

EFORTT

**EFORTT: Ethical Frameworks for Telecare technologies for
older people at home**

Project 217787

Deliverable 7: Final Research Report

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Part One: Executive Summary

The development of telecare systems for older people has largely occurred in industry or service contexts while their social, ethical and democratic implications have received little or no attention. Debate about the possible far-reaching consequences of these systems for individual users, carers, citizens and practitioners should therefore be stimulated. The EFORTT project examined the ethical, social and gender implications of technological care interventions for older citizens in Spain, England, Norway and the Netherlands. We used ethnographic and deliberative methods (older citizens' panels) to achieve this. We found that telecare does not offer a 'technological fix' to replace either traditional health care services or informal care networks: it is not an easy solution to demographic ageing, 'care crises', personnel crises, or budget crises in ageing societies. Telecare does not perform care on its own. Project respondents expressed grave concerns that telecare technologies might be used to replace face-to-face or hands-on care in order to cut costs. Citizens' panels were adamant that ethical and social questions should be considered in tandem with technical, political and economic ones, and older people were very keen to be involved in all of these discussions. Telecare either sustains/develops a network that is already in place, or needs to mobilise and install a new network if there is no existing one. There are clear limitations to what telecare systems can do. Some telecare systems make users aware and conscious of themselves in new ways, and teach them to examine and evaluate themselves, their bodies and themselves as persons, in ways they previously did not. Other forms of telecare which are more 'passive', or monitoring based, shift agency away from the older person. Monitoring (call) centre workers, predominantly women, carry out invisible emotional labour in their responses to older people's calls using telecare. It is recommended that commissioners of telecare services specify the *care* element in telecare work (rather than tele-sales) and the need to maintain this in the recruitment and training of 'tele-carers', and that policymakers consider how to protect this form of work from the effects of globalization. Building on e-Inclusion policies, future research programmes announced by state funders and the European Commission could specify older people's panels and other forms of inclusive research methodology (i.e. diary keeping) in drafting research and development programmes in the domains of ageing and technology. We recommend that the EC finds ways to encourage industry/telecare companies to engage with critical research as well as more applied research, perhaps by setting up a small facility to offer mediation of these relationships once funding has been agreed. It is in the interest of all parties to develop systems that are ethical and inclusive.

Where older people want to stay in their homes rather than move into collective living settings, societies need to think more creatively about how to provide care at home that is meaningful, sufficient and dignified.

Characteristics of ethical telecare development:

- Ongoing engagement: older people want to be involved in designing, developing and decision making about care.
- On-site system evolution, rather than being seen as a one-off installation of a fixed system.
- Feedback loops built into the installation and implementation process so that older people are 'living with' telecare rather than 'living because' of it.

Part Two - EFORTT Project Context and Objectives

Telecare technologies are expected to enable older people to play a more active role in managing their own health and well-being and are seen by developers to be in tune with European policy shifts towards increased emphasis on individual responsibility. While home telecare may have the potential to enhance independence, these developments cannot be accepted uncritically, as stressed by the EU's advisory group on ICTs and ambient technologies (ISTAG, 2004). There is a need to examine their wider social and ethical implications – particularly for one of Europe's most vulnerable social groups, frail older people, who form the single largest group receiving home-based care services (OECD, 2005). Uncritical acceptance of how these technologies shape the domestic space and experience of home may thus impact quality of life in ways yet to be fully understood.

Telecare and 'smart home' technologies raise new ethical and legal problems concerning safety; the reliability of information; new types of provider-patient interaction; new knowledges generated, and the ethical implications of increased surveillance (including potential uses and abuses of data). More fundamentally they raise questions about what constitutes good care for home-dwelling older people.

'Telecare' covers a wide range of innovations, from those already functioning to those that are prospective and/or theoretical. EFORTT researchers examined the ethical, social and gender implications of technological interventions for older citizens in 'preventive' (such as home environmental sensors, GPS tracking devices or home based health monitoring devices) and 'responsive' (e.g. pendant alarm systems) modes of telecare. We argued that these interventions were occurring in a social, ethical and democratic vacuum and that debate about the possible far-reaching consequences of these developments, for both individual users, carers, citizens and practitioners should be stimulated. Accordingly, we carried out empirical and deliberative studies examining both the everyday and more futuristic forms of development. Telecare raises questions about the appropriate point at which research should investigate or policy might intervene. We investigate telecare practices in four regions of Europe, and in different care contexts. Existing telecare systems were studied using ethnographic approaches and developed futuristic systems were studied normatively by creating deliberative citizens' panels.

EFORTT objectives according to the Description of Work were:

1. To develop qualitative (ethnographic) approaches to understand *practices* of remote care, in cases of preventive and responsive telecare modes.
2. To develop deliberative approaches to the making of telecare *policy* at a European level by recruiting citizens' panels to generate foresight into new care technologies and relations and to consider findings from the ethnographies.
3. To develop an *empirical ethics* of evolving and future care technologies based on data arising from the ethnographic and deliberative work. NB Analysis of this material was carried out according to three research questions and is presented in Part 3.
4. To use the above to provide appropriate ethical frameworks for the development and implementation of telecare technologies

The report below shows how we have fulfilled all of the above objectives.

Objective 1 - To develop qualitative (ethnographic) approaches to understand *practices* of remote care, in cases of preventive and responsive telecare modes.

EFORTT was designed around two axes of investigation: deliberative and ethnographic. Objective 1 was achieved through **Work Package 2: Ethnographies**, in which all partners gathered original data from extensive and complex fieldwork in a range of remote care settings. This data gathering involved a combination of documentary analysis; direct and sustained observations of telecare in practice; interviews with users, carers, a range of practitioners, managers, voluntary and third sector actors, industrial/commercial telecare companies.

Objective 2 - To develop deliberative approaches to the making of telecare *policy* at a European level by recruiting citizens' panels to generate foresight into new care technologies and relations and consider findings from the ethnographies.

This deliberative axis was achieved through **WP3: Citizens' Panels** (see Table 1). This consisted of two rounds of citizens' panels (approximately 18 months apart) in each of the four partner countries. The panels comprised older people and carers who were not otherwise involved in our research. In the first meetings, panel members reflected on the issues at stake in the field of telecare for older people living at home and in the second meetings they provided critical and engaged reflection on the findings of the EFORTT ethnographic work. We conceptualize these panels more as policy forums than user forums, offering independent critical views on care, telecare and the future direction of care. The table below shows the panels convened a) Introductory: to familiarize groups with the aims of the project, the changing nature of care and the potential role of new care technologies b) Follow-up panels: to outline the preliminary findings from the EFORTT ethnographic work, to obtain feedback on those findings and to develop principles for the development of an ethical framework for telecare technologies.

Objective 3 To develop an *empirical ethics* of evolving and future care technologies based on ethnographic and deliberative methodologies.

This was achieved through combining results from **WP4 (Data clinic)** and **WP5 (Participative Conference)**. The data clinic took place in Rondane, Norway, 9-11 February 2010 with the aim of bring together analysis of the four ethnographies and citizens' panels. We developed analytical themes, highlighting issues that could become organizing strands/discussion topics at the EFORTT participative conference in Barcelona. Data and preliminary analyses from each country was previously translated and distributed to partners. This included field notes from the ethnographic material, transcripts from the citizens' panels and key extracts from relevant policy documents.

The data were selected, organised and analysed according to three questions, developed from the EFORTT 'Description of Work', and previous discussions at project meetings.

- * What new care arrangements, practices and relations do remote care technologies contribute to; how do they redistribute tasks, in/dependencies and responsibilities, and what new definitions of (good) care do these new arrangements imply?
- * What normative visions and programs do these technologies carry/embody, and what norms /normativities are being manifested in the care practices they are involved in? How do the norms/normativities of telecare, their design, policy documents and investment programs relate to actual care practices? And how can we build an ethics or 'ethical framework' to guide both the development of AND the evaluation of telecare systems?
- * To what extent, and how, do actors negotiate and creatively reshape these technologies/visions when they effectively become integrated in their daily lives?

