Ethics of passive wellbeing monitoring and focus group report

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ETHICS OF PASSIVE WELLBEING MONITORING AND FOCUS GROUP REPORT

EXECUTIVE SUMMARY

The following report was commissioned by Kemuri Ltd (with funding obtained by Innovate UK) to gain insight on the ethics of passive monitoring in the home, and the ethics of sharing monitoring data to others. The report provides an overview of academic literature on the ethical considerations of using passive remote monitoring devices in the home to support older adults with cognitive and physical impairment, such as dementia. A systematic review of the literature was conducted, with a total of 106 papers meeting the inclusion criteria. These included three existing literature reviews, which used related, though not identical, search criteria. These are discussed separately in this report. The source papers were coded and organised into associated categories and are presented in this report according to frequency of occurrence, and the key aspects of these issues are discussed. Since most sources used in this review describe a number of ethical issues relevant to their concerns (perhaps because they are conducting a review), they often reference other academic sources. Due to the limited scope of this review, we have not sought to map these or reference all sources provided in each instance. Where there are particular issues raised and a particular source is relevant to the discussion, the reference is provided.

The ethical review concludes by summarising how this literature might apply to the particular affordances of the Kemurisense® monitor. Whilst issues of obtrusiveness (in the home and on the person) experienced by users of assistive living technologies are minimised by its location within a mundane common household fitting, the passive and 'always on' nature of the device may generate concerns about continued informed consent. The use of smartphone technology as the alert and monitoring tool raises issues of data security, as data enables access in public spaces (perhaps in the presence of other family members, friends and neighbours), which is outside the control of the observed person. The representation of the observed person in graphical form on a smartphone interface raises ethical issues about the potential for diminished sense of self in the remote caring experience, and may potentially lead to stigmatisation of the observed person. In addition, the constant availability of regular data has a number of potential consequences. The carer may experience a sense of greater responsibility (and indeed liability) because of their greater access to knowledge of indicators of wellbeing of the observed person. The carer, with regular access to data, especially if indicating positive data, may result in reduced face-to-face or telephone communication with the person they care for. The literature also points to ethical concerns about greater risk of increased social isolation. However, as most of the academic literature points out, there is a degree of caution needed to avoid over-emphasis of these potential harms relating to particular devices over others, and these concerns should be balanced against the likelihood of improved outcomes.

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INTRODUCTION

Ageing Society

People across the globe are living longer. According to World Health Organisation statistics, (WHO, 2014), this increased longevity is the result of improvements in the treatment of non-communicable disease (such as heart disease) and declining tobacco use in high income countries. In low income countries, infectious diseases and related conditions still cause the majority of deaths (70%), however trends suggest that over 100 countries are transitioning to the high-income country profile. One of the consequences of increased longevity, particularly in high-income countries, is the prevalence of the oldest old (aged 85 and over). In the UK, for example, there are over 500,000 people over 90 years old, and over 13,000 over 100 years old (ONS, 2014). Rising life expectancy is a significant achievement, presenting both opportunities and challenges. An ageing population can contribute to the global economy in terms of their contribution to productivity and in the consumption of products and services, adding substantially to economic growth.

Ageing and health

As the population ages, people face increased risks of spending many more years in physical and cognitive decline. These risks are not based solely on one's genetic predispositions to particular diseases, but can be contingent upon a number of factors, decisions and behaviours made throughout adulthood: eating and drinking habits; living conditions; medical interventions; work histories and so on (Parr 2003; Andrews et al 2006; Bowlby et al 2010).

Caring for Older People at Home

As longevity increased the risks of chronic ill health in later life, there has been a concern to support people to stay in their own homes for longer as formal options become stretched. The expansion of community services and domiciliary home-care poses a continuing challenge in terms of the costs of personal care and the shortage of good quality provision - exacerbated by a reluctance of many people to plan and save for social care costs in old age and a reluctance by political parties to increase taxation to cover the increased demand for increased social care requirements. Greater reliance on informal caring by family members has followed as a result. This has expanded the market for privately-funded self and family managed care support.

Carers draw upon moral rationalities in establishing the 'right thing to do' (Duncan and Edwards 1999, 2003). This can reflect divergent social and cultural moral values, depending upon one's aspirations and fears, and with a concern to avoid the moral censure of one's peers. These can be explicitly articulated and discussed with others or can take the form of 'internal conversations' (Archer 2000) in which we seek to reconcile our concerns and dilemmas with our given circumstances. These internal conversations act as commentaries on our human concerns and help forge our sense of self and our moral position. We seek to construct coherent narratives for our actions and justifications in terms of improved outcomes. Carers of older people can hold anxieties about how best to ensure the safety of the care-receiver whilst at home; which care provider to choose; whether assistive living technologies are appropriate; and if and when residential care is required. At the heart of these concerns is the position of responsibility they have assumed or have accepted, the risks to the older person in terms of their health and mental wellbeing, and the reflection of their situation upon their role as spouse, daughter, and son and so on. These are important as they shape the willingness of carers to engage with various support options.

Pragmatic reasons can inform which options are chosen. For example, Baxter et al (2008) found that people stayed with familiar care agencies because of an unwillingness to take risks, even when accepted measures of quality positioned their choice as inferior. Moral considerations of the right thing to do interleave with practical constraints to a produce a 'good enough' fit, often arrived at to allow some flexibility. If tensions emerge in an individual's life, such as might occur when juggling competing priorities (such as work and care responsibilities) which disrupt existing care routines and practices, failure to resolve these adequately (according to our value systems, expectations and practical abilities) can induce a psychological state known as 'cognitive dissonance' (Festinger 1957). Guilt and stress can result from circumstances in which our goals become misaligned with our expectations and abilities, and when we are unable to reconcile competing demands on our time.

Self-care and assistive living technologies

In order to accommodate the changing age structure of our population and the increased desire to stay at home for longer (even to the end of life), new or modified inclusive products and services are needed to meet the wider variation of needs and aspirations in the older population. Therefore, there is a growing business case for assistive technologies which can support older people to live a meaningful and enjoyable life at home for as long as possible. ICTs can offer significant help to older people who wish to live well at home, and help carers to detect changes in behaviour and decline in capacity. Where physical presence in caring contexts is limited for a number of reasons, technological solutions can replace, supplement or help to coordinate existing care provision, and provide round the clock reassurance for family carers of older people in need of support. They collectively address a number of concerns, such as: reducing risks of accidents in the home or providing alerts when they occur; hypothermia; poor eating and drinking; wandering outside or not engaging in other health and wellbeing critical activities. The variety of products available on the market gives scope to adapt to changing needs and circumstances.

However, whether these technologies form a comprehensive system, or a set of individual solutions for specific concerns, they may face a number of barriers to uptake, practical as well as ethical. In the UK, the 2013 HM Government report 'Supporting Working Carers: the benefits to family, business and the economy' cites research showing that working carers are largely unaware of assistive technologies or how make choices in the current market.

They also suggested that carer perceptions of technology can initially be negative. They suggest that advice and recommendations from trusted sources can increase their confidence (Carers UK for DAP Connect 2013).

In the specific domain of technologies to support people living with dementia, the 'Dementia-Friendly Technology Charter' contained within the UK Prime Minister's Challenge recommends finding solutions that work within existing personal routines, which will help minimise disruptions. In relation to the ethical issues arising from the use of assistive technologies, the charter advises avoiding unintentional harm, respect for privacy and confidentiality and ensuring data security. They note the Mental Capacity Act (2005) which provides a legal framework for keeping the person with dementia at the centre of decisions. If a person lacks capacity to consent, those making a decision on their behalf must do so on the basis that it is in the person's best interests and previous wishes. The charter recommends an annual review of any technology solution to account for changes in needs and circumstances. The Charter is keen to note that technological solutions can only be effective when combined with good care, and should not be about replacing human contact or restricting independence. Good care can be enhanced if technology can support family carers to maintain the wellbeing of a person with dementia.

