MEDUSE Policy Paper: the Emergence of New Technologies and Responsibilities for Health Care at Home in Europe November 2006

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This paper outlines the key themes that will form the basis for the MEDUSE conference on care of older people, emergent technologies and the home, to be held in Utrecht, Netherlands in September 2007. The conference objective is to open up dialogue between social scientists and non-academic actors involved in the design, development, implementation and daily use of these technologies from across Europe. Participation will be by invitation and will consist of an audience and speakers drawn from clinicians, designers of new care technologies, older people and carers, as well as health policy makers operating at national and European levels

This paper draws upon selected academic and 'grey' literature to highlight key developments in the field of care technology – both within Europe and beyond. It identifies what these new technologies are and how they are contributing to a change in care and care practice. It considers how this is manifest, as well as where that care takes place.

However, the conference is not just designed to reflect the 'state of the art', but also to identify ways in which knowledge can be exchanged and transferred across and within different groups for whom these issues are of interest. It further aims to identify issues within this field of interest which have, to date, received only limited attention. The intention is to foster new collaborative mechanisms for developing research and effective policy-making.

New and emerging care technologies are the visible, material signs of attempts to solve a range of health related problems in Western economies. Given the current and projected growth of those in the older age groups and policies aimed at 'aging in place', many of these technologies are targeted at supporting the care needs (or perceived needs) of frail older people within the domestic environment. A spectrum of care technologies exists or is being developed to address these needs. While we acknowledge the importance and ubiquity of assistive devices (such as hoists, canes and rails) this conference will specifically focus on new and emerging care technologies many of which employ information and communication technologies (ICTs).

The conference will address four themes of importance to care policy and implementation as outlined below. Overarching all four themes, however, is the question of how the spectrum of these new care technologies is spread across Europe, and what this means for the care of older citizens across the continent.

THEME 1: WHO BENEFITS FROM THE DEVELOPMENT OF NEW CARE TECHNOLOGIES?

Critical to understanding how and in what way new care technologies are being developed and distributed is an understanding of the goals being set for these developments. Who are the intended and actual beneficiaries of new care technologies? How are the sometimes conflicting needs of health professionals, family carers and service users addressed in their design and implementation?

In their work on smart homes and affective computing, both Wu & Miller (2005) and Lundell & Morris (2006) highlight concerns about who has access to ICT based data gathered by these technologies, how it is being used, and the extent to which it affects the roles and relationships between service recipients, family carers and health professionals.

McCreadie & Tinker (2005) suggest that the development of home telecare can be read as having more to do with 'risk avoidance', a key concern of the health professional, than with improved quality of life for the service user. Further, Mort et al. (2003) show in design and implementation, the 'users' of telemedicine technologies are often understood to be the professionals, rather than patients or carers. We argue that it is important to consider how the user is perceived and configured in new care developments for older people in the home. From the design perspective it is also important to consider who the imagined users of emerging technologies are.

Critical issues for discussion and policy development, then, focus on the need for a clear understanding of:

- Who is perceived to be the main beneficiary of telecare services older people, formal carers, informal carers or medical professionals?
- What goals are being set for these new care technologies and systems?
- Whose perceived needs figure in the design and implementation of technologies which shift how and where care is delivered and by whom?
- Who are the imagined users and beneficiaries of prototypical care technologies?

THEME 2: HOW ARE NEW CARE TECHNOLOGIES SHAPING HOME AND WORK?

Sub-theme: How are new care technologies reshaping the experience of home? This conference is concerned with new technologies and systems designed with the expressed aim of enabling older people to remain longer in their own homes (commonly referred to in policy terms as 'aging in place'). It is important then, to consider how care technologies are shaping 'the home' and affecting how older people identify with home. Some researchers (Twigg, 2000: Milligan, 2000, 2003) have drawn attention to the ways in which policies focused on aging in place can a) create changes in how people use their homes; and b) create shifting power relationships within the home - between service recipients, health professionals and family carers. Willems (2006) also notes that technologies used at home can affect the nature of home, until it is almost unrecognisable. This sub-theme, then, will focus on what kinds of homes older people and their carers want. Can technologies make homes 'better places to live in', or do they change the spaces and functions of homes so much that they are no longer recognisable or desirable? To what extent is an older person's sense of security and identity associated with the home and to what extent is this altered by the introduction of new technologies? How do individuals adapt their lifestyles following the introduction of these technologies to the home – and to what extent does this impact on how they use the home, and on their social and emotional lives?