The two-day event: 'Ageing with Technologies: a participative conference on care in Europe', took place on 13-14th Sept 2010 in Barcelona. The objective was to provide an opportunity for practitioners, users, carers, policymakers and scholars involved with or working on care and technology to meet and talk about their experience. The organising team from the Autonomous University of Barcelona (UAB) publicised the conference among scholars, users and carers' organisations, policymakers, practitioners and commercial companies. Some co-funding was received from the UAB, the Generalitat de Catalunya and the Spanish Ministerio of Education for additional conference expenses. To manage these activities and inform the general public, a website was built in Castillian, Catalan and English: http://psicologiasocial.uab.es/efortt_conference

After an introduction by Lino Paula (EFORTT Project Officer), each plenary session began with a brief presentation from the EFORTT project to help frame the topic and introduce the international guest-speakers who examined different experiences and perspectives around telecare: scholars, technology companies, organisations for older people and service providers (for details see website). Plenaries concluded with a general debate, followed by workgroup discussions, each day was summarised by rapporteurs, and the concluding session synthesised the different proposals and priorities for future action on telecare in Europe that had emerged. **118 participants** attended from all over the world, but particularly Europe. Communication was facilitated by a simultaneous translation service.

Objective 4: To provide appropriate ethical frameworks for the development and implementation of telecare technologies.

This objective has been achieved through bringing together the analyses of findings from the deliberative and ethnographic primary research and is described in Part 3.

Part 3: Description of the main Scientific and Technological results

Findings from the deliberative research (citizens' panels)

The citizens' panels (Table 1) provided a set of views about the role of new care technologies in the care of older people living at home that are, in many ways, surprisingly consistent across the four countries. Despite living within quite different health and social care systems, older people and their carers held fundamentally similar views about home based telecare.

Primarily there were grave concerns that telecare technology might be used to replace face-to-face or hands-on care in order to cut costs. Panels in each country strongly articulated the need for older people to have social contact and physically present carers: telecare, they argued, must be viewed as an additional resource, not as a substitute for such care. Within this framework, however, most panel members viewed at least some elements of telecare systems as potentially positive: having the ability to contact someone quickly in an emergency, for example, was very much valued. There was agreement across each country that the quality of telecare very much depended on its human components: there is no point, panel members suggested, having 'cutting edge' technologies unless the support services attached to them are also excellent. When you 'press the red button' it is imperative that your call be answered and, if needed, the appropriate service must come to the home.

Panel members were very aware that the introduction of telecare systems may have profound social effects: not only for individuals and their families (what might it mean for an adult son or daughter to be contacted in an emergency, or for them to be able to view or track one's movements on a screen?), but also for communities and societies. The EFORTT panels were adamant that ethical and social questions should be considered in tandem with technical, political and economic ones, and were very keen to be involved in *all of these discussions*. Indeed, many stated that they welcomed the opportunity to be involved in the panels and to be recognized as citizens who had the capacity and the desire to make a meaningful contribution to these debates.

INTRODUCTORY PANELS			
COUNTRY	DATE	PARTICIPANTS	COMPOSITION
England	14/07/08	8	Older people
England	11/08/08	10	Older people in independent assisted accommodation
England	26/05/09	8	Informal carers
England	11/09	6	Older people/ informal carers
England	12/09	6	Older people/ informal carers
Netherlands	10/11/08	8	Older people
Netherlands	24/11/08	5	Informal carers
Netherlands	02/12/08	7	Informal carers
Norway	08/09/08	6	Older people
Norway	10/09/08	8	Carers
Norway	29/10/08	8	Older people/carers
Spain	19/07/08	7	Older people
Spain	19/07/08	4	Carers
FOLLOW-UP PANELS			
COUNTRY	DATE	PARTICIPANTS	COMPOSITION
England	10/06/10	15	Older people in independent assisted accommodation
England	10/06/10	5	Older people/ informal carers
England	18/06/10	14	Older people/ informal carers
Netherlands	12/05/10	7	Older people /informal carers
Netherlands	17/05/10	8	Older people /informal carers
Norway	16/06/10	5	Older people
Norway	17/06/10	3	Carers
Spain	26/07/10	9	Older people
Spain	26/07/10	9	Carers

Table 1 EFORTT Older Citizens' Panels

The citizens' panel process: how it works as a way of researching with older people

The experiences of the citizens' panel process across all four-partner countries also revealed remarkable similarities. Here we draw these experiences together, reflecting firstly on the benefits and 'added value' of this methodological technique over other methods; and secondly on some of the challenges we experienced in using this technique with carers and older participants, and thoughts on how these challenges might be addressed.

Benefits of citizens' panels

Deliberative panels of citizens facilitate a more 'horizontal' approach to research. They create spaces in which participants can not only learn about a specific topic, but also question, and express doubts, agreement and differences. Unlike research designed to use more traditional interview or group discussion techniques, research involving citizens' panels creates both time and space for greater dialogue between the researchers and research participants. EFORTT citizens' panels proved highly effective as a means of having older people and carers engage in discussion around their wants, needs and aspirations for care, both now and in the future, as well as the ethical issues surrounding the implementation of telecare.

The panels also gave participants an opportunity to explore their opinions, understanding and experiences of the topic and an opportunity to engage with the EFORTT fieldwork and data. Participants thus became actively involved in shaping the emerging research themes. In sum it entailed a more participatory and ethical form of research and a leveling of traditional 'hierarchies' between researcher and researched.

In the EFORTT Project we separated the citizens' panels process from the ethnographic fieldwork. This made it clear how, as a research technique, the panels process acknowledges older citizens' often neglected role in making decisions. Indeed, panelists' levels of engagement in the process were very high. As such, citizens' panels provided an essential supplement to the ethnographic data. We acknowledge, of course, that (unlike the ethnographic work) citizens' panel discussions are framed by the aims and objectives of the research; nevertheless we maintain that they are of direct benefit to participants as they offer a very rare opportunity to deliberate collectively a topic of serious concern, and to researchers who gain information about a subject that is directly related to the participants' lives. For the research team this requires some initial effort in both preparing and giving contextual information to participants about the topic for discussion, but this effort is largely what distinguishes citizens' panels from 'focus groups'.

Whilst in general the level of participation in panels was high, the Spanish partners noted in the 'follow-up' panels that older panelists found it more difficult to engage in debate around some of the more abstract questions arising from the research. Their participants tended to prefer to draw on their own more concrete experiences. This was not a generalised experience across other partner countries and may be a reflection of the make-up of the Spanish panels. What seems evident from this experience, however, is that the way findings are presented to participants needs to be very clear and where participants experience difficulties in engaging with more abstract concepts, extra effort needs to be taken by researchers to 'translate' between abstract and general ideas on one hand, and experiences and narratives on the other.

A particular benefit of the follow-up panels is that they allowed researchers to relay back the results of ethnographic fieldwork and data analysis in a participative and productive way. Participants could thus reflect on much more concrete projects. In our research, the second round of citizens' panels

also enabled researchers to draw a contrast between their own country-specific findings and those of other partner countries. In some instances, these comparisons facilitated panel members' ability to refine or modify early findings. They also enabled us to take the discussion out of the sphere of 'what do we think will happen?' to 'what do we think about concrete applications?' thus facilitating our understanding of what forms of care and telecare older people can and will support, and the policy recommendations that flow from those. Citizens' panels can thus be said to provide an opportunity for participants to express their opinions and understandings of the research and emergent data, giving them a sense of 'ownership' of the findings and recommendations.