Kemuri Device

SME's such as Kemuri® are seeking to enter this marketplace, bringing potential solutions for older people who wish to stay in their own home for as long as possible in safety. Kemuri has recognised an opportunity to develop a product and service which provides additional information to remote and working carers of older people who require assistance to live well at home. The Kemurisense® device is intended as a solution to support working and remote carers who are looking for reassurance that their loved ones are safe and comfortable in their absence. The device is intended to support carers of people with assisted living needs (e.g. people living alone who have cognitive or physical impairment) by providing regular access to data concerning the wellbeing of the person they care for when they are not with them.

LITERATURE REVIEW METHOD

The purpose of the literature review is to identify issues in academic literature which relate to ethical considerations of assisted living technologies. The review does not seek to evaluate the validity of the assertions or concerns contained within this literature, or assess their relevance to the Kemuri device. The second element of the report includes user feedback following a product demonstration and focus group discussion which was intended to reflect on ethical considerations and inform the next iteration of the device.

The search terms used were: (1) “ethics” AND “ambient assisted living”; (2) “ethics” AND “passive monitoring”; (3) “ethics” AND “assistive technology” AND “home”; and “ethics” AND “remote” and “technology”. The following databases were used to compile relevant literature:

Source	Passive monitoring home	Ethics ambient assisted living	Ethics passive monitoring	Ethics assistive technology home	Ethics remote technology
PubMed/Medline	156	3	16	3	26
Web of Science	212	4	4	2	17
Science Direct	123	19	30	218	
Scopus	619	6	2	20	
Total	1,110	32	52	243	43
					1,480

Table 1: Search strategy

The number of hits (including overlaps and duplications) was 1,480. The relevance of the results were assessed manually according to information derived from title content. Most records were excluded as not relevant to the search. Ten sources were added from manual searching from within the reference lists of the collected sources, and from a search of well-known authors in the field. A variety of types of records were evident in the search results, including journal articles, chapters of books and reports. The important distinctions are between those which systematically review the literature (Novitsky et al 2014; Niemeijer et al 2010; Zwijsen et al 2011); think pieces on the ethics of technology (Mahoney et al 2007; Milligan et al 2011); and papers which refer to ethical issues emerging in empirical studies (Essén 2008; Berridge 2014; Chaaraoui et al 2014). The sources emerged from sub-disciplines including: psychiatry; medicine; gerontology; science and technology; nursing; human computer interaction; biomedicine; engineering; informatics; social science of medicine; and law. Most were written in English, two in French and one German. The sources date from 1988 to 2015, with most sources published after 2009.

In total, there were 106 relevant sources included in this literature review. The first stage of the review involved reviewing the abstracts of the 106 records to identify their topic focus, noting headings or sections which provided more detail on the content of their ethical discussion. From these, 27 of the most relevant sources (which were identified from the initial reading of the 106 abstracts) were read in full to derive more in-depth understanding of the issues (see Appendix A).

Frequency of Occurrence

We recorded the number of times the identified ethical issues were discussed across the 106 sources. Some issues were closely related, with some variation in description but dealing with the same or similar issues. These were combined to form umbrella sub-headings, however a full list is available in Appendix B. There were 12 codes (comprising 105 sub-codes) derived from the 27 academic sources. The most prevalent codes were: autonomy (42 sub-code occurrences); care relations (40); efficacy (34); personhood (22); privacy (21); balancing risks and benefits (19); (un)obtrusiveness (18); ethical models (13); home (12) and use of data (12).

Note on terminology

Ethics – defining the term ethics can be complex. There is an entire sub-discipline devoted to considering its features and applications. Broadly understood, ethics relate to our moral concerns, our weighing up of right or wrong, good or bad. From our ethical deliberations (private and dialogic), we develop our codes of behaviour for use in everyday life. The Collins dictionary defines ethics as ‘the moral fitness of a decision, course of action’.

Assistive Living Technology – there are a number of potential terms that could be used to describe the Kemurisense® device, and from which to construct a suitable literature search. The search terms identified above were used because of their general application (especially ‘assistive technology’ and ‘ambient assisted living’). Together with the search terms ‘home’ and ‘ethics’, it was hoped this would identify a broad range of literatures discussing a number of cognate technologies. The term ‘passive monitoring’ was included to include literature which might specifically deal with the affordances offered by the Kemurisense® device.

Users - There is considerable variation in the literature on descriptions of users and other stakeholders. For the purposes of this review we describe the observed person (the older person) as the ‘older person’, the ‘observed person’ or ‘monitored’ person; and the observer (the carer) as the ‘observer’ or ‘carer’. Other stakeholders include product developers, engineers, researchers, designers, technicians and installers, who we collectively refer to as ‘product developers’ where appropriate unless a more specific label is required for clarity.

Existing literature reviews

The search results included three systematic literature reviews. Because the scope and terms of these literature reviews were somewhat different our own, we have not simply added the list of topics they identify into this review. However, they are highly pertinent to aid understanding of the issues and so we return to them later in the report.

The first was compiled by Niemeijer et al (2010) titled “Ethics and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: an overview of the literature”. The review is focused on residential care settings, and therefore the issues identified may not be entirely relevant to home-care contexts. In addition, the review includes discussion of the practical concerns of surveillance technologies rather than a focus on ethical concerns alone. However, as we have stated, practical concerns can highlight ethical judgements and vice versa, around the concept of acceptability. Niemeijer et al organised their review around: institutional aims (identified as functional efficacy; safety/risk and staff burden) care relations (including duty of care v autonomy; person-centred care; substitution of care) and resident concerns (freedom and consent; privacy; and dignity/stigma). In conducting their review using their selected search terms, they found that it was necessary to go beyond these to retrieve relevant articles by citation tracking, for example. However, they noted that if they had included additional search terms, this would have added to the inclusion of irrelevant articles. They suggest that the variety of terms used to describe the range of technologies available within different settings has contributed to the difficulty of conducting a comprehensive review easily.

The second was compiled by Zwijsen et al (2011) ‘Ethics of using assistive technology in the care of community-dwelling elderly people: an overview of the literature’. They organised the review around three main themes: personal living environment, (with sub-themes of privacy, autonomy and obtrusiveness); the outside world (with sub-themes of stigma and human contact) and the design of devices (including individual approach, affordability and safety).

The third literature review by Novitsky et al (2014) was organised around three key phases of product development: research and development; clinical trials and clinical applications. They identified the key stakeholders whose perspectives should be taken into account when considering the ethics of such ALT’s. These include people with dementia; formal and informal care-givers; researchers and clinicians; software/hardware engineers; and designers and technicians. Using an ethical analysis matrix established by Mepham (2008) they developed a checklist of concerns, or an ‘ethical map’ based on a set of principles such as wellbeing, autonomy and fairness. This checklist was then rated for importance, and an analysis undertaken to identify the distribution of existing literature across these elements.

LITERATURE REVIEW RESULTS

This section presents the ethical issues raised within the 106 sources contained within the literature search derived from the terms outlined above. They are organised according to personal and social considerations of ethics and remote sensing technology at home use: citizenship and personhood; representations and experiences of home; inter-personal relations and data security. Many of the discussion points raised below could fit more than one category, for example perceived obtrusiveness can impact upon stigma, the loss of privacy could be regarded as reduced autonomy and so on. In order to avoid repetition, literature has been reviewed where it most closely aligns with the subject heading, pointing to areas of cross-over.

Changing care relations

The most commonly occurring ethical concern evident in the literature search related to the effect of assistive living technologies on caring roles, relations and practices. Care is defined by the Oxford English Dictionary as: ‘the provision of what is necessary for the welfare and protection of someone or something’ and ‘serious attention or consideration applied to avoid damage, risk, or error’. Care has been described as both material caring for, and emotional caring about (Milligan and Wiles 2010). These definitions suggest care is regarded as an all-embracing willingness to provide assistance in order to avoid harm.

