for older people]’ (Draper and Sorell 2012) and that can reduce social contact more generally (Mahood et al. 2008).

### 13.2.1 *Motivating a Re-imagination of AAL/Telecare*

In summary, what we are seeing across these different studies, reviews and methodological approaches are what Greenhalgh et al. (2012) identify as different discourses around AAL/telecare. These are ‘*modernist* (technology focused, futuristic, utopian), *humanist* (person centred, small scale, grounded in present reality), *political economy* (critical, cautious) and *change management* (recognising complicatedness but not conflict)’ (Greenhalgh et al. 2012). The authors go on to call for closer working across discourses, stakeholders and perspectives.

Hardisty et al. (2011) move in this direction, and whilst their systematic review could be regarded as taking more of a modernist perspective, their conclusions clearly point out the need to integrate more of a humanist and change management perspective (to use the categories above): ‘Attempts at implementation have paid insufficient attention to understanding patient and clinical needs and the complex dynamics and accountabilities that rise at the level of service models. A suggested way ahead is to co-design technology and services collaboratively with all stakeholders’ (p. 734). This is an important call and highlights the value of taking a socio-technical practice-based perspective and involving all stakeholder concerns.

Roberts and Mort (2009), coming from a humanist perspective, characterise three distinct areas of telecare discourses: monitoring, physical care and social–emotional care. They argue that telecare only tends to deal with monitoring (that can be seen as a modernist perspective) and that this ‘fails to account for the complexities of all kinds of care (physical, social-emotional and telecare)’. They go on to argue that ‘what counts as care needs to be rethought if telecare is to make a positive contribution to the lives of older people and those who care for and about them’ (Roberts and Mort 2009) and that it is time for ‘re-imagining the aims of telecare

and redesigning systems to allow for creative engagement with technologies and the co-production of care relations' (Mort et al. 2012).

This is the call we take up in this chapter, to reimagine the aims of telecare and from this redesign such systems to allow for creative engagement and the co-production of care relations. Mort et al. (2012) started this re-imagination by reframing 'telecare users as embodied, located at home [. . . and care] as a temporal and negotiated achievement that requires shared work' (p. 11). We build on this to add a more practical design-oriented view. Significant in our reimagining of telecare is a decentring of the notion of 'practice' away from the formal care practices via the delivery of health and social *care* and towards the everyday lived experiences and practices of *ageing* (and later discussed in Sect. 13.6, as 'situated elderliness') as experienced by older people themselves. It is also informed by understanding some of the processual and experiential issues noted above and by considering how to address some of the barriers to adoption noted by Sanders et al. (2012).

The contribution of this chapter then is to add to this re-imagination of the design of AAL/telecare by focusing on the patients' perspectives. In saying this, it is also worth stating two aspects that are equally important for this re-imagination but beyond the scope of this chapter to address. Firstly, in an ultimate solution, the needs of both the clinicians/service organisations *and* the patients, and their family/friends, have to be considered, as argued by Hardisty et al. (2011); to manage scope here and to address what we see as a 'stakeholder' group that has received least attention, we put the focus first on older people. Future work will also need to reimagine, e.g. service delivery models from an organisational or clinical perspective. Secondly, a focus on the patient's perspective and on taking a more 'everyday ageing' practice-based view of AAL/telecare raises the challenge of finding evaluation methods that can account not just for the medical system-oriented outcomes, but also the practical everyday processes through which such outcomes are achieved by all participants, the older person, their peers/informal cares and the formal care system, as well as evaluating the lived experiences of such systems. Future work is needed to develop these new holistic methods of evaluation.

What we focus on here is a re-imagination of AAL/telecare that integrates both modernist and humanist perspectives and reframes the wireless- and sensor-based technologies of *AAL/telecare as modular infrastructures* for the home that can be *adapted and repurposed*. In this way the same base infrastructure can address personal quality of life and social needs in the first instance and can also involve monitoring for physical and social care needs as relevant for a person. It can make use of explicit communication channels and more implicit mutual awareness opportunities, e.g. by the appropriation of AAL-/telecare-type sensors in the person's home and providing engaging creative visualisations of the activities of others in the care network. That is, the same base infrastructure can be used for social interaction, preventative health/health promotion and more formal care and monitoring arrangements as needs evolve (illustrated in the 'future scenario' below and also later in Case 5).

*Future scenario: adaptive solutions for AAL/telecare from peer care to healthcare*

In our imagined future, social care and healthcare services offer an integrated support service. Mr. Jones and his neighbour had read about the range of community modules on offer by the service. After his neighbour's wife died, they discussed how they could keep a better eye on each other, so during their next annual 'health and well-being' check with the community care officer, they took up the offer of a base 'neighbour-aware' system. This involved having a video camera and video conferencing system installed in each of their homes that they could use to connect to each other by touching their photos. It also involved having some basic movement sensors installed in the living room. By giving permission for this information to be shared at a very simplified and privacy-preserving level, they can both see some abstract images that they have chosen to indicate a general sense of themselves and the other person. They use this as additional means to be in contact between their weekly card games and to keep an eye on each other.

Some time later, Mr. Jones has a cardiac episode, and on return from the hospital, the community nurse and his cardiologist suggest that he has some additional sensors installed in more rooms at home and that could detect if he falls. He thinks this is a good idea because he knows now how they work and discusses with the nurse exactly where they should be installed and who can see what level of information about him. He is also given a heart rate monitor to wear that communicates with his base station.

His neighbour still keeps a close eye on him with the very simple living room information and the video connection as before, but now, the data being collected by his additional sensors and the heart rate monitor are further processed and sent to his community nurse so that she can monitor his health status. Mr. Jones is also interested to see how his heart rate changes with different activity levels, and it helps him keep up with his activities at a more even pace.

This re-imagination reframes therefore *when* such technologies can be considered, creating an adoption path that can start with self-motivated social needs and opportunities, connecting with informal peer care networks, in a nonthreatening and noncritical context. The installation and use of these technologies also lay the foundation for people to gain familiarity and technical expertise in a relaxed way, hence addressing issues of self-efficacy; i.e. 'to develop training for users to use telecare, it is likely to be helpful to reduce users' anxiety and improve usage of telecare' as stated by Huang (2011). The goal then is that issues of acceptance can be dealt with via the motivation to accept the technologies because of their perceived social usefulness and providing an opportunity to contribute and that the subsequent familiarity with the technology will increase ongoing adoption (Mahmood et al. 2008) when more critical care needs arise.

In taking the patients' perspective for this re-imagination, we go back to the first principles and revisit notions of ageing, emphasising positive views of ageing as an adaptive developmental process and embedding the concerns about health conditions into an everyday life perspective (Sect. 13.3). This shifts the emphasis and language, from 'patients' to 'people'. We also use the terms 'seniors' and 'older people' interchangeably to reflect more positive stances on ageing.<sup>4</sup>

We then go on in Sect. 13.4 to explore new person-centred opportunities for AAL/telecare technologies as infrastructure, focusing particularly on notions of agency and reciprocity as key principles. Sections 13.5 and 13.6 then explore some of the technical and methodological challenges to designing reimagined AAL/telecare services.