Challenges of citizens' panels in telecare research

Whilst those participating in the panels were highly engaged, all four research teams found that at times recruitment proved challenging - particularly in terms of our efforts to engage a wide range of participants. In particular we found it difficult to access and engage 'vulnerable' citizens in this process - such as those who are receiving care services (both home-based and institutional). Despite engaging a wide range of groups and key contacts to identify respondents (including health and social services, voluntary/community organizations, older people's forums, senior citizen centres, carers' support groups, allied health professionals) most research partners found panel members consisted largely of some of the fittest and most resourceful of our older people. In the 18 months between the introductory and follow-up panels a significant number of panel members had experienced deterioration in health, some had died, and others had gained more experience of both telecare and paid carers.

Across all four countries, telecare is primarily used by frail older people who have limited ability to travel; hence it is difficult to involve them in group discussions requiring their presence at a specific location beyond the home/institution. As a consequence, not many panel members had hands-on experience of telecare technologies. This was exacerbated in the Norwegian context where home-based telecare (as opposed to telemedicine) is not widely used. Where panels included one or more participants with direct experience of using telecare it proved a significant advantage in that they were able to describe the everyday use and challenges of telecare, moving discussion away from the more generalist issues of the 'pros and cons' of care technology. One way that the English researchers sought to address this problem was to run an additional panel for older users of telecare within a communal sitting room in assisted living accommodation. This worked effectively for both the introductory and follow-up panels. However it has to be acknowledged that the quality of service and care in assisted living in the UK varies with cost, and is frequently quite an expensive option, meaning that poorer older telecare users were more difficult to engage panel discussions. In England we had to rely on individual interviews to address this. However, it should not be overlooked that whilst many of those older panel participants were not current users of telecare, they are nevertheless potential future users. Their views are thus of importance in learning what form of care older people want in the near future and what role telecare should play in the provision of that care.

Due to their caring responsibilities, informal (family) carers can also find it difficult to participate in group discussions of this kind. For them, the key issue is ensuring there is support/funding to 'cover' for them whilst they participate in the panel. In many instances formal carers were unable to obtain leave from (care) work in order to attend the citizens' panels. In Norway, the research team sought to address this by rescheduling panels from daytime to the evening. However, getting people to attend panel meetings in their spare time was also an issue. Unlike the English example, the Norwegian team did not offer any payment for attendance, and it is possible that this would have made recruitment easier. As a consequence certain groups are likely to be excluded from deliberations about new care systems, so real efforts need to be made to find alternative ways of ensuring their views are heard.

Finally, whilst the second round of panels provided some extremely useful data, all research partners found it difficult to ‘retain’ the same participants for both rounds of panels (for reasons detailed above) resulting in a mix of continuing and new participants being recruited to this phase. Clearly this has an impact on the dynamic of the panels.

Future role for older peoples’ panels

Overall, the majority of participants became very engaged in what were quite lengthy and demanding discussions, and expressed great interest in receiving a copy of the EFORTT leaflet and final report. To us, this indicates the success of the panels in stimulating and engaging older people and carers in deliberating these significant social issues. The high quality of debate in the panels only served to confirm that older people have a critical and indispensable role to play in the future shaping of policy and practice around telecare development.

Findings from ethnographic/observational research

Country- and system-specific findings

The Spanish material: is based on excerpts from fieldwork/interviews from Red Cross call centers following installations of pendant alarms; interviews with home telecare managers and tele-operators, users and volunteers; interviews with telecare designers, and excerpts from telecare users/health care professionals’ focus group.

The Dutch material: is based on excerpts from field notes from two projects involving medical remote care technologies: the Health Buddy project in oncology care and a project in home care, PAL4, where a web camera system is used next to the health buddy.

The UK material: is based on excerpts from citizen panels and policy documents as well as field note transcripts from observations and interviews of telecare system monitoring centre workers, installers and older telecare users, all collected as part of a study of a telecare service in one county in England

The Norwegian material: is based on excerpts of field notes and interviews from two different forms of technology-care constellations: the SecurityNet (TrygghetsNett) and the use of GPS devices in dementia care.

England

Telecare with environmental monitors

The English study focused on the ways in which ‘care’ is understood with Northshire’s telecare system, looking critically at how ‘care’ is divided up within the implemented system. We also considered cultural understandings and lived experiences of ‘home’ and how telecare affects these. We observed the work undertaken to provide telecare in detail: from the bureaucratic procedures and practices of social services managers and assessment tasks of social workers to the ‘technical’ labours of system installation and the caring work provided in monitoring centres. We have observed in particular that the latter two tasks (installation and tele-operating) are far from the simple ‘technical’ tasks described in promotional materials or service agreements. The tele-operation work in monitoring centres, for example, involves managing anxiety and the ‘unseen and/or unknown’ aspects of the work, what we would call *emotional labour*. To do this work well also involves a high degree of intuitive, tacit skill.

Spain

Home Telecare system

In Spain we studied the implementation of a Home Telecare System (HTS) in Barcelona and other Catalan villages. We found that ideas about feeling secure at home seem to have changed with the implementation of 'risk technologies': the HTS does not appear to work as a rigid system protecting older people against any possible threat, but as a flexible system that is able to turn any 'incident' into a trigger for mobilizing the aid resources already at user's disposal in a specific way.

Contracting for and installing the HTS is a complex negotiation process between company/providers, users and relatives/carers. During this process, the notions of responsibility, needs and 'correct use' are fluid and distributed among all these agents. This means it becomes important to ask what kinds of older people are being 'installed' or configured through this process. We found that the HTS was best suited to older people who already received support from relatives, neighbors or professional caregivers. The HTS seems to enhance the help that the user is already receiving but cannot substitute it.

We also discovered that the emergence of private/commercial companies in telecare market is unleashing some fears amongst users and professionals. The emergence of these companies runs the risk of devaluing the 'social' aspects of the HTS (compared with the health aspects of it) and promoting 'management solutions' which do not sufficiently take into account the personal experience of users and workers/practitioners.

Norway

a) Network systems for carers

The participants involved in the SecurityNet experience this network of contact and services as very important. Many of the participants are in daily contact with each other, and view the other network members as a form of extended family. They share their experiences with each other and with the staff at the base-station. The fact that they can see each other through the web-camera is very significant. The base-station serves as a direct link to the municipality's services. The base-staff give information about services, advise the participants on any medical matters and, for example, assist in filling in forms. As the tone is informal and friendly, the threshold for getting in touch with the base is very low. But it is also a two-way contact as the base-staff get in touch with participants at regular intervals, for example to get an update on the older person's and their carer's situation. The MPower project shows that very simple technological solutions have an important function for the individuals using them. The fact that very simple and mainstream solutions (which both SecurityNet and MPower are based upon) make such a difference for the individuals involved was the most surprising finding of the fieldwork.

b) Global Position Systems in Dementia settings

Observation of policy development brought legal and further ethical issues of telecare to the forefront. Much effort has been spent in Norway on discussing and defining the legal/ethical boundaries of the use of telecare. Lawyers and legal experts have a key position in this work in the Norwegian health-bureaucracy. This is particularly evident in the use of GPS-technology as a part of formal care services. It is the legal experts of the Regional Health Authorities (RHA) who decide whether the use of GPS devices in dementia care can be approved. So far, the RHA have been very restrictive in giving the permission for the use of GPS in formal care. This is because the continuous monitoring made possible by the GPS device is considered highly intrusive of the patient's right to privacy.

On the other hand, however, both health care workers and next-of-kin point out the positive aspects

of such monitoring. The use of GPS devices does, for example, make it possible for next-of-kin living with a person with dementia to have another life; to pursue hobbies, a social life and even employment. It can also enable the person with dementia to maintain an active lifestyle. At the same time the use of GPS devices in dementia care does involve new forms of vulnerability. How is it possible, for example, to ensure that the person remembers to carry the GPS device when going outdoors? The study revealed also a number of technical issues related to short battery life in cold weather, inaccurate mapping and over-complicated technology.

