Periodic Report (18 Months) EFORTT 217787
Ethical Frameworks for Telecare Technologies for older people at home

According to the Description of Work (Annexe 1) the EFORTT project objectives are:

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 ethnographic and deliberative methodologies.
4. To use the above to provide appropriate ethical frameworks for the development and implementation of telecare technologies

WP 2 Ethnographies of Telecare Interventions

Work progress and achievements during the period

Overview – the report below details the telecare applications being examined in detail in each partner country with progress on the ethnographic data collection. Each beneficiary has collected extremely interesting and valuable data. All however, report fieldwork delays: in some cases the start of the ethnographies was later than expected due to delays in obtaining ethical committee approval, other report access problems to the field. While this has not resulted in any major deviation from the timetable in the first reporting period, <u>it is possible that we might need to request 1-2 extra months for delivery of the report of WP2 due in month 27).</u>

Tasks outlined in Description of Work:

- Contact appropriate sites and make initial visits (Month 3) **DONE**
- Secure approval to conduct research at the site, including approval from relevant ethics committees, if appropriate **DONE**
- Discuss and circulate a shared interview topic list amongst partners. This will be frequently reviewed as ethnographies progress **DONE**
- Begin ethnographic research (12 months field observation; taking fieldnotes; interviews; collecting grey literature) (months 4-16) **ONGOING DUE TO DELAYS**
- Transcribe interviews and fieldnotes continuously and develop both setting-specific and shared analytic grids, to ensure comparability over specific contexts **ONGOING**
- Complete ethnographic data collection (month 16) and continue ongoing analysis of data **ONGOING** (see above)
- Select field notes and transcriptions for translation into English for WP 4 (month 21) **UNDERWAY**
- Each beneficiary to produce report for WP2, to be circulated with field notes and transcription samples, as part of WP 4 (month 22).

Spain

Fieldwork has been organised in collaboration with the Red Cross-Catalunya and the Red Cross-Madrid. We have signed two different agreements between these local organizations and the Universitat Autònoma de Barcelona. Specifically, the ethnography focuses on their Home Telecare Service and SIMAP Service (Personal Location Service on Intelligent System of Monitorisation of Personal Alarm). Both fieldworks take into account all the places and agents involved in these services. Thus fieldwork has taken place in the alarm centre and offices and also followed the workers' day (routine) and the users' home and daily life.

So far, ethnography of the **SIMAP Service** (GPS tracking system for people with dementia in Catalunya) has been only developed using documentary data. The next research steps will be observations on the alarm centre, observations with users' families and workers, discussion groups and in-depth interviews with carers, users and their families.

Ethnography of **Home Telecare Service (HTS)** (in Catalunya and Madrid) is designed in six different methodological stages and techniques: documentary analysis, observations of the alarm centre, observations with installers, observations with volunteers, discussion groups and in-depth interviews. In both places, Catalunya and Madrid, we aim for the most heterogeneous sample of cases. We are studying rural and urban context, public and private services (depending on whether the service is funded by city councils or users), different health situations and ages of users.

As we are analysing the HTS's ‘daily course’, the fieldwork proceeds from service design and implementation, through users signing the telecare contract, to installation and use. In this sense, we are compiling and analysing documents about laws, design and testing, and we continue observing the work of the Red Cross Organization. We observe the process of contracting with the user, installation of the service and then we research how it is being used by users, and also by their carers and families.

Documents

We have compiled different brochures and documents about technical, legal and political regulations of HTS. We have also analysed internal documents and national and international literature.

Observations

We have made observations in the alarm centre and with installers, going with them during their working day. We have also made observations with volunteers, going with them to some users’ homes. This brings us into contact with the users who will subsequently be interviewed. We have collected field notes and also some photographs and graphical documents.

Observations so far in Catalunya: we have attended 10 installations, 6 breakdowns, 3 follow-up visits, and 1 change from private to public service. In Madrid, we have attended 12 installations, 27 breakdowns, 9 withdrawals, and 2 changes from public to private service.