### 13.3 Reconceptualising Ageing

A key starting point for this reimagining is a re-conceptualisation of the notion of ageing so that it can reflect the lived experiences of older people themselves and characterise them as active agents in their own care. We look at this issue from two different disciplinary perspectives, Gerontology and Psychology, where theories in both point to similar underlying phenomena of agency and adaptivity. This also means acknowledging the opportunities for social and self-development that persist as significant markers of well-being into advanced age alongside the more formal care demands that may develop and point to the opportunities around social connectivity and reciprocity.

#### 13.3.1 *Lived Experiences and a Turn to Agency and Adaptivity*

A dominant focus on 'modernist' or monitoring approaches tends to conceptualise old age from an objective and deficit-driven perspective perpetuating a notion of ageing as an ongoing 'diminishment' of function. This can obscure older people's sense of agency in the context of care and undermine opportunities for ongoing development in other areas of life. Several theoretical notions have been put forward to support the view that significant development does continue in later life.<sup>5</sup> In particular here, we draw on theories of ageing that regard *ageing as a positive developmental lifespan process* (Tornstam 1989), which emphasises our

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<sup>4</sup>We note that the use of language/terminology here is politically sensitive, but we also note that what is regarded as a more 'politically correct' term is often dependent on culture and context and that there is no universal agreement. In the end it is the attitudes, values and practices we bring as practitioners that will speak louder than words.

<sup>5</sup>We recognise too that there are many different theories of ageing and that there is no universal agreement across disciplines about how to conceptualise ageing. In presenting a range of different theorists' positions, our intention is not to advocate a particular one but rather to stimulate thinking differently about older people and to orient to more positive developmental notions of ageing.

focus on the relational and self-oriented aspects of daily life as significant in maintaining well-being. For example, Baltes and colleagues (Baltes 1993; Baltes and Baltes 1990; Baltes and Carstensen 1999) suggest that the developmental opportunities of 'successful ageing' take place when there is an awareness of ageing limitations married to *selectivity with optimisation and compensation*. This allows older people to maintain their quality of life by deliberately narrowing their life choices (selectivity) so that they can optimise existing capabilities (e.g. optimising arithmetic skills by doing Sudoku puzzles) and/or compensate for those that are in decline (e.g. compensating for poor memory by writing things down). Joyce and Loe (2010) extend a similar view of older adults as active adaptive agents to technology, arguing that 'far from passive consumers, elders are technogenarians, creatively utilizing and adapting technological artefacts such as walking aids and medications to fit their needs'.

Carstensen extends the selectivity model to include *socioemotional* goals highlighting the increasing significance of social connections as we age. Carstensen suggests we see, as a positive choice by older people, a deliberate narrowing of social connections in favour of longstanding intimate social ties in order to maintain ongoing activities, a sense of purpose in life and ultimately the integrity of the self in lieu of approaching death (Carstensen 1992, 2006; Carstensen et al. 1999). Others have suggested that advanced age may also invite a contemplative form of development through which an older person comes to reframe their relationship to themselves and others. Through this process of *gerotranscendence*, they may become more altruistic, lose their fear of death and learn to appreciate solitude and the mundane aspects of their life (Tornstam 2005).

Such theories of ageing show older people not as passive recipients of the physical ageing process (and the prescribed care that may accompany it) but as self-aware agents of change who are resourceful in dealing with the failings of their own body and adapting their behaviour, self-concept and relationships with others to maintain a quality of life. These adaptations are central to the lived experience of ageing and can be seen to constitute an individual's own particular 'practice' in relation to it. However, these can also be at odds with the practices of health and social care. Tornstam and Toernqvist (2000) found that gerotranscendent behaviours such as changes in the perception of time and the seeking of solitude were often interpreted as signs of dementia by care staff rather than as anything positive for that individual. Interestingly, the limiting of social contact described by socioemotional selectivity theory (Carstensen 1992) would similarly be deemed unhealthy by proponents of Active Aging,<sup>6</sup> an influential paradigm for health and social care throughout Europe and beyond (WHO 2002).

Self-determination theory (SDT) from Psychology also provides interesting perspectives to consider in reimagining AAL/telecare. Whilst not specifically targeted to older people, but in line with the fuller and more active characterisation of old

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<sup>6</sup>Active Aging – a competing paradigm which suggests greater social involvement in society is always a good thing

age from above, SDT takes as a starting position that people have deep tendencies towards psychological growth and development, where well-being is defined as vital and full functioning (Ryan and Deci 2001). Self-determination theory postulates a number of key components for well-being: autonomy, competence and relatedness. First, *autonomy* refers to the universal urge to be the causal agent of one's own life. This does not imply, however, that one necessarily needs to be independent of others (Deci and Vansteenkiste 2004).

Second, *competence* refers to the extent to which an individual is effective in dealing with the environment in which one finds oneself. This is closely tied to concepts of *independence and self-efficacy*, which is of special relevance to the relationship seniors have with self-efficacy of care and their relation to modern technology in general. A necessary ingredient of satisfying interaction with technology is self-efficacy (Bessiere et al. 2006), defined as a person's belief about their own capabilities to produce designated levels of performance that exercise influence over events that affect their lives (Bandura 1977). Lack of self-efficacy can hinder adoption of new technology, as has been found in relation to the WSD discussed earlier. The level of self-efficacy is also related to stress. Increasing self-efficacy is associated with decreasing stress, and seniors in particular are more vulnerable to stress than younger adults (Hawkley and Cacioppo 2004), especially when stress affects, and is affected by, interface use (Hawthorn 2000). In particular older users could be negatively affected by stress during interaction with new media.

Finally, *relatedness* is the universal need to be socially connected to others in meaningful ways and involves both caring for others and having others care for you. Relatedness is experienced as a sense of communion/community through developing close and intimate relationships with others, and different people will have different needs for degrees of relatedness. Whilst SDT is largely defined with respect to the individual and to explore issues of motivation, the principles of SDT can also be practically interpreted as always being embedded in a social context and for older adults; such issues of relatedness can also be interpreted in relation to the socioemotional selectivity noted above.

When these three needs are supported and satisfied within a social context, people experience more vitality, self-motivation and well-being. In cases where such needs are systematically frustrated, this has been associated with psychopathology (Ryan et al. 2006). Hirsch et al. (2000) similarly point to the importance of independence (e.g. being able to care for oneself) and engagement (e.g. being able to participate in social activities) for quality of life and physical and cognitive health.