Netherlands

a) Health Buddy system in cancer oncology settings

The Health Buddy is a tabletop device to help care for older people or people with chronic diseases. Our research found that most people fear a loss of human contact and ‘warmth’ when using telecare technologies. In the ‘low-tech high-touch’ environment of palliative care this seems particularly prominent. The findings, however, also point to patients who feel very well cared for and very much in contact with their oncology nurse. Many saw the telecare device as a direct line of contact with the nurse. They also experienced it as a way to help the nurse care for them. They reported feeling safe and secure. Often, the questions asked about the telecare device served to engage spouses in conversation about what lay ahead of them. Clearly, when one partner has cancer, the other suffers from it too. Telecare devices could develop more in this direction. For some older people, the personal questions asked through the Health Buddy were ‘too confronting’, leading to a rejection of the system. It is ethically essential that people should be able to refuse to use the device.

b) The Personal Assistant for Life platform in chronic illness

In the PAL4 (Personal Assistant for Life platform) project most users lived alone and experienced the system as a way to stay in touch with the outside world, while living at home independently. This connection took place by keeping oneself informed about the news, things going on in the neighbourhood, games, shows or the World Wide Web, but also in interaction with care institutions, family and others. For patients with severe COPD there were weekly contacts with the nurse about the developments of their condition. This is a large increase in the frequency of contacts with a nurse, which would have previously been once every three to four months. The patients were happy that their questions were answered quickly, and that solutions were suggested to them when they had complaints. Generally, patients using the system felt safe and secure. Most users appreciated the distraction offered by PAL4, as well as the possibility to increase contacts with family living far away. Family members were seen to provide a great deal of support to help their older relatives with the use of the computer. The idea of informal contacts between elderly users proved to be difficult, because people who did not know each other felt embarrassed to call each other and did not know what they would have to discuss with them.

Joint findings

The findings here result from synthesis of ethnographic findings across the four countries and the diverse range of telecare systems studied. In each country, the distribution of telecare is organized differently. In England, government, through social care commissioners (usually municipalities/County Councils) and the National Health Service, promotes telecare developments, whereas in other countries the distribution of telecare is organised more locally. In Spain this happens largely via municipalities; in the Netherlands via care organizations and project financing by government; Norway in part via financing by government through the National Insurance and House Bank, in part project-based financing, and some private care systems at home. By the different ways of framing to what problem telecare should be a solution, there are different target groups identified

in each of the countries. In England and Spain, telecare is aimed at the general ageing population, whereas in the Netherlands the care for chronic diseases that older people may develop is the central focus. In Norway, the researchers looked into telecare for people with dementia and their carers; most strikingly, the use of telecare devices is not encouraged for people who cannot give clear consent.

Findings are divided into three key themes.

Theme 1: New care arrangements

Questions: *What new care arrangements, practices and relations do remote care technologies contribute to? How do they redistribute tasks, in/dependencies and responsibilities? And what new definitions of (good) care do these new arrangements imply?*

Telecare does not offer a ‘technological fix’ to replace either traditional health care services or informal care networks: it is not an easy solution to care crises, personnel crises, or budget crises in ageing societies. Telecare does not perform care on its own. Instead it creates a lot of new work; it introduces new tasks, skills, responsibilities and actors. These include installers, tele-operators, instructors, service providers and service workers, in addition to drawing on family carers, neighbours, friends and volunteers. Telecare is one part of a large socio-technical system or network, and does not work effectively if the user has no social network.

Telecare either sustains/develops a network that is already in place, or needs to mobilise and install a new network if there is no existing one. In the latter case, relatives, friends, neighbours may become part of a new network in which relations become more functional, qualified and formalised. Indeed, relations become tested, defined and qualified. Some relations may become intensified, some relieved, some both intensified and relieved. Many actors and figures, old and new, are involved in this work of relating, organizing, negotiating, adapting, smoothing and tinkering, in order to make the system or package work, and work better. But, crucially, one has to provide a system or network together with the technologies, because otherwise the technology is seen to be useless.

There are clear limits and limitations to what telecare systems can do – they cannot for instance help people to the toilet or clean the house. The aim of telecare policy, then, that telecare will be effective for people living alone and lacking social networks, is not grounded in practice. It needs to be acknowledged that telecare rests upon and is dependent upon networks, and that either these are already in place or they have to be made anew by bringing actors, including volunteers and informal carers, into the system. In this way, telecare makes multiple caring practices, many carers, and the care networks they sustain, visible in new ways.

Through telecare, the responsibilities for care in the networks are shifted and delegated in new ways. Indeed, in some forms of telecare more responsibility is shifted onto the individual user/ older person, who is now attributed the task of caring for and looking after her/himself. Such telecare systems make users aware and conscious of themselves in new ways, and teach them to examine and evaluate themselves, their bodies and themselves as persons, in ways they previously did not. Other forms of telecare which are more ‘passive’, or monitoring based, shift agency away from the older person, where decisions can be taken based on sensor/movement data about which the client may not be aware. However in both modes, what is seen as good care has become strongly identified with currently powerful social norms such as independence (e.g. staying in one’s own home) and being able to ‘care for oneself’.

Theme 2: Normative visions

Questions: *What normative visions and programs do these technologies carry/embody, and what norms /normativities are being manifested in the care practices they are involved in? How do the norms/normativities of telecare technologies, their design, policy documents and investment programs relate to actual care practices?*

To answer these questions we did not look primarily at ‘visions’ of care as they are expressed in policy documents (although they were examined as background material), but how such visions are working out in practice with telecare systems. The advantage of this ‘bottom-up’ approach is that it gives a more realistic view on the ethics of telecare. In examining telecare practices, the question became not how to define good care once and for all, but how to prioritise ‘goods’, to show the situatedness of what is good and bad care. From our data, we identified six such visions of good care present in different degrees across the systems we studied:

- Good care is care that engages its users. Advanced telecare that is not closely identified with the activities of the user could place older people in a completely inactive, passive role.
- A version of good care as embodied in almost all telecare programs, is that care should allow for ‘ageing in place’: staying ‘at home’ as long as possible. This vision of good care may, however, also oblige people to stay at home longer than is appropriate for them. Telecare may be continued even when care in a collective setting would be better. As a result alternative collective settings may disappear as a consequence of the ‘success’ of telecare.
- Good care is also care for the carers, but this is understood differently in different sites. For example, carers’ rights are currently taken to be more important in England than in Norway. In England, carers’ consent may be as important as that of the ‘user’.
- One of the ‘goods’ revealed in our material could be called reciprocity, which can be seen most clearly in more medically related examples. This is when the telecare technologies not only assist formal and informal carers in caring for the older person, but when these enable the older person to help the carers.
- Good care sustains privacy; the material shows that telecare may be a way to increase privacy and personal continuity. However, in some situations privacy may also be threatened, for instance by practices using GPS tracking. There is however room for negotiation between the alternatives of perceived loss of privacy and loss of possible increased liberty that might be enabled by GPS. This also applies to, for instance, health monitoring telecare. Some clients using telecare for health monitoring feel that it sometimes comes ‘too close’, as it confronts them with their condition too much, for example where patients are required to answer a set of questions about their illness on a daily basis.
- A last vision of good care that came out of the data concerning several of the telecare arrangements we studied was the provision of ‘peace of mind’. This is particularly noticeable in the use of alarm pendants: even if the pendant is never or hardly actually activated, it is however still an important part of good care because it provides reassurance for the older person and her or his family and friends.

Theme 3: Creative reshaping

Questions: *How do older people actually use telecare? How do they try to change it to meet their needs? How do providers respond to these attempts and what do these attempts reveal?*

In data from all four countries, it is clear that all kinds of actors involved in telecare negotiate and creatively reshape/adapt telecare technologies and visions as they integrate these into their daily lives. Indeed, it could be argued that such integration inevitably involves such reshaping. Therefore adaptation/reshaping is not evidence of failure, rather reshaping provides insights into the ways in which telecare might meet older people's and their carers' needs more effectively. Exploring such reshaping and creative use of telecare is an important sociotechnical endeavor that provides material evidence to support the creation of an ethical framework for telecare development and practice.