Interviews
We have finished interview stage with Red Cross' workers: coordinators, managers, installers, volunteers and other academic people who work on this field.
Going out with installers and volunteers and observing their daily work, puts us in contact those users who will be interviewed in depth. This way, volunteers act as 'key informants' during observations for meeting users and relatives. Once we have made the contact through volunteers and technicians, we arrange the appointments directly with users. In this way a period of observation ends up with in-depth interviews in order to complete all the information collected up to date. Currently we are conducting interviews with users and their carers or relatives.

In Catalunya, we have planned eight in-depth interviews with recent and long time users from rural and urban context. They have also different ages and personal situations (living alone, with their partner/spouse, with relatives or formal carers). We have also planned four interviews with volunteers and four with carers or relatives. In Madrid, we have planned four interviews with recent and long time users from rural and urban context, two with volunteers and four with carers or relatives.

Group Discussions
In Catalunya we have carried out discussions with one group of users, one of volunteers and technicians, one of professionals carers (nurses, doctors, politicians/policymakers, social workers) and one mixed group. We are planning two more groups of users (one with older people from social housing), one more group of volunteers and technicians, one of tele-operators, and two groups of carers and relatives. In Madrid we have planned one group of users, one of volunteers and technicians, one of tele-operators, one of carers and relatives and another mixed group.

Most of the interviews are transcribed verbatim and ready for analysis. Detailed fieldnotes were made. At the end of the project, a brief report will be written for the Red Cross Organization, in order to evaluate their home telecare service and users' opinions.

Literature
A literature review of telecare, autonomy and ageing was carried out as planned.

Ethics committee approval
All observations have been carried out within an ethical framework defined by the agreement signed between the Red Cross (Catalunya and Madrid) and UAB. In addition, every in-depth interview is made only after an informed consent form is signed by respondents. This form was designed following the indications and protocol of UAB's ethical committee.

Time schedule deviations
Because of the newness of the SIMAP service and the lack of users (only 16 people in Catalunya), we have not been able to start the observation stage of the fieldwork. As this system depends on the political agreement between Red Cross and the Catalonian Government and this has been delayed, we may focus on the Home Telecare Service and make a wider analysis of it. That is one reason why we are working in two locations: Catalunya and Madrid.

The interviews and group discussions' stage of the fieldwork lasted longer than planned because of the difficulty in accessing respondents. As the sample of users needs to be heterogeneous it can be quite difficult to arrange an appointment for eight people in one group. Because of this delay fieldwork may progress more slowly than planned.

Results
Although the analysis in ongoing, some remarks can already be made.

Ideas about feeling secure at home seem to have changed with the implementation of 'risk technologies'. The notion of immediate attention offered by HTS has also changed, in that HTS does not appear to work as a rigid system protecting older people against uncertainty, but more as a way to manage uncertainty in a productive way.

Contracting for and installing the HTS is a complex negotiation process between company/providers, users and relatives/carers. At the moment, the notions of responsibility, needs and 'correct' use are fluid and distributed among all these agents, not only users nor company. This means it becomes important to ask what kind of older people are being configured (installed) through this process.

The emergence of private/commercial companies in telecare market is unleashing some fears between users and also professionals: there is possibly some devaluation of the 'social' aspects of the HTS (compared with the health aspects of it) and an increase in 'management solutions' without sufficiently taking into account the personal experience of users and workers/practitioners.

Norway
Ethnographic fieldwork has been conducted in three settings:

1. TrygghetsNett (SecurityNet)
2. Mpower
3. Participation in a workgroup organized by the Norwegian Health Directorate with an aim of producing a new guideline for the use of technology in care of persons with cognitive impairments.