So what do these mean for the re-imagination of AAL/telecare? Overall, these theories point to the importance of *taking agency seriously* and raise challenges for how agency can be maintained and supported by new technologies. This can play out in a number of ways. Firstly, we suggest that the notions of active agency and autonomy provide arguments against system approaches that rely solely on passive monitoring or being surrogate data collectors for others' use. Currently, monitoring systems rarely give the seniors the chance to interact with and adjust the system; instead, the systems, and the data they collect, are mostly used by the service provider and/or informal carers to check on the seniors' situation.

This, as noted previously, ‘actually undermines independence [for older people]’ (Draper and Sorell 2012). Secondly, if we understand the importance of self-efficacy and competence, coupled with active agency, then strategies that enable people to develop skills and understandings around AAL/telecare in nonthreatening ways become important for adoption (Mahmood et al. 2008). Thirdly, if we understand the importance of ‘selectivity with optimisation and compensation’ as a positive adaptive strategy for maintaining a quality of life, it points to opportunities to further develop AAL/telecare as modular infrastructure that seniors can interact with to support their adaptation practices.

These theories also point to the importance of *meaningful social connectivity and relatedness*, with specific understandings of the need for more in-depth relationships (rather than many social ties, which seems to be the focus of Facebook and such) and the sense of purpose. We move on to discuss these social issues in more detail.

### ***13.3.2 Social Connectivity and a Turn to Reciprocity***

The importance of meaningful social connectivity and relatedness for well-being and quality of life is shown by studies of people who do not have the level of social contact that they want (as opposed to the positive sense of having fewer but more in-depth friendships noted above).

The experience of growing older in many societies is often associated with increasing levels of social isolation and reduced community involvement. This can be due, for example, to increased mobility and geographic distribution of families, to a decrease in physical mobility and ability on the part of the older person to engage in local communities and to their diminishing social networks due to bereavement and frailty (Lindley et al. 2008; Pedell et al. 2010). Social isolation, when experienced as loneliness, has been shown to negatively impact on emotional and psychological well-being, increasing an older person’s susceptibility to depression (Choi and McDougall 2007), and cognitive decline (Zunzunegui et al. 2003), as well as being linked to poor functional health (Thomson and Heller 1990) and all causes of mortality and morbidity (House et al. 1988). Conversely, good social relationships have been identified as a key contributing factor to the quality of life for people over 65 (Gabriel and Bowling 2004, cited in Lindley et al. 2008).

However, such characterisations of social relationships tend to oversimplify the nature and complexity of relationships in later life, pointed to above in terms of expected and positively framed decreases in the size of social networks, but also in terms of differences in relationships with families versus friends/peers, and the more nuanced aspects of social interactions in terms of reciprocity, symmetry, dignity and self-worth, responsibilities, etc. (Lindley et al. 2008).

*Reciprocity and symmetry*, for example, are important aspects to draw attention to and highlight the two-way nature of social connectivity. This can be contrasted to the current framing of many AAL/telecare solutions which puts the person into a position of being a generator of signals to be sensed and a recipient of care,

captured in the concerns above about loss of identity and independence. This in turn puts them in a disadvantaged position where systematically being in a receiving position may be associated with potential negative consequences such as mental distress and discontinuities or disruptions of relationships (Gregory 1994). An over-benefited status (receiving more than giving) typically undermines a person's sense of self-worth and independence, and seniors generally share a reluctance to accept 'charity', as this is closely associated with feelings of indebtedness, dependency, incompetence, shame and decreased self-worth. As DePaulo (1982) stated: 'In our eagerness to find ways to help needy populations (such as the elderly and the handicapped), perhaps we have too often overlooked one of the most genuinely rewarding and mutually satisfying arrangements- encouraging the "needy" to give useful help as well as to receive it'.

Moreover, current imagining of AAL/telecare may lead to further detachment from one's social network, as seniors generally find it more acceptable to give than to receive, causing a reluctance to seek help or maintain relationships where one is on the receiving end. This can further increase the level of social isolation and reduced community involvement that is associated with old age where social support networks tend to become smaller and less accessible. Both the decreased size of the social network as well as its reciprocal imbalance are known to have a negative impact on emotional and physical well-being (Choi and McDougall 2007; House et al. 1988). However, the impact of this imbalance can be dependent on the type of relationship, where, for example, parent/child relationships may tolerate a larger imbalance in reciprocity than relationships with friends, neighbours or more distant relations (James et al. 1984).

Therefore, central to our re-imagination of AAL/telecare is the concept of *reciprocity*: the process of 'give and take' that creates balance and stability in people's social relations. Reciprocity is one of the basic mechanisms underlying social relationships and is known to predict better mental health and life quality, than being in an over-benefited position (see Fyrand 2010 for a review). By taking this notion of reciprocity as a point of departure, our re-imagination moves AAL/telecare on from the current discourse around old age as primarily a period of loss, decline and consequent 'over-benefited' dependency through being 'done to' and 'monitored' by a formal care system: it moves it instead towards one of the continued engagements with an extended social network on the basis of continuous, mutual exchange of both instrumental and noninstrumental support, adapting to abilities and practicalities as the individual's issues and needs evolve. In so doing, it also mobilises an informal peer network in complement to, and parallel with, a formal care network.

In the following section, we move on to explore how such re-imaginings of AAL/telecare solutions might be realised, taking agency and reciprocity as core principles and embracing it as a socio-technical design challenge. A key element of the approach is the exploration of how sensors and devices that are part of AAL/telecare solutions can be taken as basic infrastructures to be repurposed to support other needs and so extend the adoption path back into healthier older age.

## 13.4 New Opportunities for Designing AAL/Telecare as Social Infrastructure

A number of authors, especially in the areas of human–computer interaction (HCI) and computer-supported cooperative work (CSCW), have started to draw attention to the design challenges associated with older people and the design of care technologies for the home (e.g. see Axelrod et al. 2009; Blythe et al. 2005; Fitzpatrick 2012; Grönvall and Kyng 2012). Blythe et al. (2005) point to the importance of considering a design perspective through understanding the ‘users’ and settings by labelling it as ‘socially dependable design’. The home has also been identified as having very particular characteristics as a setting for care technologies (e.g. Aarhus and Ballegaard 2010; Axelrod et al. 2009; Blythe et al. 2005; Fitzpatrick 2012). This creates very specific design-related challenges, recognising that technologies designed to support a medicalised model of care in hospital need to be ‘fit for care’, but technologies designed for care at home need to be ‘fit for life’ and able ‘to take account of the huge complexity and diversity of lived experiences at home’ (Fitzpatrick 2012). Two general challenges arise then: design for integration, e.g. into everyday spaces, routines and practices and into the social context of the home, and design for active participation, e.g. via collaborative control and interpretation and active reflective engagement (Fitzpatrick 2012).