Our research material demonstrates a wide range of different forms of telecare usage: refusal, intermittent use, misunderstanding, target driven installation, 'misuse', adaptation, creative use, customization and supplementation. All of this evidence about the creative use of telecare (and the non-use of telecare) raises questions about what 'proper use' is thought to be in each context.

The evidence about reshaping/adaptation shows that this varies across different contexts and that telecare should not be understood as a universal solution, but a situated one. We argue that people's creativity in customising systems is actually essential to the 'ethical' use of telecare and that this customisation process should be respected. In this way telecare systems (in design and implementation) can avoid becoming totalising and coercive.

Findings from Participative Conference group discussions

The group discussions were guided by three questions:

- How does telecare reshape care interactions within the home and what it means to feel at home?
- How does telecare reshape who is involved in the delivery of care and where it takes place?
- What forms of telecare in the home go beyond what can be seen as ethically acceptable for those involved in the care process?

1. How does telecare reshape care interactions within the home and what it means to feel at home?

2.

Feeling at home can mean different things: some participants stressed staying at home when sick or disabled; ability to do daily activities; for others the ability to go anywhere without anyone to watch over you; to embody your own story, to remember what you have been or have had was important. Many people would accept using telecare and telecare devices if it would allow them to remain at home and if they feel that what 'home' means is not going to change. But not all people want to live in their homes and many prefer to live in protected places such as nursing homes or sheltered housing schemes.

Without doubt, telecare changes the meaning of home. Not only physically and spatially (some devices or the ways in which they are installed, are rejected by users - that they are available does not mean that are accepted/acceptable), but telecare itself is an indication that you have changed and you have some care needs. Telecare has an ambiguous connotation: it indicates that you are vulnerable, but at the same time it can give reassurance and a feeling of safety. That is why the widespread

reason for accepting a telecare service is the aim to feel safe in case something goes wrong, to take or regain control of your life. In relation to this, most of the time, telecare is not installed at the request of users, but at the desire of the older person's offspring who may live far away. And 'users', in many cases, like to satisfy the wishes of their family.

In medical monitoring, for many older people, having a telemedicine unit at home is like having a piece of hospital at home, whereas before they had to visit the doctor. However, the fact that the home is the referent area of health care is not something new, as before the hospitalisation process, home, rather than hospital, was the privileged place for care. The difference between a home from the 'pre-hospitalisation' era, and a home with telemedicine devices is their connectivity.

Privacy is also a highly valued aspect of home, being able to control your own space. In this sense, telecare is interesting because it implies that what is 'outside' can enter the home, at least symbolically. And on the other hand, telecare is used to maintain 'order' (safety, security, independence, peace of mind, some daily activities) at home. The difference between telephone/computers (i.e. devices that also allow input from the outside to home) and telecare systems is that telecare devices are linked to monitoring centres. In relation to privacy, there is a curious effect. While researchers and policymakers focus on privacy issues, criticizing the potential erosion of privacy in the domestic space, it seems that users, when asked, relate few problems about it. In the case of pendant alarms, if they did not want to use the service, they would simply leave the device in a drawer or cupboard. (This is less easy with more totalizing or passive systems such as environmental home monitoring). But fears were expressed about the changing nature of home, in the sense that it appears to be shifting from being a intimate but public care space, to a space increasingly privatised and commercialised with the entry of enterprises and companies into the world of care. It has also become an increasingly medicalised and technologised space.

Another point to note is that the home has variable meanings: the less mobile you are, the more important the surrounding areas are, as well as the neighbourhood. The relationship established between inside the home and outside the home is an interesting research question. It was considered that the home is not only the building, but also a set of practices that include the environment and the local area where it belongs.

Nor are there universal solutions: it is important not to take anything for granted, not to assume too much, because the home can also be a place of mistreatment and abuse. Some people do not want to stay in their homes but they may not be able to move into a care home because there are no places available. Resources are limited. Each person/setting is different and we need to analyse these differences and needs to evaluate each case carefully. In this sense, conference discussion group members argued that many older people prefer to be in 'sheltered' accommodation, which is seen as 'half-way' between home and institution.

In this context it is important to consider what makes a space a desirable place to live. This may include friendly carers, maintaining established relationships, being part of a community or being close to family. This implies that the home where people have lived for many years is not necessarily the preferred place to live, as other areas may offer new or better opportunities and in that sense be more 'homely'. In the rhetoric of telecare however, the home is generally regarded as the only place where it is better to live.

Thus, governments usually promote telecare technologies for all situations, and every problem seems to have a technical solution. Other solutions, however, should be equally possible, such as not staying 'at home'. In any case, those who choose to live in their existing homes should be able to

choose which technologies they want to live with.

2. How does telecare reshape who is involved in care work and where it takes place?

Telecare reshapes the role of caregivers, the relationship established with older people and the interactions among caregivers. Telecare also modifies responsibilities, so that, for example, if caregivers press the alarm, they are co-responsible for the older person who has for example, fallen on the ground. Also tele-operators who act wrongly are responsible for what happens. When you delegate tasks to the machine, you are still (as user and family) responsible for the machine, but it is important to distinguish between civil responsibilities and filial/family obligations. There is a difference between feeling and being responsible. Nor should we forget that we are responsible for taking care of ourselves. In this sense, telecare fits neatly with the neo-liberal emphasis that each individual is responsible for themselves. Telecare would then be only an instrument that increases the possibility for contact or help.

3. What forms of telecare in the home go beyond what can be seen as ethically acceptable for those involved in care process?

Telecare is not ethically acceptable when it separates you from your environment, it moves you away from it and it restricts you. Continuous monitoring of your daily life and activities generate ethical doubts, (although many older people who were asked about this were not worried about it), it threatens the sense of freedom at home. If you come to the point that, to live independently, you need so many devices, sensors and controls, perhaps you should no longer live at home. The installation of a plethora of monitoring devices and sensors will force you to use them, for example, making you get out of your bed when the alarm sounds, or changing your habits, making you open the refrigerator too often. This leads to a concern: are the suppliers of this technology finding that the devices are being used correctly? The current problem for suppliers in relation to monitoring habits and practices is that they do not know exactly what data is collected about each habit and practice and what happens to this data. They hope that one day all the devices will work effectively and all the necessary informational systems will be integrated.

Participants asked: why do companies sell systems which generate information they do not know what to do with? People are concerned about confidentiality and transparency in the use of data from these devices and sensors: who will use these data, why, where and for what? What is the relationship between costs and efficiency generated with all these devices? Telecare would be ethically unacceptable if it makes false promises about what it offers, what you can choose. Also, since the family often assumes the use of the service on the older person's behalf, there is some implicit coercion. Thus, although telecare should not be an obligation, it may be forced upon the user.

In England telecare is promoted by the Government as a solution for demographic ageing. If every older person's home is full of devices and sensors, might this end up becoming unethical? What matters ultimately is the willingness, acceptance or refusal, and choice of each person. If there are abuses of installations and of use of devices, users may reject them and not use them anymore. There should be a range of possibilities but agreement and consent can be complex issue with frail older people. If those concerned cannot choose, others may make the selection. However, in some cases, telecare may not be the best option for them. And if those concerned cannot choose for themselves,

and others have to make the choice for them, it could be that telecare is not a suitable option for them.

The debate on ethics in telecare was also seen to relate to the quality of services and the care and support provided. In this sense, ethics are more longitudinal and complex than a simple 'yes or no' to the adoption of a device. We must also ask whether the telecare in question is a service free of charge and for whom, and what happens to those who cannot afford it.

The discussion turned to the notion of choice and, in particular, the choice to live independently at home. Participants asked which are the options in the context of telecare and whether the notion of choice is a good basis for the definition of an ethical framework for telecare. It appears that in the context of older (vulnerable) people the idea of choice is a complex concept. This should not be seen as a simple decision in certain situations, but as an ongoing process that takes place in a complex and changing context, an ambivalent context of dependence and independence.