1. TrygghetsNett (SecurityNet) is an internet-based service for next-of-kin whose spouse is suffering from dementia or stroke. The aim is to provide a support-network for this group, partly by linking the next-of-kin together through the internet-based service. The service also involves a base, which is run by health care staff from the municipality. This base is open three hours a day, Monday to Friday. The participants, who are enrolled by the municipality, have to pay for their own equipment: a computer, an internet camera, and modem/cable access. Within the network the participants can contact other individual participants and participate in discussion forums. TrygghetsNett was organized as a time-limited project, and limited to one municipality. However, due to the overwhelming positive response from the participants, the service is from 2009 to be extended to 12 municipalities in the same

region. This means that three more bases are to be established in the region. However, due to technical problems the extended service is not as yet fully operative.

Observations and interviews
Observations are being done by being present at the base of the initial municipality, following the (electronic) written discussions of the forum, as well as listening to the conversations the base-staff have with the individual participants. Five field visits have been are conducted, more are planned in the coming months. Repeated requests for field visits to the new base-stations have been made. However, due to technical problems and other practical issues, these requests have not been met so far, though are expected in the coming months. Interviews are conducted with participants. One was conducted over the SecurityNet, which meant that it was possible to have face-to-face contact through the webcam, one interview was conducted at the base and one interview was conducted over the telephone. More individual interviews, with base-staff, administrators and participants are planned in the coming weeks. In addition participation in different group interviews organized by the local University College as a part of a formal evaluation of the expansion of the SecurityNet services has been agreed.

Other sources of data
Transcripts from the discussion forums dating back to 2004, when the SecurityNet was first established are studied and categorized. Also information-letters, notes from meetings and newspaper articles on the SecurityNet are included in the analysis.

2. MPower is an EC-funded project which involves the Norwegian Association for dementia care research. An ICT-based calendar-function is developed and tested out as a part of the project. The target group is elderly persons living at home with a mild cognitive impairment. By providing on-going and up-to-date information about important events and tasks through the calendar, the aim is to make it possible for the person in the early stages of a dementia illness to be more self-sufficient and to be able to live at home for longer.

Observations and interviews
The technology has been tested on three recipients of home-based services in the city of Trondheim. Two home visits made it possible to see the technology in use and to interview the participants. We have also interviewed the nurse in charge at the home-based services and the dementia-services coordinator, who was responsible for the implementation of services. Further interviews are planned, involving next-of-kin and (technological) service providers.

3. Participation in policy-work, establishment of new guidelines
The Norwegian Health Directorate has invited Hilde Thygesen (EFORTT researcher) to participate in a reference-group working to establish new guidelines for the use of technology in care of persons with cognitive impairments. The process of compiling the new guideline is expected to be completed in 2010. So far she has attended three meetings. Extensive field-notes are taken from the meetings, and are written out verbatim. Interviews with key members of the group have been set up.

Time schedule deviations
The fieldwork was delayed by several months, partly as the project had to be approved by the Regional Ethical Committee. This approval was only granted in November 2008. Another major reason for delay has been difficulties getting access to my main fieldwork-arena, SecurityNet (TrygghetsNett). This has partly to do with the planned expansion of the SecurityNet and unforeseen technical problems that have taken a long time to be solved. Another important issue with regards to getting access to SecurityNet is related to the fact that there are already a number of researchers involved. Involvement has had to be coordinated with other researchers to avoid putting too much strain on the participants. This coordination has proved to be time-consuming. Fieldwork started in February 2009.

Results
Analysis is ongoing, however, it is clear that the participants involved in the SecurityNet experience this network of contact and services to be very important. Many of the participants are in daily contact with each other, and view the other members of the network 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 clearly very important. The base-station serves as a direct link to the Municipality's services. The base-staff inform users about services, advise the participants on any medical matters and for example assist in filling in forms. And 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 on regular intervals, for example to get an update on the situation. Also in the MPower project it is clear that very simple technological solutions have an important function for the individuals using them. The fact that very simple solutions (which both SecurityNet and MPower are based upon) makes such a difference for the individuals involved, has been most surprising finding so far in the fieldwork.

The participation in policy-work brings the legal and ethical issues of telecare to the forefront. Much effort is put into 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.