There have been long debates in care literature about the meaning of care practices. Whilst they are beyond the scope of this literature review and rarely discussed in ALT literature, they are important for alerting us to the significance of alterations to caring practice and its impact on family roles and relations. A key debate focuses on when we can know whether care (or good care) has been successfully provided, or whether it is sufficient that the intention is appropriate. However, this positions privileges carer perspectives and renders the care-recipient into a passive role. Kittay (2011) favours an evaluation of the achievement of care by focusing on care-receivers’ ‘gracious’ acceptance and acknowledgement. This places similar issues in marginalising the role of care-givers in what is a relational process. An alternative approach is to focus on outcomes, but this is difficult to measure in the face of degenerative health conditions. Good outcomes may occur even when the care offer is sub-optimal, and alternatively, a carer may not succeed in improving circumstances despite best efforts. One might conclude that care is more likely when care is given in good faith, received graciously, and has produced positive outcomes. By regarding care as negotiated relational process, we can observe that care emerges in practice as a ‘good enough’ approximation of these ideals (Simon 1957; Duncan and Edwards 1999; Deacon and Williams 2004).

The adoption and enrolment of new technologies within a ‘circle of care’ can reframe what ‘counts’ as care, or how we assess what is ‘good enough’ care. A key concern was the ability of assistive living technologies to replace human proximity and care as remote caring is facilitated (Sparrow and Sparrow 2006). A key ethical consideration is the impact on family relations. The use of technologies in the home are usually accompanied by a 'safety net' of care givers and responsible people, which mitigate the effects of technology failure. The technologies are not merely additional aspects of a circle of care – they can materially influence the way other members of this circle of support relate to each other and to the cared-for-person. As argued by Mahoney et al, '*protocols for monitoring systems must be developed with acute sensitivity to how family relationships will be affected in the home and other family environments' (2007:220).*

The ethical responsibility and legal liability placed upon informal carers was also discussed. Caregivers may develop additional concerns about the risks to the older person when relying on technology to inform them of potential risk, and also their possible misuse or misreading of the technology or data, which could leave them vulnerable to moral and/or legal censure (Kosta et al 2010).

There is an impact on the way ALTs can alter the way an older person is represented (discussed later in the report), so that they become (in part) data to be 'read' rather than as a person to engage with. This clearly has a potential consequence for the experience of giving and receiving care. Reading a person's data can transform the notion of the person in the mind of the carer to a disembodied set of indicators that can be monitored from a distance. This could be produce an 'objectification' of the older person by users of the technology (Sharkey and Sharkey, 2012). A representational issue for carers themselves was raised by Vallor (2011) who noted that in assistive living technology discourse, care is usually represented as a burden to be solved, thereby diminishing the value of care-giving itself.

The literature raised issues relating to surveillance, privacy and control (discussed below) that may impact upon persons visiting the home, such as paid domiciliary care-workers. There was a concern that technologies which monitor activities of daily life in the home can be used to impose greater controls on the care workforce through the increased potential to time activities, check compliance to particular tasks and so on. The introduction of these technologies can therefore have unintended consequences for the social relations between paid care-workers and family carers and the cared-for person.

Privacy and Surveillance

One of the questions we may ask is whether surveillance in the home by family members carries more or less ethical dilemmas around protection and control that may be found in residential care contexts. The conceptual frameworks surrounding the term surveillance identify it as a problematic activity. Often used in relation to the surveillance of public space by government agencies, concerns have arisen about 'panopticon' or 'Big Brother' technologies that remove some of the privacies of the individual in order to protect public order and generate social conformity (Foucault 1975; Orwell 1949).

The pervasiveness of ALT's challenges personal privacy. However, whilst the intention and the act of watching and listening may be the same, the context of surveillance in the home is arguably different to monitoring by private or state agencies. On the one hand, more alarming as remote watching moves into ever-more intimate and private spaces, but on the other, less alarming as more akin to watching and listening as a form of care, since the observer may already possess intimate knowledge of the observed person's everyday routines and practices at home. There is a grey middle ground when surveillance takes place in care homes, as not-quite home and not-quite public space; not quite-intimate knower and not-quite stranger.

Literature on the use of surveillance technologies in care home settings suggest that management and care-workers attempt to strike a balance between autonomy and safety of residents, often putting safety as a priority because of their duty of care. They can often display less tolerance of risk than family carers owing to the fear of litigation. However, family attitudes to risk within care settings may be different to those within a person's own home, especially if they are not co-resident. Much of the literature on the ethics of assistive technologies in a person's own home is understandably approached from the perspective of the 'surveilled' person. However, the literature points a need to consider the feelings of family carers, who are also potential beneficiaries of the assistive technology (in reducing stress and anxiety when away from the home).

A related issue to the act of surveillance is the form this surveillance takes. Technologies which passively monitor potentially overcome issues of obtrusiveness of some ALT's, which is regarded as potentially detrimental to personal identity. However, unobtrusive and/or passive monitoring devices can raise further issues around personal autonomy. Vines et al (2013) suggest passive monitoring can lead to the observed person being disempowered as they do not know how and when the device is working:

> *"Some participants felt the general lack of presence the technology had in their home was problematic. None of the sensors had any visual or audible alerts that signalled when they were activated or not, which confused some of the participants during the study: "… if you go into all the other rooms you don't know whether it's registering or not because you go into the bedroom"* (2013:613).

Autonomy

One of the key anticipated benefits of ALT's from a carer perspective is the possibility for continuous monitoring (Darwish and Hassanien 2011). This raises an issue for autonomy. It is important to note that the fear of dependence and the possibilities for independence in later life are perhaps over-stated. There are a series of reciprocal dependencies occurring across the life-course (Remmers 2010) which continue into old age. Furthermore, as Remmers points out, within contemporary western society there has been an increasing if gradual reliance on technologies that could be perceived as dependence. Therefore, to situate technological dependence in later life may not raise the same type of objections than may have arisen in the past.

One element of autonomy that has been raised is around control of the technologies. This could be related to adoption of the technology in the first instance (Kosta et al, 2010) and the level of day-to-day control an older person has - in being able to discontinue use or disconnect the system, and in having the potential to raise an alarm (or at least be informed that an alarm triggered by sensor technologies has been activated.

There are also external factors in the political economy of ALT's that should be taken into account. Novitsky et al (2015) contends that we do not know how the use of ALT's may be shaped in future by the requirements and demands of health insurance companies, or whether an older person or their proxy may have the right to refuse such technologies.

Efficacy

While it is not the purpose of this literature review to deal with questions of efficacy, it was notable how the assistive technology literature itself focused on these questions. As referred to in the notes on terminology, in the case of assisted living technologies for older adults, efficacy can relate strongly to questions of ethics, since carers often make ethical judgements about their caring role in relation to whether or not their practices (or the support they have enrolled) succeeds in achieving positive outcomes.

Part of the concern for efficacy related to the reliability of the technology, and the need for upkeep. Overly complex technology or the need to frequently change batteries and components, or regular requirement to reset systems was felt to generate a burden on caring practice which may not be sustained.

An efficacy issue that was raised related to the number of prompts or alarms that may be received. Too many prompts may lead to fatigue and a lack of attention in the event of a real need to respond (van Hoof et al, 2011). The literature also points to a concern that too many data points may prove less effective as they would be distracting and onerous to review regularly. At the same time, over-reliance on prompts and alarms to indicate problems can be problematic in the event of loss of communications/power and web access, for example. As Greenhalgh noted in relation to acceptance of ALT by carers:

> *"They served, at best, to provide objective information (biometric data, emergency alerts) to health and/or social care providers. But they did not improve the lived experience of impairment. Indeed, they were not designed to do so but therein may lie one explanation for their limited uptake and use"* (Greenhalgh et al 2013:91).

Efficacy issues could relate to difficulties older people may have with the hardware, user interface (such as screen size, height etc.) and data interpretation. Passive monitoring by care-givers which require no action by the older person themselves overcomes these issues to some extent, however, it should be remembered that many care-givers are older people with health conditions of their own.

Over-claiming benefits was seen to generate risks to the care receiver if this led to an over-reliance on the technology by care-givers. For example, Mahoney (2007) suggests avoiding language which implies the technology "wakes up" or "provides assistance" to an older person should be avoided if it does not do so.

Doing harm: stigma and issues of representation

There is a concern in the literature that ALT should not lead to harm to the user. Darwish and Hassanien (2011) consider the effect of ALTs on the mobility of user, while others have focused on their capacity to reduce regular social contact (Sparrow and Sparrow 2006; Van Hoof et al 2011). Van Hoof et al (2011) found that use of video-telephony did not always lead to reduced feelings of loneliness or increased social contact, and argue there is a need to be aware of the social context of users.