What does dependence and independence mean? Often, independence - for example, in the sense of being able to live independently at home - is only possible thanks to dependence on somebody or something, for example, depending on children, neighbours, technologies. Independence and dependence are closely linked. You can only choose to live independently if there is already a network of dependencies, i.e. relationships on which to rely. In this sense, we are not dependent or independent, but we achieve independence only because we are dependent (have reliable support). Therefore, being in need of care (dependent) is not necessarily negative, and having a single notion of living independently may be too simplistic. Ethical telecare technologies recognise that dependence and independence are not opposites but are intimately linked, and that decision-making takes place in this context. The debate concluded with the question of whether it would be better, therefore, to talk about desire or willingness rather than choice.

An Ethical Framework for Telecare

Introduction – what counts as ethics in this context?

A formal ‘Ethics Committee’ process usually involves posing a set of questions that must be answered. These are based on established ethical principles derived from classical philosophical texts, and concern, for example informed consent, avoidance of harm, right to privacy (Beauchamp & Childress 2009). Whilst such questions certainly should be addressed, we argue that in the context of telecare for older people living at home, they do not reach all the core issues encountered. New and unexpected normative issues may show up, issues that are not defined by ethicists in advance, but emerge in the ‘nitty gritty’ of using telecare devices. To address these, a different kind of ethical analysis is required, based on empirical research to unravel the issues encountered in actual practices: empirical ethics (Pols 2008; Pols & Willems 2010). A careful analysis of the normativities embedded in practice leads to questions such as: what new forms of ‘good care’ are being defined in the process of using new technologies (Pols 2009)? What normativities do the devices bring with them? (Willems 2010). To what ways of living with chronic disease does the use of particular devices contribute, and in the process what new dilemmas emerge (Pols 2010)? And how do these new forms of ‘good care’ relate to the goals that were formulated by policy makers, such as efficiency and self-management? So the empirical tradition approaches ethics from *within* care practices. Whether care is good is not judged from the outside, based on abstract ideas of what good care should be, as in traditional (bio)ethics, but engages instead the situated ideals, limits and reflections in care practice.

The EFORTT ethical framework is based on primary empirical research into telecare practices. It is topic-specific rather than universal and stems both from ethnographic analysis of existing systems and sustained debate with older citizens about the social and ethical implications of telecare. To assist this we developed a leaflet for families, carers and users based on the questions below but in a simplified form (Deliverable 5 Leaflet). The framework is laid out as a series of questions that should always be asked before designing, promoting, prescribing or installing telecare. These questions need to be asked at many levels: at design levels when considering who should be involved in both designing and trialling telecare systems; policy levels when decisions are being made about commissioning or funding telecare systems, and at the level of individuals and their families (when decisions are being made about installing a particular system in a particular home). The questions should be openly considered and deliberated: this is not a checklist for ‘yes/no’ answers, but a framework for ongoing debate and questioning.

1. What is telecare; and what could it be?

Who shapes telecare? Who is consulted, who participates in design? Who decides which needs are going to be met? Telecare should be designed and shaped through consultation with a broad range of actors. Older people are ready and willing to participate in these processes: it is up to industry, government and providers to facilitate this activity, in collaboration with established networks of older people. Telecare that is produced without appropriate and meaningful consultation and engagement will not meet the needs of older people.

2. What problems can telecare help with? How do other problems fit in or not?

Although telecare can be very useful in an emergency situation, and has other specific roles, it cannot function as a panacea for the problems associated with ageing. There are needs that

it cannot recognise or meet. When telecare is designed to enhance (or can be used for) social support, it seems very popular. More often, though, it is used to monitor older people who remain rather passive: if they are more active in using the system for social contact this is seen as 'mis-use'. How might telecare be used to promote social relationships that are more horizontal and active rather than vertical and passive?

3. Who is connected to the telecare system?

The installation of a telecare system opens up questions of privacy and confidentiality, highlighting complex issues about the ownership, use and control of personal information and sensor data. The availability of data raises questions about access to it. Information about an older person's activities in their home, or their feelings about their chronic illness, is powerful. The sharing of such information has the potential to change relationships of care: between parents and adult offspring and between paid carers and older people. Some developers recommend the use of telecare to monitor the capacities of older people living alone. It must be made clear to the older person at the point of installation that this might happen.

4. How might a telecare device change an older person's home?

The aim of staying at home should be opened up to question, rather than assumed. Although many older people strongly desire to remain in their own homes as long as possible, this might not be so appealing if 'home' is under scrutiny and is the object of constant monitoring through telecare. Telecare systems run the risk of turning homes into 'institutions'. Strong efforts should be made to minimise the disturbance to people's homes and designers, prescribers and installers must take seriously the objections of older people to such intrusions. Telecare devices can diminish people's sense of security despite their aims to do the opposite: they can make people feel vulnerable and scrutinised.

5. Who is the active user of the telecare system: the older person/and or somebody else?

Becoming a user of telecare is to take on a new identity and to accept a new network of connection in which older people have a particular (and quite limited) set of socio-material roles. There are notable differences in older peoples' experiences of telecare systems in which they maintain physical control in relation to activation (where they push alarms to request help) and those in which alarms are triggered environmentally. The latter lead to more 'false alarms' which create difficult work for tele-operators and others involved in monitoring, and can create unnecessary concerns for older people and their families. Using telecare systems puts older people into new relations both with people they know, and with people they have never met (but may come to know). These changes should be reflected upon and openly discussed with prospective users of telecare.

6. Is it worth the effort?

Telecare involves a lot of work for many different groups of people. Telecare creates new forms of labour, both for providers and so-called users. Telecare is not necessarily time or cost saving. In most cases, telecare cannot prevent negative incidents: it cannot stop people falling, becoming ill, or getting lost. Its two main functions are to triage assistance and/or to

provide support. Some telecare systems require a lot of effort from users, who need to log on daily or weekly to answer difficult questions and report on their health. Given that the telecare system is not usually going to prevent negative occurrences, is it really worth all this effort? Potential users and others need to balance the costs of the (material and emotional) labour involved against the benefits of being involved.

7. How might an older person acquire a telecare system, how long can they keep it and how can they remove it if they want to?

The prescription and installation of telecare is a complex process. Practical questions of cost to individuals and to health services are paramount. In some countries, national policies put pressure on local authorities to commission telecare services, which may then be prescribed to individuals who will not benefit. Families may also put pressure on individuals to accept systems they do not actually understand or want. There is a widespread presumption that telecare saves money by reducing demand for collective living and reducing demand on other care services. This assumption may be simplistic and needs to be carefully scrutinised and analysed. Who benefits from older people living at home?

Sometimes older people receive telecare as part of trials or pilot studies designed to test the acceptability and workability of particular systems. This is often a positive experience for older people, who enjoy being involved in a detailed analysis. It should also be recognised that trial results are often positive due to the care and attention this stage of development attracts from all concerned. Difficult decisions must then be made at the conclusion of such studies: it would be unethical to remove technologies from people who had become dependent on them without an adequate substitute. Conversely, it is sometimes unclear to older people how they can have telecare removed from their homes. This process must always be clear and easy to access. People must be able to change their minds about accepting telecare and the telecare itself should be adaptable (and open to supplementation or reduction).

8. What would happen if the older person's condition deteriorated?

Older people's lives can be subject to rapid change: often telecare is prescribed to very vulnerable people who are on the edge of being unable to manage on their own or who have serious chronic disease, with high support needs. Telecare systems are often installed as a 'last ditch' effort to help people stay 'at home'. The systems themselves, however, tend to be rather static, and unable to change according to individuals' changing needs. Some devices can be reprogrammed (e.g. bed sensors) but this requires ongoing analysis of how the current arrangements are benefiting the 'users'. In some countries telecare is not well supported, so devices remain unused: either because older people and their families do not understand how to use the device, or because the device no longer meets the person's needs. Individuals – both professionals and others – need ongoing training about telecare systems so they can use them as effectively as possible. Communication between all elements of the telecare network needs to be considered and planned: how will social services workers come to know whether a device is helping an older person or not.