Milligan (2005) has suggested that for frail older people and their carers, the affective experience of home can be as important as the physical structure. This suggests, then, that improving how older people respond to the use of new health care technologies in the home requires policy makers to recognise that design needs take account of not just the impact on the physical, but also on the affective aspects of the home.

In addition, this theme will explore how designers imagine homes. Is class and ethnicity built into such imaginings – and if so how? Very few studies have focused on how class-based assumptions are made about the kinds of houses that the technologies will be placed in: assumptions based on both the material layouts and sizes of homes, and on the social experience of home.

Linked to this is the issue of how cultural difference will affect the implementation of care technologies across Europe. If ideas about 'home' and 'care' are different across Europe and within different ethnic groups, how will technologies take account of such differences? Do technology designers always assume a (middle class) white European older person or family/ social context? As yet, these are issues that have received only limited attention but with the widening of the EU they are of critical importance for any future policy development.

Key questions should address:

• How new care technologies affect the home lives of older people

• What kinds of homes older people and their carers want and whether technological systems can make homes better places to live in

- Whether the introduction of new technologies within the home increases or reduces an older person's sense of security and identification with their home
- The extent to which new technologies may be contributing to a greater
- 'institutionalisation of the home' and shifting power relations within it
- How technology design takes account of issues of class, ethnicity and culture.

Sub-theme: Changing modes of care work and gender

Many new and emerging technologies change patterns of care work, shifting work activities in a kind of downwards cascade: from doctors to nurses (Starren et al 2005; Martin and Coyle, 2006; Engstrom et al 2005); from nurses to call centre staff (Soopramanien et al 2005); from clinicians to patients (Oudshoorn 2006). As the division of labour in the health field is still notably gendered (with women typically clustered at the lower ends of labour hierarchies), these cascades have implications for who cares for older people in Europe. This then will address the question of how new landscapes of responsibility both depend on, and reinforce, existing gender relations.

These shifts in work also create new responsibilities: call centre staff have to make decisions about the responses of older people to automated calls; patients have to decide when to take medical measurements (Oudshoorn 2006); and nursing and other clinical staff have to learn to make medical assessments via videoconferencing (Laflamme et al, 2005; Mahoney et al, 2001). These changes in work release time for some groups and allocate new activities to others (a redistribution which may, or may not be burdensome).

With regard to older people, existing research indicates that they very often delay seeking care support, preferring to 'soldier on' with pain or discomfort, accepting that these are part of their everyday life (Milligan et al, 2005). If they are now asked to monitor and report on their physical condition, such expectations may need to be challenged. New care technologies may produce new anxieties and stresses for a wide range of workers and patients (Mahoney et al, 2003).

THEME 3: MATERIAL, SOCIAL AND AFFECTIVE DESIGN ISSUES

The majority of new and emerging care technologies described in the existing literature focus on medical and/or practical needs of older people and/or their carers (see e.g. Curry et al, 2002 for a review of technologies used in the English context). These technologies, usually involving sensors, alarms and web-based or telephone links, remind older people to take medication, to eat, or to close their doors and windows, for example. They alert carers when the older person deviates from his/her daily routine and/or fails to respond to automated reminders to follow this routine. The focus, then, is on averting health risks rather than enhancing the lives of older people.

A small number of emerging care technologies are now focusing on the social and/or affective needs of older people (Morris 2003; Morris et al., 2003; Morris et al, 2004; Lundell and Morris, 2005; Paro website 2006). These technologies help older people to monitor and broaden their social interactions, or express affection – for example, through stroking a robotic pet. Studies also show that new care technologies are often used by older people in ways that blur the distinction between material/medical needs and social/affective needs.

Some studies have also demonstrated how older participants develop ways of using care systems provided to do more 'social' things, such as playing solitaire, or using telecare systems in inventive and even disruptive ways. This example raises the issue of 'mis-use' of care technologies, although some studies (e.g. Wu & Miller, 2005) note that the local adaptation of technology often continues to provide the cognitive activities it was designed for, albeit in different ways.

This raises questions about the extent to which older people are able to adapt the technologies offered to them in ways that better meet their needs. What are the examples of this? What can we learn from this 'resistance'? How could this learning be fed into a design process? Can technologies be designed so that they are more open to resistant/ creative use by older people and their carers? Whose interests might this serve?

Other research also notes that new technologies need to take seriously older people's ongoing and ever-changing needs for meaningful human interactions. Morris et al (2003) for example, found that older people with varying states of cognitive decline felt very strongly about loneliness and the need to maintain social ties (see also Morris 2003; Morris et al, 2004). They argue that meeting these social needs is central to older people's health status. Indeed, given that technologies designed to support the physical needs of older people in the home can also result in a reduction of home visits from clinicians and carers, it is important to consider the extent to which this might impact on older people's mental well-being.