The growing prevalence of consumer technologies carried about (and even within) the person and at home has led to new perceptions of the human body as mediated through technologies. Some of these technologies attract positive associations with modernity and youthfulness, whilst others attract negative associations with ageing and dependency. Negative associations can be resisted in the design process to position the technology as an attractive offer, such as the introduction of more creative wearable technologies.

The obtrusiveness of ALT's are arguably stigmatising because they provide visible reminders of the dependent status of older people at home. However, as Zweisjen et al (2011) argue, the term 'obtrusiveness' is commonly used when referring to the ethics of ALT's in academic literature. They note that the term is rarely described in detail, and is often used as a container for a set of other undefined concerns.

It is not simply in the design of ALT devices that one might anticipate stigmatising effects. Stigma can occur at the point of installation, for example, in the user guidance language and instructions, and when interacting with installation engineers - issues which may be overlooked (Mahoney 2007). Furthermore, Greenhalgh et al (2013) suggests the 'informationally represented' person may be rendered 'less human' because of the increased focus on metrics and the flow of information, rather than on lived experience. Furthermore, leakage of personal health indicators could attract stigma and could lead to embarrassment or other harms to the user of the system (Sixsmith and Sixsmith 2008; Wright and McCarthy 2010). This is made more likely when mobile technologies are used to access data. Smartphones able to access data in public spaces, perhaps in front of others (without the knowledge or consent of the care-receiver) can lead to sharing of delicate personal information.

> *…"illness experiences and assisted living needs of older people are diverse and unique, hence do not lend themselves to simple or standardised technological solutions. Participants managed their health conditions subjectively and experientially, appropriating or adapting technologies so as to enhance their capacity to sense and act on their world"* (Greenhalgh et al, 2013:92)

Use of Data

Related to issues of privacy raised earlier, trust in the conveyance of private data is a key consideration. Assistive living technologies aim to protect the dignity and safety of people so that they can live in their own homes for longer by maintaining capacities. They can support social inclusion and helping care-givers with prevention and monitoring (Novitsky 2014:709).

Where data can be accessed using mobile technologies, this can increase convenience and affordability. However, it also raises issues of data security, with the potential for unintended consequences if third parties access this data.

The range of individuals and organisations who are involved in installation and management of ALT's is worth noting, such as internet providers, heating suppliers, mobile phone companies etc. (Hoffman et al 2012, van Hoof et al 2011). The influence these external organisations have to the functioning of the device is crucial to account for – unexpected loss of service could have tragic consequences for someone using a health-logging sensors. Another issue raised within the data was a concern about how the data was stored of and disposed. A lack of understanding by the end user may lead to a failure to properly take account of the risks involved.

Informed Consent and Refusal

One of the ethical concerns emerging from the literature related to the capacity of the users of the system to give informed consent. In addition, there are consent issues for other inhabitants or visitors to the home. As older people may have cognitive impairments which restrict their capacity to understand and decisions without support. Ensuring people living with dementia are in a position to give informed consent to the deployment of assistive technologies in the home can be difficult to achieve in practice, and may require ongoing negotiation. This is because there is a need to comprehend often quite complex technical information about how the device works and a need to retain this information to reach a decision about its application to support their wellbeing at home. For people with fluctuating mental capacity, it is important that discussions reflect the wishes a person may have expressed while they still had capacity. People with dementia have a particular vulnerability regarding informed consent (Novitsky et al, 2014). There may be challenges particularly in later stages of dementia in terms of decision-making, and may require carers to act as a proxy. A key consideration is determining who is making the decision to purchase the system (Gammon and Christiansen 2009). It may be that carer's will take these decisions on an older person's behalf as the technology provides peace of mind for them, rather than to provide direct benefits for the observed person. It may be that multiple consents should be in place (particularly in research contexts), including the older person, their family care-giver or legal guardian and professional care-givers (if their data is to be shared with other parties).

> "*We need to find ways to meaningfully categorise monitoring options, moral issues and stakeholders on a level that is sufficiently general to remain relevant over time, but at the same time sufficiently specific to be useful for stakeholders in their given circumstances*" (Gammon and Christiansen 2009:427)

Altering the sense of home

In policy as well as public discourse, the most desirable site for providing care for older people is the home. The promotion of community-based options coincides with media stories and word-of-mouth accounts which raise awareness of bad practice, abuse and neglect within residential care. Failing to enable an older person to stay at home may generate distress and unhappiness for carers as evidence of failure. This concern may exerts pressure to cope and disguise difficulties or discontent, in order to secure the social expectation to enable an older person to stay at home, seen as the place most likely to secure contentment.

Unpicking assumptions that being in one's own home is necessarily more desirable prompts questions about its connection with the current policy agenda. Gott et al (2004) in their empirical research on preferences for home as opposed to hospital as a site for end of life care, suggest the characteristics of these sites should not to be taken for granted, since they are dependent on how practices, spaces and experiences are constructed within them, and the way these enable or constrain agency and choice. This point could be made concerning the preference of home-based care more generally. Over-emphasising the value of home-based care over care homes may be counter-productive, as negative discourses and scare stories may overshadow the benefits of residential care, and trivialise the profound difficulties and compromises involved in caring for older people at home.

The presence of ALT's can challenge the symbolic meaning of home as a place of safety, privacy and comfort (Dekkers 2009). These symbolic meanings can be diminished by effectively 'bringing the hospital home' (Arras 1995). The medicalisation of the home (by increasingly moving health services into the home) aided by the introduction of technology is regarded as an ethical question (Homer et al 2009; Chdzambwa et al 2013). However, unlike literature surrounding the medicalisation of the home-space, the discourses surrounding the notion of a 'smart-home' do not carry the same negative connotations.

Other issues

Distributional fairness could pose a potential ethical issue that should be considered by researchers and developers of assistive living technologies. Where there is scarcity of resources, consideration should be given to who is able to benefit, and who is excluded from these technologies. These devices can potentially extend access to good quality care where it was not previously possible (Walsh and Callan 2011) but issues of affordability and familiarity with using such technologies can negatively impact on distributional fairness.

Another issue raised concerns the use of ALT's in research. These issues include ensuring older people and families are aware that the researched technologies may not be available beyond the terms of the research participation. Furthermore, additional safeguards need to be put in place to ensure that there is adequate back-up, especially if the research is intended to test the efficacy or reliability of the device. Research participants may attach more trust and reliance than the device warrants at its stage in development (Mahoney 2007:224).

SUMMARY OF ETHICAL INSIGHTS FOR KEMURISENSE®

Many of the sources utilised within this review suggest that within the larger body of research literature on ALT's tend to focus on the perceived benefits and questions of user acceptance and functional efficacy. Some of the sources drawn upon in this review are perhaps best understood as purposeful responses to the inattention to these issues in the wider body of literature. They claim they can support better care; more comprehensive care; more affordable care compared to personal support; and could support greater independence and autonomy which would enable older people to stay at home for longer. It is argued by Mahoney et al (2007) that this positive stance counters a perceived negative technology bias in wider society, and among peer-reviewers in particular. Therefore, the papers used within this literature review do not represent the common level of ethical discussion in assistive living technology academic literature. The ethical challenges identified in the sources used reflect research and development across a range of products and services, with variations in the needs and circumstances of users. Common to all sources was a view that the fear of doing harm was at the heart of ethical concerns, and this underpinned each of the elements and discussion points posed.

As this review has shown, ethical questions can rarely be abstracted from questions of practical use. The distinction between user acceptance and ethics of using a certain technology can be blurred in the literature as one aspect can sometimes have implications for the other, and vice versa. Indeed, there are some umbrella terms that 'flag' the association to questions of ethics, such as 'surveillance' as they have a conceptual framework around state/police interference in the public realm, and increasingly into ever-more private aspects of our lives which are perhaps less relevant than first imagined. We may wish to reflect whether the types of discussions embarked upon in relation to technological interventions at home are in fact ethical issues. In many instances, what is actually being discussed are the psychosocial impacts, functional efficacy questions or use acceptance issues of introducing technologies in the home. For example, psychosocial impacts are often framed as ethical questions according to the value judgements of the author if they view these negatively. At the same time, functional efficacy questions (such as the reliability of the device) take on an ethical dimension which influences whether the observer and observed trust the system and feels safe changing their usual care routine as a result. Therefore, reliability is not an ethical issue as such, but it points to the ethics of substituting care responsibility.