Part Four: Implications for policy and practice

EFORTT's Critical contribution to policy debate

Current Technology Policy on Ageing

That populations in Western societies are growing older is routinely figured in European and national policy and research reports in terms of impending crisis for health services. Descriptions of a 'coming global wave of elderly people' are common. Claims about unsustainable future demand on health services are often supported by demographics such as projections for Europe indicating that the proportion of the population aged over 60 is set to rise from 15.9% in 2005 to 27.6% 2050 (UN World Population Prospects, 2005). Projecting the numbers of older people as 'the problem' which needs technological solutions is unethical and stigmatising and would be severely challenged if this was for example set in the context of disability. The European Commission's Thematic Portal, for example, notes:

Europeans are living longer than ever thanks to economic growth and advances in health care. Average life expectancy is now over 80, and by 2020 around 25% of the population will be over 65. Fortunately, the Information Society offers older people the chance to live independently and continue to enjoy a high quality of life.

(http://ec.europa.eu/information_society/activities/einclusion/policy/ageing/index_en.htm,

accessed 16 Feb 2011)

For policy makers and clinicians, telecare, telehealth and smart homes appear to offer solutions to rising demand while increasing monitoring (surveillance) and the speed of referral (efficiency) and health management decisions (Dept of Health 1998; Kendall 2001; Audit Commission 2004). The EC's portal continues:

ICTs can help older people overcome isolation and loneliness, increasing possibilities for keeping in contact with friends and also extending social networks.... Products like smart homes technologies (to control heating, lighting, and even food stocks remotely), electronic alarm systems and tele-health facilities can also help older people live in their own homes, ensuring that they keep their independence for longer.

(http://ec.europa.eu/information_society/activities/einclusion/policy/ageing/index_en.htm,

accessed 16 Feb 2011)

Health and social care service users also provide a conveniently large population for new technologies: without doubt, the most significant population groups targeted by telecare and smart home developers are frail older people, their carers and care providers. The EC describes the size of this market and the potential cost savings to 'society':

Europe's over 65s are estimated to be worth over €300 billion and the smart homes market is expected to triple between 2005 and 2020. New markets such as tele-health could help older people to get out of hospital and back home more quickly, thereby improving the sense of well-being and reducing society's health costs.

http://ec.europa.eu/information_society/activities/einclusion/policy/ageing/index_en.htm,
accessed 16 Feb 2011

However, on the basis of EFORTT research we think that this approach has three basic problems.

- A) That the population is ageing also means it is healthier – not everyone over 65 is in need of care. The 'crisis account of ageing' should be treated with caution, especially in so far as it is also stigmatising for older people.
- B) That the proposition that ICTs can help people live in their own homes and be independent, is to misunderstand what independence means and to place too heavy a burden on technology's role in providing 'solutions'. This also means that directing resources to telecare system development could potentially undermine independence, if it means that support for informal and formal carers, who provide the essential networks in order for telecare itself to work, is cut or neglected.
- C) That telecare implementation can be unethical, even coercive, if it is introduced primarily in order to 'solve the crisis' or save resources. If these are the conditions for telecare development and implementation, we believe this could leave older people trapped at home, isolated and while measures may be taken to protect privacy, this would come at the expense of dignity.

The myth of technological 'solutions'

The paradox of telecare systems is that they introduce scale and a new form of distance into home care work, whilst simultaneously making care appear more immediate. The 'carer' can be located far away and can therefore 'care for' multiple clients, whilst the availability of instant or continuous signs and signals about the client means that care appears proximal and continuous. Most of the older people we spoke with have either been carers in the recent past or are actually still caring for another person. In this way 'care recipients' can also themselves be carers. Again, there are paid carers (such as domiciliary home care assistants) and unpaid carers, such as family members. Sometimes these are termed 'formal' and 'informal' carers respectively, but that in itself does not do justice to the range of tasks being carried out in either case. We have noted that 'tele-care' is critically dependent on human interactions, the emotional labour that takes place between carers, cared for, and in telecare monitoring centres. There is a danger that these human interactions and sociotechnical relationships become invisible to commissioners and policymakers in search of technological 'solutions'.

Ethical Telecare: Recommendations and Proposals for Implementation

1. Gender and Care Work - Since home care is predominantly undertaken by women both as informal and (low) paid caregivers, telecare developments may have important consequences for gendered distributions of work. The introduction of telecare systems has seen the creation of a new tier of care workers – the telecare system operators. Again these workers are predominantly women, predominantly low paid. Telecare providers have initially recruited these workers from care backgrounds (such as care home wardens) and thus they have brought important face-to-face care experience to inform telecare work. This aspect of telecare quality is largely unrecognized. As telecare systems expand, it is feared by older people that these workers may be recruited from ‘tele-sales’ and other backgrounds, thus affecting the quality of service. It is also feared that this work may be outsourced beyond Europe. This would both reinforce the gendering of care work and the economic disadvantage to those workers.

There are dangers in further divisions of care labour in the context of older people living at home. Telecare attempts to produce a rational, cost effective and streamlined system in which:

- Monitoring or checking is reduced to a ‘purely technical’ procedure that can largely be done by machines, backed up by monitoring centre staff when alerts are triggered;
- ‘Physical’ care is seen as basic labour and is left in the hands of poorly paid women, often migrants; and
- ‘Social and emotional’ care is performed by loving, but busy, family members.

In practice, this attempt to reshape care tasks denies several complexities, and may work to sustain, and even deepen, a gendered, racial and classed division of care labour. **It is recommended that commissioners of telecare services specify the care element in telecare work and the need to maintain this in the recruitment of workers, and that policymakers consider how to protect this form of work from the effects of globalization.**

2. More effective inclusion of ethics in policies regarding technology development for telecare – our recommendation here would be to enhance and develop the use of older peoples’ citizens’ panels as discussed above. The inclusion of older people in the domain of telecare development is in itself an ethical principle, but it would also ensure that ethical issues were brought into practice in design, implementation and evaluation. The benefits of technical innovation are asserted by the European Commission in statements on e-inclusion. These statements also insist, however, that technologies should be (re)designed so that older people can access them:

The Commission recognises the power of ICTs to support older people and the community around them....Many older people face barriers in exploiting ICT products, services and applications to their full potential... Ageing is not always considered when designing mainstream products and there can be a distinct lack of industry awareness about older users’ capabilities. Even when assistive technologies are developed to help vulnerable groups, a lack of interoperability can hamper uptake.

(http://ec.europa.eu/information_society/activities/einclusion/policy/ageing/index_en.htm, accessed 16 Feb 2011)

However, we note that there is no specific mention of older people in the agenda for the 1st Digital Agenda Assembly to be held in Brussels in June 2011. We hope that the organisers will be able to use this report to build more explicit inclusion of older people for the 2nd Assembly.

Building on e-Inclusion policies, future research programmes announced by state funders and the European Commission could specify older people's panels and other forms of inclusive research methodology (i.e. diary keeping) in calls for proposals in the domains of care and technology.