Netherlands
Fieldwork has been organised in collaboration with a hospital in the north of the Netherlands (Sneek, Friesland). A telecare device called the 'Health Buddy' has been studied in use in palliative oncology care. The patients were receiving another round of chemotherapy treatment, not for the purpose of cure but for life prolongation and symptom relief. This telecare project aims to provide better quality of care to a group of patients that tended to stay away from the hospital, even if they had problems. The aim is that this should be achieved without extra costs.

Interviews
With patients, 15 interviews were done (two more will follow). Five of the interviews were with couples rather than the patient alone. All respondents were over the age of 50. The oncology nurse was interviewed several times: twice face to face, frequently on the telephone (progress reports). The interviews are transcribed verbatim and ready for analysis.

Observations
Observations were made during home visits with the oncology nurse at a patients' house. The patient got instructions for chemotherapy and was introduced to the telecare device. During the home visits the placing and the use of the telecare device were observed. The nurse using the telecare device was observed, which had the effect of asking her to 'think aloud'. Detailed fieldnotes were made. A report will be written for the hospital, who may use this in their discussions with financial partners.

A second research site was contacted for fieldwork study: the use of a web based system for video communication (with nurses and friends), including a range of other services (shopping, entertainment etc). The system is called PAL4. The aim of this project is to enable older people to assist each other and to lower the threshold for asking for care by 'wrapping it' with other kinds of services. The fieldwork has been scheduled for October 2009. Interviews with and observations of users are planned, as well as with the professional integrated in the service.

Other sources
Study of information leaflet on cancer, palliative cancer care and chemotherapy. Study of project documents. Visits to the project team meetings. Two follow up calls for patients.

Literature
(Grey) literature study was carried out as planned.

Ethical approval
Because it is qualitative research, no ethical approval is needed in the Netherlands. However researchers are bound/required to cause no harm or distress in their work. For this study a privacy protocol was devised and so that patient respondents would be contacted by their nurse. She would give them an information leaflet and an informed consent form. When this form was returned to the nurse, she would forward it to the researchers, who were then able to contact them.

Time schedule deviations
Because of difficulties in finding accessible field sites (the Dutch telecare projects are often over-researched) and the start of the Friesland project, the fieldwork started later than we planned: in October rather than in June (month 8 rather than month 4). Because of the delay, and the addition of a second site, fieldwork may progress somewhat longer than planned.

Results
Although the analysis is ongoing, some remarks can already be made.
What was interesting was 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 (use of telecare technology) seems particularly ambitious.

Initial findings, however, 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 to the nurse. They also experienced it as a way to help the nurse care for them. They felt safe and secure. Often, the questions asked about the telecare device served to engage the spouses in conversation about what lay ahead of them. Clearly, when one of the partners has cancer, the other suffers from it too. Telecare devices could develop more in this direction.

England

The Lancaster ethnography has focussed on the implementation of state-funded telecare in one particular county (municipality) of England that we call ‘Northshire’. Details of activities undertaken are listed below. Recorded interviews have been transcribed verbatim and detailed field notes made of each observation.

Interviews

To date we have: formally and informally interviewed key players: county-level managers; project leaders; county and local telecare ‘champions’; social workers, and technology providers (N=9). Interviewed a carer whose father had been prescribed telecare (N=1) – follow up on effect of the system has been scheduled. Convened a local group of occupational therapists involved in ‘prescribing’ telecare (two meetings, not recorded but notes taken)

Observations

To date we have observed: the work undertaken in two telecare monitoring centres and interviewed workers (6 visits); visits by social workers to older people in the homes in connection with telecare (N=3); telecare installations (N= 2); one social worker undertaking an annual review of telecare provision (N=1); regular meetings of the county’s Telecare Steering Group (N = 8); a promotional event hosted by a key telecare provider (N=1); a telecare project evaluation conference held by Northshire (N=1).

Other sources

We have been collecting relevant media articles, promotional and informational leaflets and exploring relevant websites.