The general insights contained in the existing literature reviews mentioned above, and the sources obtained for this review are useful as they can help to position Kemurisense® within the ethical landscape of assistive technologies more broadly. Some of the ethical challenges raised in the literature are not obviously applicable to the device because they have been intentionally taken into account during conceptual development. Such issues include the stigmatising effects of wearable devices, or of unsightly 'medicalised' devices in the home.

The ordinariness of the Kemurisense® mitigates against these concerns by blending into the background of everyday life. However, new ethical issues about control and refusal emerge because of the passivity and invisibility of technology which is embedded into everyday objects.

The developments in mobile smartphone technologies raises additional questions about data protection and anonymity. The ability to access data on a vulnerable person from any number of locations and situations means that those who access this information bear additional responsibilities for ensuring the data is protected from observation or collection by third parties, from theft of the device and so on.

Most of the literature used within this review employed methodologies to elicit the views of older people and/or their carers about using ALT's at home, and the ethical issues that emerge from their considerations. Some of these accounts point to a next step for exploring the ethical as well as the acceptance issues of ambient assistive technologies. Home tour studies allow researchers to gather in-situ understandings of the key issues for the various stakeholders involved. This is likely to be a useful next step for exploring the ethics and efficacy of the Kemurisense® device. Another possibility would be to undertake study of mobile phone use which could explore where, when, and how access to the Kemurisense® data occurs; and the impact this has on the care-givers and care-receivers in context.

INTRODUCTION TO VOICENORTH FOCUS GROUP

The second part of the report provides an overview of the main findings of a focus group discussion with carers of older people with assistive living needs. This focus group was conducted by the Dementia Innovation Hub at the Centre for Ageing and Vitality, Newcastle University and commissioned by Kemuri Ltd. The purpose was to explore issues relating to use of the device as a means of supporting older people with assisted living needs to remain in their own home. An important aim of the focus group was to understand carer experiences, particularly carers who are not always proximate to the person they care for (because of geographical distance to where they live, or because of work and other commitments). The parallel aim of the focus group was to obtain the perspectives of carers on the use of assisted living technologies, and an exploration of the potential of the Kemurisense device to offer additional reassurances.

Methodology

Focus groups are contrived settings for exploring attitudes and experiences since they are not often collected in natural settings. Morgan and Spanish (1984:260) have provided a useful synopsis of the strengths and limitations of the focus group as a method in consumer research. The strengths derived from those found in other qualitative methods: they allow insight into interaction between people in similar or different circumstances. They allow access to content about the attitudes and experiences of people from particular sub-sets of the population, or from particular interest groups. Focus groups provide a compromise which affords some of the benefits of participant observation with some the benefits of face-to-face interviewing. This method can be useful in initial research stages to validate the participants' perspectives on a given topic, concept or product (Threlfall 1999).

The focus group was undertaken on Saturday 12th September on university premises in a large meeting room, which was set out conference style. Focus group participants were recruited from members of VOICENorth, which is an organisation providing a means to engage with a wide, representative range of people and their communities and to consult with them on key issues around ageing and demographic change. Coordinated by the Newcastle Initiative on Changing Age at Newcastle University, VOICENorth provides real opportunities for lay people to become involved to help to shape future research and policy-making.

Twelve focus group participants were selected to represent the kinds of people who may access the services and products that Kemuri Ltd is developing. All participants lived in the North East and were predominately from the Tyne and Wear and Northumberland sub-regions. The panel included an equal number of men and women, with most participants aged between 65 and 75 years.

The focus group was audio recorded using a digital transcription device. It was conducted over four hours, including a lunch break. Twelve participants took part in the focus group, however, for small group discussions, this larger group was split into three groups of four. Paper and post-it notes were supplied to assist note-taking, and each sub-group was asked to feed back to the larger group after each activity. The facilitator noted down the key points emerging from each of the activities, and retained the participant notes for further reflection on the key points. The data includes the summative points raised in a focus group with carers of people with assisted living needs, and draws upon facilitator notes, audio recording and paper notes by participants.

Structure

The first part of the session was spent understanding carer experiences of supporting a person with assisted living needs. Following a demonstration of the Kemuri device, the second part of the session focused on issues that emerged from the demonstration, taking into account participants' responses to the device, design issues and marketing considerations. Participants were asked to share their ideas and experiences with the facilitator in the presence of a representative of Kemuri Ltd. Participation involved three activities:

- a discussion about participant's caring experiences
- a demonstration of the device and associated service
- an opportunity to respond to questions intended to generate ideas for improvements to the prototype and service offer

These three activities were designed to provide answers to the following questions:

- What matters to carers of older people with assisted living needs?
- How does your current experiences affect your confidence in using assistive technologies?
- How does the design of assistive living technologies influencing their use in the home?
- What design modifications could make assistive living devices such as Kemuri more useful and desirable to people with assisted living needs and their carers?

Carer experiences

Carer experiences were elicited by focusing attention on participant's experiences of how they adapted to the onset of illness and the caring role; by reflecting on the range of support they currently received; and by reviewing how participants currently communicate with other people involved in the circle of support. This involved a 30 minute discussion in which participants were encouraged to take written notes in preparation for a group discussion of the issues. The onset of the caring role had affected participants in a number of ways:

- Some participants felt their lives had been put on hold, with an indeterminate end-point to the caring role
- It was difficult fitting in full-time work
- Dealing with aggression from the cared for person was difficult to cope with
- Witnessing the effects of dementia, for example, led carers to fear for their own future wellbeing
- Some carers were coping with caring whilst living with a long-term illness themselves
- There was a need to become acquainted with local service provision and build relationship with key healthcare professionals
- Some found that they required support from paid care-workers to enable them to continue to work
- Visiting daily was often necessary until other care support was in place
- There was a dread of the telephone ringing, leading to increased stress when dealing with problems and repetitive interactions with the person they cared for
- The caring role could have a detrimental effect on carer health
- There was a perceived lack of support from other family members, leading to more fraught family relationships as it was usual for one person to take the lead when caring
- There was a need to build personal resilience and greater assertiveness to obtain suitable support from service providers, such as Social Services.
- Participants distinguished between the challenges involved in responding to reduced physical and mental capacities, and the way these sometimes fluctuated over time
- Despite the reliance on carers to support an individual, many carers felt there was a lack of recognition by doctors and other professionals of the impact on carer health of the caring role, focusing solely on the health consequences for the cared-for-person. There was a suspicion that recognising carer stress/burden was avoided because this would require more costly interventions.
- Carers noted how the caring role can emerge gradually as gentle changes in a person’s condition develop over time, or can emerge from sudden changes, through stroke or fall, for example, that creates a fundamental change to the relationship very quickly.
- One key adaptation when supporting someone living with dementia was the necessity to lie convincingly in order to protect the person from further upset or confusion. This could bring uncertainty about whether they were doing the right thing as it conflicted with their usual understandings of how to interact with their loved one.

The participants described a range of ways they were currently supported to provide care for someone with assisted living needs. These included:

- Door alarms – though one participant expressed concern that the response might not be adequate as they were fifteen miles away, and would be unable to respond in time to prevent the person coming to harm outside the home.
- Gas detection alarms
- Medication prompting – though this did not give complete reassurance the medication was actually being taken
- Neighbours - they can be helpful, noticing and responding if the cared-for-person leaves the house unexpectedly.
- Pendant alarms to monitor potential falls. There was a problem in that the cared-for-person might take it off and it would not fulfil its intended purpose. The issue of stigma surrounding use of the device was challenged by awareness of current innovations to embed sensors/accelerometers into pieces of jewellery which could assist with user acceptance.