3. Relationship with industry. Engagement with commercial telecare organisations, in particular on the design side, has been relatively slight in the EFORTT project following some initial enthusiasm from industry. This was disappointing and largely reflected issues to do with commercial confidentiality, i.e. protection of device development in situations of contracting or tendering for contracts. Industrial partners prefer 'research' to be in the form of product development, rather than e.g. critical studies of existing systems. This is one of the main differences between FP7 Science in Society and Ambient Assistive Living (AAL) programmes. But we argue that both initiatives should have an interest in 'responsible innovation' built on inclusive design. **We recommend that the EC finds ways to encourage industry to engage with critical research as well as more applied research, perhaps by setting up a small unit or facility to offer mediation of these relationships once research funding has been agreed.**

4. Future research programmes Many telecare systems generate copious amounts of raw or real time monitoring data which in turn generates more work for practitioners in finding ways to interpret and act on it. Some data is therefore never used, and this is an ethical issue. Discussion with developers indicate that there is an increasing interest in designing algorithms which can accommodate this problem and support or even take decisions about interventions for patients or users. Relying on algorithmic knowledge or automating decisions in this way could have serious ethical, social and direct clinical implications. **We recommend that future research examines these implications critically and thoroughly.**

5. Ethical telecare development If older people want to stay in their homes rather than move into collective living settings, societies need to think more creatively about how to provide care that is meaningful, sufficient and dignified. Ethical telecare development would be characterised by:

- **Ongoing engagement: older people want to be involved in designing, developing and decision making about care.**
- **On-site evolution, rather than being seen as a one-off installation of a fixed system.**
- **Feedback loops built into the installation and implementation process so that older people are 'living with' telecare rather than 'living because' of it.**

Implementation

In addition to the practice based implementation proposals above, the EFORTT coordinator is continuing a programme of dissemination aimed at influencing how telecare for older people is shaped. This includes meetings with commissioners of telecare, revisiting the Older Peoples' Forums to give feedback, and of course an ongoing programme of publication in a range of outlets. The training offered to the Lancaster University Older Learners Group leaves a sustainable research and consultation capacity (see below) with which commissioners and industry can engage and the

EFORTT co-ordinator is now seeking ways to have this model taken up by the other beneficiaries. This could help fulfil one of our main recommendations on ongoing engagement of older people in telecare technology and service design. Industry could make further use of ethnographic and deliberative methods and the coordinator is currently engaged with one company to promote this approach. Talks about findings are also being held with AGE UK, and the AGE PLATFORM Europe organisation has placed the EFORTT leaflet on its website and we will be following this up with them at future meetings <http://www.age-platform.eu/en/age-policy-work/accessibility/latest-news>.

The EFORTT consortium also welcomes the AGE PLATFORM Europe's response to the Green Paper on EU Research and Innovation Funding, in particular these statements:

The EU research agenda should allow not only for large projects, but also for smaller ones targeting specific issues, in particular projects on social issues involving citizens' groups. It should also smaller projects by civil society organisations to "translate" research projects outcomes into plain language to make it more accessible to the public at large, media and policy makers. This could have a significant impact on the scaling up of research outcomes.....

.... to address the challenge of demographic ageing in Europe: EU research should seek to help local and national policy makers find innovative solutions to meet the growing demands on the health and social sectors and notably on nurses, formal and informal carers.

The EFORTT group has identified the need to continue our work with policy, civil society organisations and industry in finding ways to implement 'ethical telecare'. This is new work which we feel it is essential to pursue and we hope that the EC notes the above recommendation on mediation between researchers and industry in particular.

The main dissemination activities

These include publications in academic, policy and practice outlets and a wide range of oral presentations by all members of the EFORTT research consortium. We are continuing to disseminate in all four countries to a wide range of audiences. Much of this work is around the substantive issues of care technology development, e.g. ongoing presentations to commissioners of telecare in the English case and ongoing consultation work with older people's groups. In Spain, there is also work drawing on the EFORTT methodology with officials in the Ajuntament de Barcelona which is very interested in ways of involving older people in processes of participation.

Interaction between EFORTT researchers and the Red Cross in Spain and the main telecare provider in Northshire England, prompted two different kinds of responses. First there is a technical/practical response that comes from the service providers and developers. Basically, the project is regarded as a contribution to enhance the quality of the service/technology. As we provide insights about the daily use of these kinds of devices, the results might be useful to change the design of the devices or the way care is delivered by the providers. For example, the Red Cross managers agreed after reading research reports, that it would be necessary to make the service more 'social', i.e. turn the telecare into a kind of catalyst to improve or create more social network around the users in need. Another response has been noted in both England and Spain that the results of the project (in particular as they articulate older people's concerns) corroborate the view of some professionals and practitioners, that telecare should not replace 'hands-on-care' services.

We would also draw attention to our editing of a special issue of the journal ALTER: *European Journal of Disability Research*. This journal itself is a recent development and we were invited to

bring out a special issue on Ageing, Technology and the Home. In it we raise the debate about the relationship between disability politics and activism and that of ageing and older people. **The underlying ageism we have noted above in policy development on telecare becomes more visible when compared with advances in thinking around disability. We have much to learn from the field of disability in our valuing of innovation and how we develop technologies, which can be truly inclusive of older people's needs and aspirations.**

Ongoing research by EFORTT team members on care and technologies:

Lancaster: Celia Roberts and Maggie Mort are now leading a study 'Living data: making sense of health biosensors'. The project will focus on people's everyday usage of information and communication technologies to collect, process, understand and share data about their own bodies. Funded by Intel Corporation, the Lancaster research will focus on two areas of health concern: conception and pregnancy, and personal genomics. The grant provides for two PhD scholarships for three years. The research will be broadly ethnographic, using mixed methods to address the variety of ways people make sense of health data and fit monitoring practices into their lives, and to explore how this is viewed by wider society. The ethnographic research undertaken by the PhD students will be enhanced by a deliberative forum (Citizens' Panel) to be run in the final year of the project in which members of the public will be brought together to discuss the ethnographic findings and deliberate on the social and political aspects of biosensing technologies. Our aims are to explore the 'nuts and bolts' of people's engagements with such technologies and to open up political, ethical and social questions about how biosensors might change our relationships with our own bodies, with others (humans and nonhumans) and to personal and social futures.

Christine Milligan is submitting a proposal for Marie Curie training networks in which designers and manufacturers would come to the Centre for Ageing Research (Lancaster University) to study research methods.

Several members of the Senior Learning Group at Lancaster University, who took part in citizens' panel meetings during the project, have received training in interviewing and transcription. Since the end of the study they have conducted interviews with older people to ascertain their views on the design, use and practicalities of telecare. They have used the EFORTT leaflet for users, carers and families as a basis for ongoing discussion, and are involved in running a series of workshops with the International Observatory on End of Life Care (Lancaster University) on Preparing and Planning for Future Care.

Oslo: Hilde Thygesen will spend three years from August 2011 on a project called 'care@distance' administered by the Diakonhjemmet University College and financed by the Norwegian Research Council. The overall aim of the project is to study how coordination of care services is achieved between hospital and home care services in the care of older people and those at the end of life at home. In particular it will look at the role of telecare in this.

Netherlands: A PhD researcher, Annemarie van Hout, is extending the work on telecare in palliative care project by studying a webcam and website application used by oncology nurses in home care. Jeannette Pols has sent out applications to continue research into telecare, with particular interest in patients' and nurses' use of telecare applications. The citizen panels remain available for consultations, and will receive the translated EFORTT leaflet.

Spain:

Miguel Domenech has submitted a proposal for the Spanish Ministerio de Ciencia e Innovación entitled “Consensus conferences in knowledge societies. An essay of dialogic democracy with older people and experts”. The research seeks to analyse the strengths and weaknesses of consensus conferences in terms of its capacity to assemble in the same collective experts and older people. He is also preparing another project to be submitted to the European Union, with a group of engineers developing technologies for active ageing.

Daniel Lopez is working as a Marie Curie researcher (FP7-PEOPLE-2009-IAPP) at the Vrije Universiteit Brussels in a EC-FP7 project called ‘Incorporating European Fundamental Values into ICT for Ageing: A Vital Political, Ethical, Technological, and Industrial Challenge (VALUE-AGEING)’, which continues from the work of the SENIOR project and aims to foster co-operation between commercial and non-commercial bodies to develop ethically oriented technologies to support ageing.

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