We take these challenges as given and go on to explore some specific examples showing how a person-centred socio-technical design orientation can open new types of functionalities and uses for AAL/telecare solutions for enabling peer networks and peer support. The cases paint a picture of a new path to adoption and show how sensors and devices can be repurposed to support other needs at an early stage of engagement, focusing on adaptive ‘healthy ageing’ and peer engagement, as a base for later moving to more supported ageing and professional care models, using the same core infrastructure.

### 13.4.1 Supporting Social Connectivity

An obvious and early ‘repurpose’ of AAL/telecare is the use of explicit communication channels. Many AAL/telecare solutions already include video conferencing capabilities and other communication channels such as email, chat, etc. To date, these have largely been thought about as supporting interaction with formal carers, as in doctors or nurses or a monitoring centre. However, these are *just* communication channels and form part of the communication infrastructure of the home.

Can we consider ways to install these channels earlier than just when a healthcare need arises? There is already increasing evidence about the uptake of video by seniors, especially in the form of ‘Skype’, ‘YouTube’ and similar products, motivated by a desire of seniors to keep in touch with remote family members, particularly grandchildren (Sayago et al 2011; Milliken et al 2012). There are also

many prototype devices exploring such connectivity (e.g. Lindley 2011; Waycott et al 2013). The technology can just as well be used to communicate with friends and to expand into new social networks. However, these platforms are often independent from any broader notion of care infrastructure, and there are opportunities to better integrate these as first steps of an overall AAL/telecare solution. The case of ‘geriatric1927’ (Harley 2011; Harley and Fitzpatrick 2009) (Case 1) is useful to illustrate some of the benefit of such communications.

*Case 1: geriatric1927 and reciprocal care via YouTube*

Geriatric1927 (real name Peter Oakley) is an 86-year-old video blogger from the North of England who started posting videos onto the YouTube website in August 2006. Since then, he has become a hugely popular YouTuber posting 402 videos and having 41,074 subscribers to his channel (as of 12 June, 2013). Peter who lives on his own has found his involvement with the YouTube community to be a transformative experience in terms of social opportunities and his ongoing development of self. What started off as an opportunity to tell his life story to the younger generation (Harley and Fitzpatrick 2009) quickly developed into new roles for Peter with him acting as an informal advisor to troubled teenagers, older people’s champion on the Internet, comedian and singer (Harley 2011).

Whilst these roles have come with a certain degree of responsibility, they have also provided Peter with an important opportunity for reciprocity, allowing him to give something back to this community and the younger generation. Peter’s development of an online YouTube presence has also meant that the computer is now an ever-present source of social contact and companionship within his home. When sitting down to make a new video, he says, ‘I sort of know who I’m talking to, not individually but we are back to this homogenous huggable community’ (Harley 2011, p. 163). Some of Peter’s YouTube friendships have also developed beyond YouTube with some making regular contact by email and Skype and others coming to visit him at his home.

### ***13.4.2 Supporting Informal and Implicit Social Awareness***

Whilst such social networking technologies provide opportunities for explicit interaction and communication, there are also ways to repurpose passively collected data to support implicit social awareness and peer interactions. This is data that can be captured from the embedded sensors, such as those used in AAL/telecare solutions, as well as data from smartphones if available and used (such as GPS location, accelerometer data and so on) and the data from social networking connectivity.

In a reimagined AAL/telecare scenario, peer networks can provide a first line of informal mutual care and support, where the participants' activity and lifestyle-based monitoring data can be represented in some lightweight and engaging way to be *reciprocally* shared with family and peers, as decided by the person who owns the data. For the people on the receiving end of this information, it is analogous to keeping an eye on your neighbour's curtains and getting to know their routines without needing to know the precise details of those routines (Riche and Mackay 2010). Neighbours do this for each other, hence promoting reciprocity.

Having such awareness can then trigger further opportunities to make personal contact, e.g. through visiting/meeting together or using the phone or some social networking platform for more explicit and active interactions. In this way, the opportunity for informal peer care by background awareness can also provide new non-threatening, non-stigmatising reasons to install AAL-/telecare-type activity sensors and puts in place the core monitoring technologies that can later be used for more formal care scenarios. It can also help build familiarity with those technologies.

*Case 2: neighbours engaging in reciprocal peer care and the markerClock*

In a study with 14 older participants, living independently in Paris, Riche (2008; see also Riche and Mackay 2010) explored the role of communication in maintaining independence and well-being. His results highlighted the key role of peer support in providing reciprocal care among friends and neighbours, their desire for nonintrusive means of communication and the ways they used an awareness of the other's rhythms and routines of daily life as a way of building awareness of each others' activities and well-being status.

Based on these insights, Riche (2008) developed the design concept of *PeerCare* and illustrated this with a *markerClock prototype* as an augmented clock representation with an ambient display. The display was based on implicitly collected motion data, reflecting people's home activities as if they had been sensed by AAL-/telecare-type sensors, and represented by symbolic codes to communicate status and routines. A study using the *markerClock* as a technology probe between friends 'confirmed the role of rhythm awareness in peer support and highlighted the need for value in direct communication'.

To date, AAL/telecare scenarios have largely interpreted the use of activity monitoring sensors as being embedded in the home, e.g. motion sensors in rooms, sensors to detect door openings, stove use, etc. This inadvertently frames daily life for older people as tethered to the home and does not recognise them as active participants in a broader community or indeed having mundane practices around the need to shop and so on within the limits of their abilities.

In a reimagined AAL/telecare scenario, there is also an opportunity to rethink where and how sensors are embedded, extending beyond the walls of the house or apartment, and to also embrace more everyday objects. Case 3, about Walky (Nazzi et al. 2012), illustrates this by combining an augmented walking aid and dedicated displays.

*Case 3: Walky and instrumenting everyday objects for social awareness*

The project SeniorInteraction (Brandt et al. 2010, 2012) introduced reciprocity in design for social interaction among senior citizens in two different living labs in urban neighbourhoods. Based on the idea of creating ‘tickets to talk’, everyday objects and everyday activities were augmented to establish an infrastructure for ad hoc meetings in the everyday life of senior citizens. One design concept of augmenting everyday objects with sensors is the Walky (Nazzi et al. 2012):

*Danny lives in Bloomdale senior-housing and is 75 years old. He uses a walking aid to walk. He is a member of a shopping group that he initiated with five seniors in Bloomdale housing. Danny usually goes shopping twice a week. Whilst he uses his augmented walking aid, it broadcasts status notifications to his shopping friends.*

*During his breakfast, Peter, a member of Danny’s shopping group, sees an update from his shopping friends on his tablet computer in the kitchen: ‘Danny is out shopping’. Peter remembers the four bags of coffee discount offer in the supermarket and decides to ask Danny if he would like to share this offer.*

*Simultaneously, Danny’s walking aid emits a mild vibration from its handles, making Danny notice that one of his friends has a shopping message. He calls Peter, and they decide to share the coffee offer.*

*Back at Bloomdale again, Peter – longing for company – invites Danny for a cup of coffee.*

The general mechanism behind Walky is communicating by doing. A person, by simply using a walking aid, broadcasts activity clues to her specific community. At the same time, through feedback from her walking aid or from dedicated displays, a person can receive notifications from her community friends and notice their activity. Further, through very simple actuators, also walking aids themselves can become displays of what is happening in the specific community.