For some participants, the existing realities of care-worker pay and conditions could lead to a lack of care, and the quality of local care homes meant they were reluctant to support their loved ones taking this option for additional support. It was felt that by gathering data from assistive living devices which monitor the activities of daily living of an older person, this could be used to build a picture of need, and could help to persuade Social Services to provide more support, especially if the data showed that a person's situation was getting worse/they were more at risk of harm. They noted a problem with assistive living technologies was the number of false alarms – leading to frustration and eventually ignoring the alarms completely.

Participants described having a very limited circle of support in terms of practical care activities, except when there were paid care-workers providing support. However, they did suggest that talking to friends was helpful, allowing them to share their frustrations and discuss problems. A significant issue in being a main carer was the lack of respite. A different issue was that the wellbeing of the person may not always be communicated by the person themselves (as they wish to shield the carer from worry, or wished to retain their independence), so their circle of support (or main carer) would not act to provide suitable support. Having technologies that could inform carers what the cared-for-person might not was seen as a positive prospect.

Carer concerns and aspirations

A number of prompt questions were put to participants in order to gain better understanding of both carer experiences. , which could prove helpful for marketing knowledge. The participants discussed within small groups and presented their responses orally to the facilitator. The prompt questions were posed as incomplete sentences, with the various responses retained to allow an accurate representation of the participant voice in terms of the language used.

Q1. When I think of the person I care for being at home, I hope that they are….

- Ok
- Safe
- Well
- Truthful about their health
- Warm and calm
- Not panicking
- Physically mobile
- Eating and drinking
- Responsive (to telephone)
- Not being taken advantage of; e.g. by other residents in sheltered housing or by care staff (such as ‘borrowing’ money)

Q2. When I think of the person I care for being at home, I sometimes worry that they are ….

- Worrying
- Not leaving home to socialise with others
- Turning appliances of/on appropriately
- Trying to do much for themselves
- Falling
- Not taking their medication
- Getting lost when they are out
- Opening the door to people they shouldn’t
- Not joining in socially (e.g. being deaf can make people isolated)
- Getting distrustful of other people
- Leaving the home
- Not admitting to problems, or exaggerating the problems

Q3. I struggle with my caring responsibilities the most when….

- Sitting at home at night, when the phone repeatedly rings as forgotten that already called
- I don’t see my other loved ones
- My family members don’t offer any support; you don’t have a life of your own
- I have to give up my job, or take early retirement; lose social contacts, income etc.;
- I can’t go out socially with friends at a time that fits around caring responsibilities;
- It goes on for a long time

Q4. What would improve things for me is….

- Using technology as an early warning, to bring a little peace of mind
- Technology which could offer a little respite (to allow socialising with friends etc.)
- Acceptance of caring from cared for person; cooperation is often not forthcoming

Q5. When I’m away from the person I care for, it brings me peace of mind knowing that….

- Reliable carers are going in
- Systems are in place
- People close to their age or older people (women) are providing care;
- that regular carers offer care
- Technology aids communication

However, participants noted that there are all sorts of issues that can get in the way of this peace of mind. They felt that whilst technology will never be as good as a human being as a source of care, it cannot harm a cared for person in the way as unsympathetic or incompetent carers could do.

Q6. What do you care about getting right? I.e. what do you need to know to give you peace of mind?

- Accurate and reliable information
- To know the carers well; having a personal relationship with the carer
- Person plus technology; technology can offer support when the carers are not there; offers reassurance
- Technology can make you worried, if you're getting too much or too little information, don't have a full picture; may start checking more regularly; paranoia can set in
- Maybe I do want a camera to get a fuller picture
- What happens when the technology goes wrong? Reliability may be an issue; if it doesn't work, what happens – but is something better than nothing?
- Has to be reliable or if it's no good at all;

Product Description

This section was added by Dr Anderson for clarity. A Kemurisense® Smart Power Socket is fitted in the kitchen, see Figure 1

FIGURE 1: SMART POWER SOCKET

It is permanently connected to the mains supply within 5 minutes and thereafter needs absolutely no attention from people using the device. The intention is that one socket supplies a kettle and the other a hot food preparation device, eg a microwave oven or toaster. Data is sent via an internal GSM radio with a SIM card that works countrywide. It does not require broadband or Wi-Fi.

Data is collected and analysed on the Kemuri web-site. Patterns of sensor readings are learnt by the software and processed every hour to identify changes to normal activity. The results are shown by smartphone apps to family members, see Figure 2.

FIGURE 2: SMARTPHONE APP SCREENS

The first screen shows a summary of every hour for 8 days. The colour of the day can be set to indicate the total number of changes in a day. Tapping on a day drills down to a second screen that shows the individual sensor reading and an indicator for positive or negative changes. This is shown by a square that is above or below the green line that represents the normal state of a sensor.

Demonstration of the Device

The device was described and demonstrated by Dr. Leonard Anderson of Kemuri Ltd. He advised that devise collects information frequently across the course of the day, but that the system does not need to be checked regularly by carers. One carer suggested that they might like to check as regularly as once per hour, especially when first getting used to the system.

Dr. Anderson advised that the device takes readings from five sensors, continually measuring air temperature in the kitchen; motion; and power use. The motion sensor works to 35 degrees, across a 5 metre field. The device provides data which recognises changes to usual behaviour. Recognising routine behaviours takes about 30 days to be robust. A carer asked if it was possible to use the device in a hallway, for example. Dr. Anderson agreed this would be beneficial, but he suggested there was maximum value in deploying one system in the kitchen (replacing an existing socket). One carer asked why the device was replacing an existing socket, rather than a plug-in version. Dr. Anderson advised that a plug-in system is easier to tamper with. An additional benefit of the replacement socket is that it appears more normal to the kitchen environment.

Kemurisense® - first impressions

There was an overwhelmingly positive response that the three types of information was the most appropriate to support carers to provide reassurance that all was well with the person they cared for. However, its limitations were discussed and some suggestions for improvements were made. A number of positive attributes were articulated by participants. They felt the device was:

- Unobtrusive nature of the device (compared to CCTV cameras, for example)
- Sufficient, in that it provides the basics that a carer would need to provide peace of mind
- Good if the information that was provided could be tailored to their particular requirements
- Plain and simple to use from a non-technical person perspective
- Designed to be used in an appropriate location. Most felt the kitchen was a place where ordinary day-to-day activities happen
- Able to provide useful information
- Appropriate, so long as its limitations were stated upfront
- Useful for helping carers assess whether the cared-for-person was disguising need/being deceptive about everyday routines (such as not sharing decline in mobility). One carer suggested that although confronting people was not the answer (or the purpose of the device) at least this information would make you more knowledgeable

It was recognised that there are limitations with all devices, and might work for some and not others. This should be recognised by potential users. Some limitations with the Kemuri device were observed:

- The device was unable to give assurances that although power had been used (for operating the kettle, for example) its purpose had been followed through correctly (such as drinking a cup of tea). One participant went further to suggest the device doesn’t actually ensure the observed person is eating and drinking or keeping warm as claimed.

- The regular supply of information could lead to over-reliance for monitoring wellbeing
- There was no indication of movement or temperature in the rest of the house; some felt the system needed to be expanded.
- The effectiveness of the device may be restricted beyond cities with good infrastructures and mobile phone signals.
- The system depends upon there being regular routines, otherwise the data will trigger too many change alerts.
- The time lag between an event that requires action and a response could be too great, based on the suggestions made for checking once per day. However, Dr Anderson advised that a significant event may be picked up within 8 changes, prompting an SMS message to be sent to one or more people, as desired.
- In the event of too many false alarms, it was felt carers would begin to ignore them
- A lack of broadband/poor broadband was discussed, including requirements for satellite broadband in some areas, however it was noted that this device does not need broadband to operate
- Some felt there were remaining issues of the loneliness and social isolation of the older person that the device did not address.

Suggestions for improvement included linking the device to Skype to allow visible checking when required and expanding the capabilities to allow other devices to be added onto the platform. However, some participants felt that a simple single purpose device was easier to use and would ensure the costs are kept low.

Participants discussed when and where they would use the device. Some felt that they would initially check the data readings every hour. They suggested that it was more likely that when the device is first installed, there will be an element of novelty which would encourage frequent checking, but that this is likely to diminish over time. The majority felt an SMS once per day would be a useful addition, especially if an individual could select the time they received this report. It would have the added benefit of reassuring the carer that the device was still working. Participants felt that they would be more likely to check regularly on occasions when they knew that the cared-for-person was experiencing poor health. Nearly all participants advised that they would access the data from their smartphones, though they could not specify when or where this would take place as there were too many possibilities across the group as a whole.