Literature

Our examination of the relevant academic and grey literature is ongoing.

Ethical approval

This was obtained from the relevant authorities in Northshire to conduct observations and interviews. This is not the formal National Health Service required approval, but permission under the social care services system as most telecare implementation is being carried out as social care rather than health care. For recorded interviews we ask participants to read a project information sheet and sign a consent form.

Time schedule deviations/deviations in use of resources

There have been no major deviations from the work plan as stated in the proposal. We have met our objectives so far: research is continuing as planned (details below).
We have made one minor change to our use of resources, which was to employ a consultant researcher, Elham Kashefi, to conduct some observations and interviews, particularly with members of the Asian communities in Northshire. Progress with fieldwork has however been slower than expected, particularly since the re-organisation of social services (and social workers role) has resulted in delays in arranging visits to users or referrals. This has been unfortunate since they are the main

‘gatekeepers’ to access. We are taking steps to resolve this by finding different access routes.

Results
We have begun to analyse and write about our results (see publications list). To date we have focussed on the ways in which ‘care’ is understood with Northshire’s telecare system, looking critically at the ways in which ‘care’ is divided up within the implemented system. We have also considered cultural understandings of the ‘home’ and how telecare affects these understandings. We have observed that telecare monitoring centre work is far from the simple ‘technical’ system operation that it appears in promotional material – rather it involves emotional labour: managing anxiety and the ‘unseen and/or unknown’ aspects of the work. To do this work well, also involves a high degree of intuitive, tacit skill.

WP3: Citizens’ panels

Overview The first round of panels has been conducted with very useful results for the project as a whole. It was soon realised that both older people and carers would find it difficult to meet over two days so this was shortened to one, and consequently most partners have held more than the minimum number of panels. State/municipality provided telecare by its nature is targeted at those who are ill, frail or very elderly. This section of the general population is hard to reach and often lives in a ‘parallel society’, often visible only to those who care for them. This explains some of the difficulty which research projects have in recruiting respondents from this population group and their under-representation in governance systems generally. Therefore the panels we have convened so far have been made up largely of older people who are not yet classed as ‘frail’. It was also realised that many carers may also be elderly themselves. Contacts with frail older people (who cannot attend group meetings) are taking place in the course of the ethnographic work, with individual or with families. The report below covers only the first round of panels. The second round will attempt to reconvene the first panels (where it is possible for members to attend) and will discuss the emerging findings and develop principles for the ethical framing of telecare services.

- Recruitment of panels by each beneficiary (month 3) **DONE**
- Development of common presentation about the project and its goals (month 4)
- Gaining informed consent of participants **DONE**
- Panels consider the research questions (panel 1, day 1) (month 5)
- Panels debate, proceedings recorded (panel 1, day 2) (month 5) **DONE AMALGAMATED**
- Reconvening of panels (month 24)
- Presentation to panels of initial findings from WP2 & data clinic analysis (panel 2, day 1) (month 25)
- Recorded debate on the above (panel 2, day 2) (month 25)
- Consultation with industry representatives on draft report (month 28)
- Production of report (month 30)

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Spain

1st Session: *19th July 2008, Casa Convalecencia. Barcelona*

This session was dedicated to collecting the opinions of participants about ethical needs for telecare, technological perspective of the field and some guidelines for designing health politics.

Groups of participants: *(All of them signed an informed consent form)*

Older People (7 persons)

- Ms. An. (Terrassa) Alone / No-Telecare service
- Ms. L. (BCN) Alone / Telecare service at social rent building
- Ms. M.J. (BCN) 24h. Domestic caregiver / No-Telecare service
- Mr. X. (BCN) Alone / Telecare service (Red Cross)
- Mr. Jo. (BCN) Alone / Telecare service (Red Cross)
- Mr. Ba. (BCN) Alone / Telecare service (Red Cross)
- Mr. E. (BCN) With sister / Telecare service at social rent building