This scenario illustrates the role of everyday objects in mediating a situated human-to-human communication using a sensor-based infrastructure, the situatedness of the technology intended to facilitate seniors in the process of making their activity noticeable for others and to notice others’ activity, the possibilities for social interactions opened up by simple reciprocal exchanges of clues and previous knowledge about each other’s routines. The strategy of Walky for non-stigmatising social interaction is to enable senior citizens’ act of sharing everyday activities for different purposes, without explicitly having to reveal what they are doing.

### 13.4.3 *Supporting Self-Awareness and Reflection*

In some cases, the collected sensor-based data could also be made available for the individual, whose data has been collected, for personal reflection and self-awareness.

#### *Case 4: eHome project and data for self-reflection*

The eHome project (Fitzpatrick 2012; Panek and Hlauschek 2011) involved a prototype AAL environment of an adaptive network of wireless sensors for activity monitoring where the system could learn and adapt to the behaviour patterns of the user. The prototype system was deployed in the homes of 11 people for a period of 3 months as part of a pilot study. To help researchers validate the sensor data (as this was a prototype), participants were asked to fill in a paper diary about their activities and movements.

One of the participants had always thought she cooked a lot for herself, but it wasn't until she looked back over the data she was recording about her actual cooking habits (used to check that the sensors on the stove top were working) that she realised she actually didn't cook very much at all for herself and that her diet was not good. She used this as a stimulus to change her habits towards better cooking and eating.

Whilst the data that prompted her to reflect on and change her behaviours was from a paper diary, it still points to the potential of having such data available from automatic sensor detection and being able to present it back in interesting ways, to the people about whom the data is being collected, for their own sensemaking purposes.

Working with the data in these ways could also help address self-efficacy and empowerment issues and lay the foundation for increased agency in more formal care scenarios. It can help educate the person about what sort of data can be collected by AAL/telecare infrastructures and empower them through knowledge to better engage in discussions about how and to whom to make such information available. When the technologies are installed by free choice for a positive self-benefit, rather than being framed as putting the person into an over-benefited needy position, it can also be envisaged that there would be higher acceptance and in the end greater self-efficacy through voluntary engagement.

In summary, there are many ways that AAL-type technologies can be repurposed to support earlier adoption in support of quality of life needs around social interaction, reciprocity and self-reflection. We emphasise here too that when we have talked about 'peer care', we have been talking about people caring for each other, supporting each other within a community and being complements to, rather than surrogates for, the formal healthcare system. The illustrative cases further show that the type of sensing that can be done (in AAL) is not only useful for seniors who are 'needy' in some way but to the whole community. In the YouTube case

(Case 1), the younger people benefited as much as Peter from their intergenerational engagement with him. The Walky example (Case 3) could also be used by younger or more mobile people in a community to optimise their shopping and time (e.g. by people who are very busy). The sensors could be in a shopping bag instead of a walker. For the reflection case (Case 4), again, learning about one's habits could be equally interesting for the old and young. An interesting aspect of this reimagined use of AAL/telecare is that it can help to significantly reduce the stigma if the solutions are not specifically for the older and less mobile people.

### **13.5 Open Technical Challenges for a Reimagined AAL/Telecare Agenda**

In this chapter we have reconsidered AAL/telecare from a broader socio-technical perspective, taking the senior's perspective and their everyday practices as a point of departure. We have proposed that reimagining both the purposes of AAL/telecare technologies, and when and how they are implemented, might help also address some of the adoption challenges associated with current AAL/telecare deployments.

To realise such a vision, however, one of the key technical challenges to be addressed is how to personalise and visualise sensed data for non-professionals and for the purposes of peer awareness, peer care and self-reflection. Example questions include:

1. How to integrate heterogeneous sources of personal data for very different 'social' and personal purposes, compared to the precision and accuracy needed for formal care purposes:
  - From outside the home, e.g. using location and mobility data from smart-phones/mobile devices
  - From inside the home, e.g. using home activity by repurposing data from AAL/telecare in-home sensors
  - From communication/social connectivity patterns, e.g. using network data from the above and perhaps from phones (calls made/received, etc.)
2. What are the new 'lightweight' ways of making this data available in different ways to peers and/or family, as chosen by the person, to support mutual awareness of each other's activities?
  - How to present creative/ambient visualisations of this data in a way that preserves privacy but gives a feel for general activity/well-being of the person?
3. How to give people control over their own data?
  - How to enable direct control by the person to configure what data is collected from which sensors?
  - How to enable adaptive personalisation of how that data is presented, so that the person is in control of who can see what at what level of granularity?

4. What sorts of display platforms can fit into the home and be easy to use (form, modalities of interaction, etc.)?
5. How can sensors be embedded into other everyday objects (similar to the Walky case) to support situated actions and keep the interaction with the sensors easy?

As an example, we go on here to discuss the visualisation of AAL/telecare data for non-professional uses in more detail.

### ***13.5.1 Example Technical Challenge: Visualisation of Sensor Data for Non-professionals***

Visualisation of sensor data in AAL/telecare more generally is an underexplored area (Cook 2012). Current approaches to personalising and visualising sensed data are mainly focused on the professional carer, where the focus is on the analysis and trend and/or event detection for raising alerts, not on the representation and particularly not on any representation for seniors and their peers and/or informal carers. Where representations of the data are used, they tend to be oriented to the monitoring service or to the system developers and take the form of complex visual/graphical interfaces with numerical data or of graphic renderings of the physical layout of sensors in space with annotations to indicate activities (Lotfi et al. 2012; Thomas and Crandall 2011). Some representational work is emerging to create visualisations of assistive smart home data for formal caregivers, e.g. using an Activity Dashboard (Cook 2012), reflecting more general trends in the use of clinical dashboards for healthcare data.

Other approaches to representing such data for the individual or carer are emerging, but these do not account for their personalisable use in a diverse peer network. Early examples of visualisations for informal carers include Digital Family Portraits (Mynatt et al. 2001) and Intel's CareNet Display (Consolvo et al. 2004), both using an image of the older person surrounded by a display indicating activity status. Whilst CareNet Display uses explicit icons to represent particular 'activities of daily living' (ADL) (e.g. knife and fork to represent a meal eaten), Digital Family Portraits uses a more abstract display of changing butterflies around the border to indicate general activity. We propose instead a more ambiguous lightweight display to indicate activity.