There was some discussion about what the device did not advise about, such as whether or not the observed person had in fact eaten or taken a hot drink when appliances might indicate this. There was also a concern about falls in the home, and many felt a falls monitor would be a useful addition. Some argued that the data the was useful as an indication and sufficient for most people, but that more direct observations (such as use of cameras around the home) could be employed if this was appropriate.

The user interface did not attract much discussion as there was unanimity that the device was user-friendly in terms of the user interface (screen, readability, and instructions). Some pointed out that though the device was very clear, there was no help text behind the screens that could prove helpful for some.

The data usage was discussed, and the majority of participants were satisfied that measures were in place to protect the data, and that they would have control over its use by third parties.

The ability for multiple users to access the system and receive data and alerts was discussed. Giving access to other family members and neighbours was seen as a benefit, though there was some discussion about who would be willing to take on this responsibility, and how this would be managed in practice to ensure someone within the circle of support was checking and responding in good time. Participants felt that it would be inappropriate to ask non-primary carers to take part in regular monitoring, but that they may be happy to allow access on occasions (such as when the primary carers are on holiday). They suggested temporary logins would be required to allow this.

A question was raised about whether it would be appropriate to generate alerts to the emergency services if the number or type of changes warranted this. Dr. Anderson advised that the data would be insufficient make this an automatic step, and the risk must be interpreted by a human before alerting any emergency services. However, one participant suggested that for certain changes, such as a significant and potentially dangerous increase in temperature, the highest alert should be signalled for immediate response, perhaps directly to the Fire Brigade.

Ethical considerations

Carers did not feel that there was an issue relating to stigma and use of the device. Its unobtrusiveness assisted with this. However, some carers pointed out that design was important. Indeed, there are developments in wearable monitoring devices that overcome some of the concerns about stigma – such as fitting accelerometers and sensing technology in jewellery and watches.

Most participants argued that the device made little difference to the older person’s autonomy at home. Many felt it was important that the device could not be tampered with, though this was not directly related to considerations of autonomy. The focus of concern was that an increased use of technology might lead to less human contact.

The way the device may change care relations and routines was discussed. A few participants worried that they might allow the technology to take over, that they could step back to a passive role. However, most felt that one’s existing familial and friendship ties would ensure the connections continued. Where impediments to face-to-face visits existed already, it was felt that the technology brought greater benefit than disadvantage to both carer and care-receiver.

All agreed that passive monitoring was preferable to visible monitoring (though perhaps not as effective as CCTV technology). The device can be used to check if care-workers were where they are supposed to be at given times. This was seen as unproblematic, and they would be happy to inform care-workers that the device had been installed as it was not primarily intended to monitor their activity.

Given the breadth of ethical issues raised in academic literature on the use of assisted living technologies, it was apparent that these were not at the forefront of carers' concerns. However, conducting a similar focus group discussion with people with assisted living needs may elevate the importance.

Marketing Issues

Marketing issues were discussed at a number of points during the focus group discussions. A number of suggestions and observations were noted by participants.

- There was disagreement whether the marketing (on website and other advertising) should mislead as to the benefits to the observed person and the carer. One participant felt the existing marketing was misleading, promising what it could not deliver. Another participant suggested that clear claims are those most likely to sell, and competitors were likely to over-claim. Some advised that being open and transparent about the device's limitations would be more appealing to them as they would have greater levels of trust.
- The data provided by the device and what it implies was regarded by as strong enough (if a kettle has been boiled, one can presume the person has taken a hot drink). Others disagreed, so felt more caution was needed in claims made.
- There was disagreement about the expansion possibilities of the system. Some felt there was a need to enable the platform to expand to accommodate multiple devices, and other sensing technologies (such as a falls monitor embedded into skin), so that carers can create a system they feel is robust for their needs. Others valued the simplicity of the existing offer, as it was easier to market to people who were wary of complex technologies.
- Most felt that they would be more inclined to purchase the device if it had been recommended by a trustworthy organisation such as Age UK, the NHS or Social Services. Dr Anderson advised that the device could be issued to people discharged from hospital (once their free telecare runs out), as part of a wider package of care.
- A few carers suggested they would prefer the device to have been subject to independent trials, organised by a research institute, or had been tested by an organisation such as 'Which?' The internet was regarded as a good route to market if the benefits and limitations were effectively described. One carer argued that Dr. Anderson was personally convincing, and that she would be persuaded to purchase directly from the website as a result of his presence.
- The use of the word 'dementia' was not seen as necessarily problematic to participants in terms of acceptability, however, most felt that this would restrict the potential target market, which they saw as being for older people with a range of physical and cognitive impairments.

- It was felt any training in use of the device should avoid large instruction manuals, and some additional support for people who are not IT literate

CONCLUSION AND INTERPRETATION

Some caring practices and roles are adopted in varying degrees of willingness: to do what is the most convenient, pleasing to others or which creates least disruption. The moral acceptability of choices within these bounded choices influence the decisions made. If tensions emerge in an individual's life, such as might occur when juggling competing priorities (such as work and care responsibilities), our expectations, value systems and practical abilities to resolve these can induce a psychological state known as 'cognitive dissonance' (Festinger 1957). This can generate such feelings as guilt, anxiety or ambivalence when seeking to reconcile competing demands and intentions. Anxiety can result when adherence to expectations becomes difficult in certain contexts, or when one's goals become misaligned with social expectations (Festinger 1957). Particularly within household decision-making, decisions are not often made for purely individual ends but are negotiated to meet conflicting and changing needs of multiple others. Being able to distinguish and select what is most appropriate for the situation can involve considerable rumination prior to action because the consequences of taking the wrong option may be potentially damaging to relationships. The lack of evidence and previous experiences with inadequate technologies in the home is likely to generate caution about over-reliance of ALT's in the absence of face-to-face support.

The literature review highlighted a number of ethical issues concerning the use of assistive technologies in the home, especially when these are intended for use by people living with dementia and other cognitive impairments. The focus group discussed many of these ethical concerns in the light of the presentation of the affordances and design features of the Kemurisense® device. Focus group members felt that some of these ethical concerns were minimal in comparison to the practical pressure, risks and anxieties involved in remote caring. Some ethical concerns could be resolved by alterations to the design of the device. Others remained, with uncertainty about how these may be resolved. These ethical considerations warrant further investigation and may become increasingly relevant in academic literature on the ethics of assistive technologies as smartphone technologies becomes more prevalent as solutions for remote caring.

Alterations to caring relations, questions of autonomy and privacy appear to be key issues identified in existing academic literature. Underlying these concerns are considerations about the personhood of the observed person. Concerns for autonomy may need to be reconsidered within care contexts as certain levels of dependency are expected throughout the life course, but perhaps more likely in the context of chronic ill health or poor mobility. Acknowledging relations between people as reciprocal and inter-dependent across the life course, with moments of dependency made more legitimate (Bowlby et al 2010) and the more generalised reliance on technologies within contemporary society (Remmers 2010) allows us to think about assistive living technologies differently. The ideal is no longer independence per se; instead, technologies may enable certain *agreed* levels of dependency to be more appropriately managed. The remaining challenge becomes how to achieve this without stigmatising the technologies and their users. From a carer's perspective, there is concern about encouraging or enabling greater independence, since they accept moral responsibilities to support a person's wellbeing. Carers may be reluctant to place trust issues around new technologies until they are shown to be reliable and consistent, and can appropriately allow them to manage and respond to a number of problems occurring in the home.

This report is not able to comment directly upon the functional efficacy of Kemurisense®. Existing literature does point to some common issues of functional efficacy with some assistive technologies in the home that may have a bearing on the ethics of their use. The heterogeneity of people living with assistive living needs means there is a challenge to reach agreement on what should be defined as normal/abnormal behaviour in order to assess the risks of particular changes to routine. Hofmann (2012) questions whether it is possible to define a standard of normal daily activities from which to measure risk. Routines and patterns of behaviour are individual and require personal knowledge of the observed person in the first instance. The focus group discussion on Kemurisense® suggests that additional work may be useful to explore these issues in more detail, what issues are encountered in the first few weeks, and in assessing the functional efficacy of the product in terms of the reliability of the metrics as measure of physical and emotional wellbeing, both from a clinical perspective and from the perspective of potential users of the device.