Carers: family, formal and informal carers (4 persons)

- Ms. T. (Terrassa) Elder woman's neighbour
- Ms. Ni. (BCN) Elder parents' daughter (one with Alzheimer’s) but not living at the same home
- Ms. V. (BCN) 24h. Domestic caregiver
- Ms. N. (BCN) Elder parents' daughter (one with Alzheimer’s and the other with reduced mobility) and living altogether

Main findings (Points of discussion)

Older People's Panel:

Home telecare users and care relationships

Participants pointed out a general deterioration in care relationships and mutual assistance related to an increase in individualism, indifference and loneliness. The entry of private companies into telecare market was thought to bring some threat already perceived by users: devaluation of the ‘social’ part of social-health services and increase of ‘management’ solutions.

Using a telecare service doesn't cancel or shouldn't cancel familiar and personal care relationships but it allows co-presence not to be necessary. But in fact, in order for the service to work beneficially, the collaboration of users' social network (relatives, neighbours or friends) is necessary. There is a consensus that staying as long as possible in one’s own home represents the ideal/desire and that older people should have autonomy.

Benefits and risks of home telecare services

There is general consensus that telecare service is beneficial. Home-telecare service is good for assistance and consolation. It may supervise the state of mind and user's health by means of, for example, controlling medication. It provides company, protection and security to users and to their relatives. They live quietly alone with ‘virtual’ company.

Conditions of use for telecare services

Reasons for installation: related to a perception of being threatened (by a ‘fright’, by prevention of risks...) or of loneliness, more than because of the advanced age or an illness.

Resistances to use of devices: Some older people don't wear the pendant alarm because they are afraid of wetting it or damaging it during their daily activities. Some of them never wear it and others don't wear it while they feel well. If they were in an emergency, then they would agree to wear it. They avoid calling the service for fear of ‘disturbing’ them. They call their families rather than the telecare service.

Future developments

Although using video-cameras at some buildings' entrances could help as a security device, video communication as part of a telecare-service is viewed negatively due to the fear of being controlled and having their intimacy and privacy invaded.

Users think that telecare service is easy to use, although it can be uncomfortable especially if they have to wear the pendant alarm while they are sleeping. There are proposals to develop a bracelet that incorporates a location system that could indicate where the user is at any given moment. Because it would be permanently connected to some location network (by GPS), there wouldn't be any risk of loss.

There are proposals to design a mobile device with capacity to detect any anomaly. It could integrate several sensors and measures, as it happens with universal remote controls. There would need to be aesthetic criteria for technological design of devices: ‘Design must be brought up to date...fashionable’. Such devices would have to meet usability, comfort and simplicity criteria, and be easy-to-use, easy to wear and understandable. Universal accessibility and social economic criteria: the devices would have to be universally affordable.

2) Carers' Panel:

Home telecare users and care relations

Participants pointed out a general deterioration of care relationships. Increasing individualization forces society to adopt these kinds of measures. There should be research into how to change people's attitudes (for increasing compromise, mutual help, collaboration). Instead of promoting social networks, telecare is promoting individualism. If loneliness has been detected as a real need/problem then the funding of telecare to try to ameliorate it), may reproduce the same problem that it is trying to solve.

Telecare service is a palliative service but can never replace affection and care among human people. Lonely people need other people for company, conversation, help.

Tasks like cooking, cleaning, etc cannot be replaced by telecare services. It means that this kind of technology doesn't materially change the situation of women.

It is considered as an additional caring tool. It can be considered as a compensating tool for lack of health, company or family. Telecare seems more valued as a health resource than as a social resource (which should be covered by the user's own social networks). Telecare services and devices are thought of by participants as complementary tools, but not as substitute ones.

In participants' opinion, good care is that which attends to the needs of the frail person (affective, living) and tries to make them happy. The definition of care depends on cared-for people's perspective about well-being. The concept of 'care' is something new (in Spain). It has professionalized some tasks and roles that in the past were assumed, naturally, by friends and family. Good care would mean to choose the conditions in which you want a caregiver - how you want your needs to be covered. Participants are afraid of 'smart' technology 'by decree'.