A key technical challenge then is exploring new 'lightweight' privacy-preserving ways of making data (from monitoring 'activities of daily living' from in-home sensors, social network activity, etc.) available to chosen peers/family to support reciprocal awareness of each other's activities. This provides a new dimension of support for peer communities, linking to AAL/telecare infrastructures and complementing formal support structures.

One approach to address this is to draw on the notion of 'ambiguity as a resource for design' (Gaver et al. 2003) and of representation 'as response rather than reality' (Boehner 2009). Presenting smart home data in an ambiguous form allows,

on the one hand, the senior to preserve their privacy, and, on the other hand, it allows multiple interpretations (Aoki and Woodfruff 2005) by the receiver of the information, i.e. peers, informal or formal caregivers. The latter can interpret the visualised information openly and act according to their own interpretation.

This can in turn address an ethical concern with regard to AAL/telecare technology that allows informal caregivers to access monitoring data of the senior at all times and thereby putting new responsibility on them to act in case something is wrong. Informal caregivers with non-stop access to data could even be made accountable for threats to the health and well-being of their senior relative/patient and maybe, thereby, experience stress not to miss any crucial data. Ambiguous data displays could prevent such risks. It also addresses another concern about the imbalance in the care relationship by promoting mutual sharing and awareness between peers using the same system or between young and old family members.

There are some examples illustrating approaches to using ambiguity with sensor-based data that can be used as initial sources of design inspiration. One example is the Affective Diary (Ståhl et al. 2009), which focusses on an individual and is designed for self-reflection. Vibe Reflector (Boehner et al. 2003) does this similarly but for a group in a shared experience situation. Examples of ambiguous displays for home-based data include the work of Shankar et al. (2012) who have created alternative ambient displays using everyday objects such as a plant and clock, augmented with visual displays of activity data via lights, to give a remote carer a 'sense' of the presence of the remote person. However, these prototypes are focussed on one person and their carer, not a peer community, and on one-way monitoring though there would be no reason to expect, they could not also be used reciprocally.

The only work we are aware of to cater for shared ambiguous peer visualisations is the design concept of PeerCare with its markerClock prototype as previously described (Riche 2008; Riche and MacKay 2010), using a clock representation and imagining access to activity data to support 'awareness of rhythms and routines' between a pair of neighbours, but not implemented. This is further described in Case 5.

#### *Case 5: markerClock revisited<sup>7</sup> and imagining evolving care need scenario*

Case 2 outlined the study that led to the design concept of *PeerCare* that was then illustrated in a *markerClock prototype* (Riche 2008). To provide more details, markerClock augments a familiar object in the home, a clock, and makes use of people's 'familiarity of the time/space mapping'. Awareness of routines is achieved using a trace of motion that is detected by a webcam in front of the markerClock, which is then represented as spiral traces in concentric rings showing the last 12 h of information for each person. There

(continued)

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<sup>7</sup><http://www.yannriche.net/markerclock.php>

are also symbolic codes to which the peers can assign their own meaning (e.g. 'I'm going to bed', 'It's time for our TV show') and then drop these onto the trace as a lightweight form of active communication.

The markerClock is displayed on a PC or tablet-sized screen, which each person locates in a central living area. Riche explicitly addresses the issues of negotiating privacy concerns by choosing not to do any aggregation or pre-interpretation of the data and using an ambiguous display. This then let the people themselves engage in the sensemaking and interpretation.

As an example of infrastructure that can evolve with care needs and creating different representations for different needs, one could imagine a situation when one of the participants later develops some healthcare needs that require more formal monitoring. The same activity data could still be collected and displayed as usual for their peer, and in parallel, the data could also be aggregated and processed to be presented in a more detailed and unambiguous way to the formal care provider, e.g. processed to look for deviations from usual patterns or indicators of decline. Additional symbolic codes could also be added in to enable the person to actively communicate their status to their formal care provider. The same familiar infrastructure evolved to meet changing needs.

## 13.6 Open Methodological Challenges

There are also methodological challenges relating to how to design reimagined AAL/telecare solutions in ways that can accommodate the lived experiences of older people themselves and the adaptations that accompany ageing, whilst maintaining an infrastructure that is suitable for health and social care needs. (There are also methodological challenges for evaluation more generally than we noted previously, but these are beyond the scope of this chapter.) This aligns with Hardisty et al. (2011) and their call for a codesign approach that would enlist older people as part of a design team. We extend this collaborative notion by building on the methodological experiences from CSCW and participatory design traditions. Following these traditions, we argue that there is a clear role for empirical and ethnographic studies, as also illustrated from many of the qualitative studies we referenced in Sect. 13.2. Here, we want to focus more on the design process itself. A central dilemma here is how best to involve older people in the design process in an empowering way so that their individual experiences of ageing are validated and remain central to design decisions. This is a particular challenge; based on reported experiences, 'design for and with the elderly carries with it some specific problems' (Müller et al. 2012).

One traditional approach to this has been participatory design (PD), but we suggest that with its democratic focus, unequal roles of users and designers can

occur in these processes. According to Ertner et al. (2010), ‘the PD researcher’s practice is guided by unconscious assumptions and socially specific knowledge, which become reproduced and embedded in methods, categories and interpretations. By this the practitioner poses a risk of dominating the users, if they neglect to focus explicitly on deconstructing the tacit aspects of their own practice’. Similarly, Borning and Muller (2012), whilst discussing ‘unintentional ventriloquism – i.e., stating the researcher’s own views as if those views had been articulated by the informants’ – suggest explicating the voice of the participants, e.g. through ‘judicious verbatim quotation, with good contextualization, [as] is [already] the most frequent response to this problem in HCI and CSCW’. Equally, the voice of the researchers and designers needs to be explicated to clarify how their background impacts theory and method.

Instead, we explore codesign as an approach that might be particularly suited to accessing the lived experience of older people and that takes as its base the theoretical perspectives on the active agency of older people in shaping their own lives. Codesign is characterised by ‘the creativity of designers and people not trained in design working together in the design development process’ (Sanders and Stappers 2008). With a shift towards codesign, the roles of researchers, users and designers are shifting, too. The user who had the passive role of being observed or interviewed has to become a co-designer, and the researcher/designer will become a facilitator, providing guidance and tools to the user to make her a co-designer. These new roles can be challenging for everyone involved.

Below, we discuss three different codesign-related approaches, moving towards greater participation by older people: starting with concept-driven design, then value-sensitive design and finally a ‘situated elderliness’ approach. These approaches are all preoccupied with exploring new roles of the researchers, users and designers and in many ways can be seen to build on experiences with from a PD tradition.