APPENDIX A: SOURCE DOCUMENTS

Alwan et al 2006	Impact of Passive in-home health status monitoring technology in home-health: outcome pilot
Barratt and Thorpe 2014	Examining Perspectives on Telecare: Factors Influencing Adoption, Implementation, and Usage
Berridge 2014	Power, ethics and normative logic related to voluntary remote monitoring used to provide independent living
Biswas et al 2011	From Context to Micro-context – Issues and Challenges in Sensorizing Smart Spaces for Assistive Living
Bowes et al 2012	Ethical implications of lifestyle monitoring data in ageing research
Brittain et al 2010	Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments
Chaaraoui et al 2014	A Vision-Based System for Intelligent Monitoring: Human Behaviour Analysis and Privacy by Context
Chander et al 2014	A Mobile Platform for Real-time Continuous Monitoring
Danielsen 2002	Video Surveillance for the rest of us: Proliferation, Privacy, and Ethics Education.
Draper and Sorrell 2013	Telecare, remote monitoring and care
Essen 2008	The two facets of electronic care surveillance: An exploration of the views of older people who live with monitoring devices

Gammon et al 2014	Exploring morally relevant issues facing families in their decisions to monitor the health-related behaviours of loved ones
Ganyo et al 2011	Ethical issues in the use of fall detectors
Mahoney et al 2007	In-home monitoring of persons with dementia: Ethical guidelines for technology research and development
Milligan et al 2011	Telecare and older people: Who cares where?
Neven 2015	By any means? Questioning the link between gerontechnological innovation and older people's wish to live at home
Niemeijer et al 2010	Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: an overview of the literature
Novitsky et al 2015	A Review of Contemporary Work on the Ethics of Ambient Assisted Living Technologies for People with Dementia
Palm et al 2013	Ethically Sound Technology? Guidelines for Interactive Ethical Assessment of Personal Health Monitoring
Percival and Hanson 2006	Big brother or brave new world? Telecare and its implications for older people's independence and social inclusion
Schermer 2015	Telecare and self-management: opportunity to change the paradigm?
Schikof et al 2010	Who will watch (over) me? Humane monitoring in dementia care
Vines et al 2013	Making Family Care Work: Dependence, Privacy and Remote Home Monitoring Telecare Systems
Wang et al 2011	Using Passive Sensing to Estimate Relative Energy Expenditure for Eldercare Monitoring
Wherton and Monk 2010	Problems people with dementia have with kitchen tasks: The challenge for pervasive computing
Yang and Hsu 2012	Original article Remote monitoring and assessment of daily activities in the home environment
Zwijsen et al 2011	Ethics of using assistive technology in the care for community-dwelling elderly people: An overview of the literature

APPENDIX B: LITERATURE REVIEW CODING

autonomy	Nodes\\Autonomy
autonomy	Nodes\\self-determination
autonomy	Nodes\\social control
autonomy	Nodes\\threat to autonomy and control over one's life
autonomy	Nodes\\undermines independence,
balancing risks and	Nodes\\complexity of autonomy related to opportunity

benefits	costs of alternatives
balancing risks and benefits	Nodes\\duty of care versus autonomy of the resident;
balancing risks and benefits	Nodes\\existing monitoring forms (non-technical))
balancing risks and benefits	Nodes\\no other viable options for the older adult to control their own lives,
balancing risks and benefits	Nodes\\capacity
care relations	Nodes\\care responsibility
care relations	Nodes\\care-giving is more than merely meeting needs.
care relations	Nodes\\collaborative care not compliance
care relations	Nodes\\peace of mind
care relations	Nodes\\prefer impersonal care
care relations	Nodes\\processes of care
care relations	Nodes\\reality of remoteness
care relations	Nodes\\reduced relations
care relations	Nodes\\Replacement of hands-on care
care relations	Nodes\\roles in system
care relations	Nodes\\substitute care
care relations	Nodes\\co-presence
care relations	Nodes\\function creep
care responsibility	Nodes\\carer autonomy and pressure
care responsibility	Nodes\\more pressure on informal carers
care responsibility	Nodes\\Remote responsibility
care responsibility	Nodes\\staff burden.
care responsibility	Nodes\\stakeholder involvement
consent	Nodes\\applying pressure by revisiting decisions
consent	Nodes\\informed consent
data	Nodes\\data storage
data	Nodes\\data to evidence need
data	Nodes\\participant interest in data
data	Nodes\\The data counselling sessions
data	Nodes\\using and linking lifestyle monitoring data.
decision-making	Nodes\\changing one’s mind
decision-making	Nodes\\decision-making
decision-making	Nodes\\no control
decision-making	Nodes\\persuasion
decision-making	Nodes\\power dynamics in the decision making process
different technologies	Nodes\\applications present different ethical challenges

different technologies	Nodes\\choice4.
different technologies	Nodes\\confusion diversity of options
efficacy	Nodes\\carer benefits
efficacy	Nodes\\proposed benefit
efficacy	Nodes\\detection of home accidents,
efficacy	Nodes\\efficacy and outcomes
efficacy	Nodes\\efficacy issue
efficacy	Nodes\\enhances supervision
efficacy	Nodes\\expectation of a regularity of routine
efficacy	Nodes\\individual outcomes
efficacy	Nodes\\reliability
efficacy	Nodes\\reliability of the technological intervention and concomitant increase in safety of the resident was seen to be a key consideration
efficacy	Nodes\\sensor utility
efficacy	Nodes\\feeling safe monitored
ethical model	Nodes\\game theory approach to ethics
ethical model	Nodes\\justice
ethical model	Nodes\\moral values
ethical model	Nodes\\principalism
ethical model	Nodes\\standard ethical guidance
ethical model	Nodes\\Affordability
factors influencing adoption	Nodes\\factors influencing adoption
factors influencing adoption	Nodes\\fear of withdrawal of face to face
factors influencing adoption	Nodes\\personal attitude to technology
harm	Nodes\\non- maleficence, beneficence,
harm	Nodes\\doing harm
home	Nodes\\altering home
home	Nodes\\home
home	Nodes\\technologies outside the home
home	Nodes\\spatial
home	Nodes\\temporal
monitoring activities	Nodes\\activity
monitoring activities	Nodes\\configurability
monitoring activities	Nodes\\linked to scenarios of use_need
monitoring activities	Nodes\\missing other signs not being monitored
personhood	Nodes\\dignity.

personhood	Nodes\\identity
personhood	Nodes\\identity impact
personhood	Nodes\\personhood,
personhood	Nodes\\representation of self
personhood	Nodes\\rights_respect
personhood	Nodes\\increased self-awareness
privacy	Nodes\\intrusive_bathroom
privacy	Nodes\\keep information about themselves private for their own personal reasons4, 5.
privacy	Nodes\\Privacy
privacy	Nodes\\reduce privacy,
refusal	Nodes\\costs of refusal
refusal	Nodes\\discontinuation;
refusal	Nodes\\distinctions of use
refusal	Nodes\\resistance
risks	Nodes\\internet safety
risks	Nodes\\labelling as risk
risks	Nodes\\misuse of system
risks	Nodes\\risks
safeguards	Nodes\\safeguards
safeguards	Nodes\\Safety
social interaction	Nodes\\how technologies influence social interaction.
social interaction	Nodes\\Human contact and social inclusion
stigma	Nodes\\stigma
surveillance	Nodes\\surveillance
unobtrusive	Nodes\\alert.
unobtrusive	Nodes\\Obtrusiveness
unobtrusive	Nodes\\continuous mobile monitoring.
unobtrusive	Nodes\\pervasive
unobtrusive	Nodes\\‘phenomenological transparency’
unobtrusive	Nodes\\passivity
unobtrusive	Nodes\\ubiquitous
unobtrusive	Nodes\\ubiquity of sensors in everyday life

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