Key questions within this theme, then, focus on:

• To what extent do new care technologies designed to meet the medical needs of older people in the home impact on their social and affective needs?

• There appears to be a gap between the care technologies that address the material needs of older people and those attempting to address their affective needs. Is this gap inevitable? What could be done to bridge it?

• Is it possible to design care technologies that might meet both kinds of needs, or recognise the blurred boundaries between these categories?

• In what ways do older people adapt the technologies offered to them in ways that better meet their needs and what can designers, practitioners and policy makers learn from this? Can technologies be designed so that they are more open to resistant/ creative use by older people and their carers?

THEME 4: HOW NEW CARE TECHNOLOGIES MODIFY CARE INTERACTIONS?

Sub-theme: Changing experiences and definitions of care and social contact New care technologies inevitably challenge existing definitions of 'good' care. Their use highlights concerns about conflicts between their potential benefits and declining social contact, raising issues of social isolation and mental well-being (Agree, 2005; Glascock & Kutzik, 2006; Mort & Finch 2005; Finch & Mort 2005). Existing research shows that social and caring relationships change through the use of new care technologies, although these tend to report from short trials with small numbers of participants. Some trial participants (older people, carers and service providers) fear a diminution in social contact and some studies find that people seriously resented new 'relationships with machines' (Wu & Miller 2005).

New technologies need to take seriously older people's ongoing and ever-changing needs for meaningful human interactions. Spending time with older people in varying stages of 'cognitive decline' and their carers, Morris found that older people felt very strongly about loneliness and the need to maintain social ties and wanted to feel that they could still contribute to the wellbeing of others (Morris et al 2003; Morris 2003; Morris et al, 2004). Older people did not want to be 'stuck' with a narrow range of others, but to maintain a diverse and extensive social network. They also desired reciprocity in social interactions: 'most participants expressed a strong desire for reciprocal relationships in which they help or in some way have an impact on others' (Morris et al, 2004: 1152). Meeting these social needs was central to older people's health status – people cannot be well unless they have meaningful and satisfying

social networks. Indeed, 'The experiences of giving to and having an impact on others could be as important for health as receiving support' (Morris, 2003: 30).

This sub-theme asks a series of questions relating to these issues:

• How do new technologies challenge and/or support existing understandings of 'good' care?

• How is social contact valued in the design of these technologies and in policy around them?

• Do technologies reduce social contact or change its character?

• How are the new versions of social contact that come with telecare technologies perceived by older people?

• How can new technologies increase older people's feelings of social connection and reciprocity?

Sub-theme: What new ethical and legal problems arise in relation to new care technologies and the data arising from their implementation?

There is a potential for care technologies to be seen as a shift towards an increased 'statization', involving surveillance and monitoring of older people (Tracy et al, 2004; Hanson and Clarke 2000). It has also been argued that call centre based homecare for older people are *extitutional* technologies, in that they seek to control (rather than actively discipline) patients and users (Domenech & Tirado 1997; Domenech et al 2006; Tirado & Domenech 2001; Lopez 2006) in contexts which are processes and programmes rather than buildings or enclosures. This raises serious ethical and legal questions about informed consent, particularly in the case of older people with cognitive decline or dementia (Wu & Miller, 2005; Bjørneby et al 1999; Colombo et al 1998; Czaja, 2002; Magnusson & Hanson 2003). Many of these technologies involve understanding the 'normal' routine of the older person and using alarms to monitor any deviation from this routine. Information about the daily activities of older people is collected, aggregated and stored in databases, and could be very valuable to a range of designers and marketers of relevant products, raising ethical and legal and governance questions about consent and data ownership (Mort & Finch 2005). These processes also raise serious questions about how monitoring technologies change older people's experiences of privacy at home.

Other new care technologies carry the potential to change relationships previously thought to be private, for example, that between adult sons and daughters and their parents. In a trial conducted by Morris (2005), adult sons and daughters had access to graphic representations of their parent's social behaviour, which detailed who they had spoken to during the day. This access had implications for the sons' and daughters' relationships with their parents and also with their own siblings and friends. Technologies such as these can stimulate helpful discussions in families or between older people and their carers about unequal or problematic caring roles (see also Wu & Miller, 2005), but they also raise ethical questions about everyday interactions, privacy and consent. These issues of privacy are closely connected to theme 3's concerns about changing definitions of the home.

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