### ***13.6.1 Concept-Driven Design***

One strategy that is about the researchers and designers rethinking how they engage in codesign has been a turn towards a *concept-driven design* approach (Stolterman and Wiberg 2010). This is a complementary approach to the user-centred approaches. Stolterman and Wiberg (2010) argue that much interaction design contains some new interactivity, whilst rarely contributing to the body of theoretical knowledge within interaction design research. Creating good concept designs aims at manifesting theoretical concepts in concrete designs, but still requires ‘a good understanding of users, use contexts, and use’ (Stolterman and Wiberg 2010, p. 5). Within the *concept-driven design* approach, methods have been developed that help put this design approach to practice. A recent example of such methods applied is found in the Walky design (Nazzi et al. 2012) mentioned in Sect. 4.2 in this chapter.

As Ertner and Malmberg (2012) point out, this concept-driven design approach involves a risk of establishing significant gaps between the way that AAL/telecare technology and services configure central concepts such as ageing, health and social interaction and the senior citizens' own accounts of this. This might have implications for both the effectiveness of services and technology developed and thus is an argument regarding the creation of better services and technologies that more people will use. However, it is also a moral and ethical argument, since by reproducing social norms, ideals and categories ascribed with certain stereotypes and values, there is a risk of reinforcing existing societal structures of in- and exclusion. This might particularly be relevant in terms of AAL/telecare scenarios, which operate with categories already embedded with stereotypes and moral judgements (as also noted earlier in the discussion about the negative rhetoric around motivations for AAL/telecare). Gaps between users' accounts and designers' visions of theoretical concepts may exist regardless of design approaches used, since design concepts, even though often invisible, also form the basis of most user-driven design approaches. Ertner and Malmberg (2012) emphasise the need for a more reflexive examination of AAL/telecare concepts and suggest the involvement of users as resource to reflect upon and challenge the imaginations and categories of 'elderliness' inscribed in design concepts and technological objects.

### ***13.6.2 Value-Sensitive Design***

Many of the ethical considerations raised in the previous discussion, in particular about the gap between designers' visions and users' account, point to the importance of foregrounding a 'value-sensitive design' (VSD) approach to designing AAL/telecare.

Many software requirements engineering methods include non-functional requirements, which deal with 'soft' characteristics of a system such as usability, flexibility and performance. However, in general, non-functional requirements differ from value considerations in that they are system specific (qualities *of a system*, reflecting more a modernist stance (Greenhalgh et al. 2012)), whereas values are primarily related to humans and human action, though they can be affected by systems. Values are more fundamental; consequences of not supporting them are worse, for example, when a person's dignity is undermined, when someone's personal autonomy is curtailed or when someone is suddenly held responsible for harm to others (examples that are prominent in systems supporting seniors and their caregivers through ICT).

The need to integrate values into design has by now been well-established within HCI (Cockton 2006; Flanagan et al. 2008; Friedman et al. 2006; Halloran et al. 2009; van den Hoven 2007). Several approaches have emerged to meet this need, of which value-sensitive design (VSD) (Friedman et al. 2006) is one of the most established. Over the last 20 years, VSD has been developed as a framework to systematically account for human values throughout the design process. VSD has been

successful in accounting for stakeholder values in many research projects, for example, to improve the safety of homeless young people (Woelfer et al. 2011). Within the VSD framework, methods and models have been developed that help put VSD to practice. A recent contribution is the value-sensitive action–reflection model (Yoo et al. 2013), which introduces value-sensitive stakeholder and designer prompts to the codesign process to provide a means for bringing empirical data on values and to create a cycle of reflection on action. Such prompts can also be seen as creative triggers or boundary objects that support stakeholders and designers/researchers to be creative, to reflect on values and to communicate their perspectives.

The majority of VSD methods are focussed on conceptualising values and are most applicable earlier in the design process, for example, during the ideation phase. Methods (Friedman et al. 2011; Miller et al. 2007; Nathan et al. 2008) have been developed in order to elicit and make trade-offs between conflicting values. However, VSD currently lacks techniques to systematically translate values into technical designs. As a result, designers are forced to come up with ways of dealing with these unfamiliar concepts, and there is little guidance on dealing with these issues in design (see, e.g. Detweiler et al. 2012).

To date, there is little evidence of specifically labelled VSD approaches being used in the design of AAL/telecare solutions with seniors as participants. Within the domain of designing care robots, for example, a few researchers have recently advocated the use of VSD as a way to deal with ethical issues in the design process. For instance, van Wynsberghe (2013) points out the importance of ‘rigorous ethical reflection to ensure [the robots] design and introduction do not impede the promotion of values and the dignity of patients at such a vulnerable and sensitive time in their lives’. She proposed a care-centred VSD framework. Sharkey and Sharkey (2012) stress the relevance of VSD approaches to handle the specific ethical issues arising due to the embodied and lifelike form of care robots. However, the works are limited to conceptual analysis and do not provide value-sensitive design cases. Such cases are still rare or in a very early stage of development, such as Fitirianie et al. (2013).

Hence, it remains an open research question how to contextualise VSD concepts and methods to an AAL/telecare context and link back to the notion of adaptivity in AAL in light of changing needs and where people might have a choice to adapt privacy levels. Values may mean very different things in different design contexts (for different individuals and also for the same individuals in different situations), as might happen over a longer adoption lifecycle in our reimagined AAL/telecare scenario.

### ***13.6.3 A Situated Elderliness Approach***

Whilst challenges with applying codesign methods and engaging stakeholders in creative activities are general, more specific challenges occur when dealing with senior citizens in codesign contexts. The first challenge is even identifying for whom

we are designing. In codesign processes, designers and future users are carrying out design activities together. As designers we may have an initial idea of who these future users are, but users are never just ‘out there’. People have to be recruited and mobilised to enact the roles of future users and to take on the membership in the ‘group of users’ that the design project enables.

Thus, applying a codesign approach addressing senior citizens creates a number of challenges related to identity, self-image and stigmatisation, when these senior citizens are to consider themselves potential co-designers. Östlund (2005) addresses this issue of stereotyping elderly in her discussion of design paradigms and senior citizens’ ability to handle new technologies (Östlund 2005). When in a lifespan, do people consider themselves ‘elderly’, ‘old’ or as ‘senior citizens’? And what does identification with such labels entail? Experience from codesign-oriented projects (Brandt et al. 2010) indicates that almost nobody among the group of people between 55 and 75 years old identifies themselves as ‘elderly’ or ‘senior citizens’. Rather, they tend to refer to ‘the others’ or even to their own parents. These experiences are in line with Riche and Mackay observing ‘that recruiting proved more difficult than anticipated, in part because people do not appreciate being stigmatized as ‘elderly’ and because they did not see a direct benefit for themselves’ (Riche and Mackay 2010, p. 78).

One methodological strategy to approach recruitment of senior citizens for codesign, whilst avoiding the risk of reproducing existing norms and stereotypes, is the introduction of *situated elderliness* (Brandt et al. 2010), based on the idea that ‘elderliness’ is related to everyday practices and situations of ‘feeling old’ as opposed to ‘being old’, which refer to age as a defining position. The idea of ‘situated elderliness’ is inspired by the concept of *communities of practice* originally coined by Lave and Wenger (1991) and further expanded by Wenger (1998) in the field of work to capture the skills and competencies enacted by people engaged in a professional practice:

In using the term community, we do not imply some primordial culture-sharing entity. We assume that members have different interests, make diverse contributions to activity, and hold varied viewpoints. In our view, participation at multiple levels is entailed in membership in a community of practice. Nor does the term community imply necessarily co-presence, a well-defined, identifiable group, or socially visible boundaries. It does imply participation in an activity system about which participants share understandings what they are doing and what that means in their lives and for their communities. (Lave and Wenger 1991, pp. 97–98)

When expanding this concept to include *everyday practices* outside work, it denotes *communities of everyday practice*, where senior citizens similarly are skilfully enacting everyday practices as seniors (reflecting the notions around adaptivity, selectivity and agency discussed in Sect. 13.3). Gradually, as they get older, they enact what is called *situated elderliness* (Brandt et al. 2010). Situated elderliness refers to specific practices and situations that involve activities that for some reason have become more challenging or perhaps even impossible to carry out. E-banking creates instances of situated elderliness when banks’ new digital solutions create a group of senior citizens considered old as they are not able to

handle their usual bank transactions due to lack of experience using the Internet. In these situations, in a contextual sense, they practice *situated elderliness*, whilst simultaneously being able to handle most other situations in their everyday life. (Interestingly, Vines et al. (2012) identified a similar situated elderliness scenario, using different languages, around the design of digital banking services, and coming up with a digital pen- and paper-based solution through a participatory design process with older people, a solution that would still afford some familiarity and fit into their everyday practices.)

This concept of situated elderliness, and communities of everyday practices, has been used as the basis for rethinking codesign workshops with older people, in particular highlighting the importance of artefacts for accessing lived experiences.

Whilst all people are commonly involved in some creative acts in their lives at some point, becoming co-designers requires a high level of passion and knowledge in a certain domain. Sanders and Westerlund (2011) pointed out that ‘it can be difficult to get people to create ideas when they feel that they have insufficient knowledge and . . . people who are brought into co-designing experiences may feel that they are not creative’. The authors suggest harnessing people’s creativity with ambiguous visual and physical artefacts. Artefacts are not only important to trigger creativity for single participants, but serve as boundary objects supporting communication between participants with different backgrounds. An example is discussed in Case 6.

*Case 6: situated elderliness and everyday practices as a codesign approach*

The SeniorInteraction project (Foverskov and Binder 2011; Brandt et al. 2012; Malmberg and Yndigejn 2013) based on codesign through Living Labs focused on such communities of everyday practices and situated elderliness as an approach to engage senior citizens in design. Rather than introducing technological devices in ideation and early concept development, artefacts and props were introduced as a way to generate a shared language to address lived experience of ageing for further design collaboration.

Social media was made tangible through the design concept of Super Dots. Super Dots was not a conventional prototype, but a carefully crafted set of props aimed at facilitating dialogue on community building among senior citizens at a codesign workshop.

Probing into the everyday life of senior participants was combined with prototyping and scenario building involving both seniors and design researchers as well as public and private service providers. Unlike what is most often the case in user-centred design, prototyping and scenario building had an emphasis not on devices or appliances but on the social media infrastructure and how people establish, relate to and engage different media spaces of this infrastructure.

(continued)

In this project the benefits of working with tangible scaffolding materials like props as a way to engage seniors in codesign based on their lived experience and the idea of situated elderliness were demonstrated. Social infrastructures and technological innovations seem to be more sustainable when grounded in lived experience of seniors' everyday life (Malmborg and Yndigejn 2013).

Across all these codesign approaches is a commitment to foreground the everyday practices of older people as active adapting agents in maintaining a quality of life that is meaningful for them. We recognise however that, in scoping this chapter to focus on the older perspective, there are still many open challenges to consider, in particular about how these approaches would scale up from smaller-scale applications at the early end of our reimagined AAL/telecare adoption path (that is more akin to everyday design, social support and informal peer care) to later on in the care path with whole-system design initiatives (involving formal care providers and diverse organisations) and where whole new models of care might be needed. Work is needed to consider how these approaches could be reinterpreted to engage all stakeholders and more importantly how to address the dependencies and complexities between these and develop the new models of care and infrastructures to support the reimagined AAL/telecare scenario. It is our hope that the methodological approaches presented here, along with the different theoretical approaches to ageing, might stimulate new thinking in these directions.

## 13.7 Conclusion

In this chapter, we have continued with Mort et al.'s (2012) challenge to reimagine AAL/telecare by taking a socio-technical design perspective that foregrounds the everyday life practices of people as they adapt to getting older. In so doing, we have provided a review of a specific domain, that of the elderly, which instantiates and evidences many of the conceptual, theoretical and methodological challenges reported in this book. Specifically, we have framed (as to Cabitza and Simone, Chap. 11) the discussion around challenges to the heroic modernist conception of the design process. We have suggested that the mixed reports on experiences with AAL/telecare to date, particularly around challenges of adoption, give cause to stop and reconceptualise when and how AAL/telecare is designed to be used. The foundation for this shift was taking a positive developmental approach to ageing and understanding the importance of agency, adaptivity and reciprocity as key elements of health and well-being for older people. We proposed that the devices and sensors of an AAL/telecare solution could be better thought of as an *infrastructure to be repurposed along a care spectrum, starting with active self-care and peer care and being adapted to the needs of formal care if and when care arises*.

The value of this approach is that it motivates uses of such technologies from a person-centred perspective, e.g. addressing social needs and providing opportunities to make meaningful contributions. At the same time, it provides nonthreatening opportunities for the person to develop expertise and competence with the technologies and empower them to actively engage in discussions of if and how these technologies are used in care and by whom. We gave examples to illustrate different uses for core sensing and communications infrastructures in this regard and also highlighted technical and methodological challenges that will need to be addressed to realise this scenario.

We have scoped this discussion deliberately around the perspectives of the older person. A challenge still remains though about how such an approach can gain broader acceptance within governmental and funding agencies, where modernist and change management discourses are more likely to dominate. Humanist and modernist approaches can, and indeed need to, coexist if this reimagined AAL/telecare is to be practically realised across the full adoption path. In particular, the same theoretical conceptualisations can be reinterpreted for all care providers and engaged stakeholders: as active agents, whose everyday practices and lived experiences matter and where codesign approaches can be used to find solutions to address these practices. We propose that it is critical to embrace this reimagining and its broader implications to properly address the challenges around adoption and delivering quality of life to the individual, not just cost savings to the system.

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