Benefits and risks of home telecare services

Related to risks & shortcomings of telecare services, participants think that older people using telecare should not have any kind of neuro-cognitive limitation. There is a 'gap' in the service in case of mentally ill or deaf people. The user needs to be conscious to be able to press the alarm button, people must have some (autonomous) capabilities. The service doesn't work outdoors (not enough range in case of big country-houses). The economic and social conditions for applying for financing of the service are very hard. The entrance of private companies into this 'care market' may deplete the quality of telecare services because it is commercialized: it may mean greater turnover of staff, at the expense of attention and quality, with less rigorous training requirements, etc...When municipal institutions are breaking down under pressure and there are a lot of demands, they subcontract to private companies and consequently lose control of the capacity for evaluation and keeping track of service quality. There are some risks of losing personal information or making poor management of information. Hiring telecare service may also have the effect of lessening the responsibility for care that relatives' might previously have felt for their older family members.

In case of benefits of telecare services, participants think that it can control users' medication better than 'present' caregivers (because of computerized medicine dispensers). It can give peace of mind to users who are afraid of falling and not being left without help. It provides company. It provides security. In relation to Public Health System, offering this kind of service could mean a large financial outlay initially but then, it could probably mean saving money.

Conditions of use of telecare

Participants pointed out that the ideal situation is being able to choose those devices that can response specifically to each person's necessity.

Telecare service should be recommended to (KIND OF USERS): Older people living alone. Caregivers whose relatives need constant attention but they also need to leave them for short periods. People who need constant care. Older people who don't want to live with a domestic caregiver.

Telecare service should NOT be recommended in case of: In case of loneliness and depression: the better option is to take up time with activities. Another option is calling *the hope telephone*, but not hiring telecare services. In case of young people, it would be good to go out but not to use telecare service. On the contrary, everybody would end up using it. People who live in an old people's home. They are assisted by nursing staff.

About installing the telecare service: It should be the users themselves who decide to hire it or not, even when the service is already included in social rent apartments. If this is not possible then relatives should do it. They think that most of people prefer to live alone while they are healthy and independent, even if they can afford to pay for care. In these cases, they prefer to hire a cleaner rather than a caregiver.

Future developments

If they could shape public policies about health...: Firstly, they would implement telecare services in order for people to be able to stay at home for as long as possible. Secondly, if people need more attention, they would suggest a domestic caregiver.

Suggestions for future designs: Improving research about ‘emotional’ technology: Mobile phone can be thought as an emotional device because it makes it possible to maintain social networks. Easy-to-use criteria: it should not require a lot of changes in their habits and daily lives. It would be necessary to protect personal data used by informational devices. When users sign the contract for telecare services (especially those where biological and personal data are constantly controlled) they should be informed about all conditions and consequences. Video-conference included in telecare services is positively valued because it can be perceived as a more intimate form of contact. But in case of people with dementia, it might confuse them.

Evaluation

Citizens' Panels have provided relevant and very useful information about older peoples’ and carers' perception of telecare services. In this sense, we consider we have achieved the objectives of this WP. Nevertheless, we think that the final number of participants (especially in carers' panel) is not enough for getting different and heterogeneous opinions and perceptions. Maybe the intensity of the program (from 10h. to 17h.) and the trip to the location (especially to older people or carers from rural areas) are two difficulties in the way of wider participation. For the second round of panels we are planning some changes and corrective actions: besides increasing the number of invitations to carers and elder people, we want to make the panel more accessible. To facilitate this, we propose to design a shorter program and organize one extra panel in an old people's home. In this way, by moving to their ‘natural’ context, maybe we can increase the number and sample of participants (related to age and personal situation) and also the heterogeneity of their opinions.

Norway

Citizen Panel meetings:

1. Elderly citizens: 8. September 2008 (6 participants aged 65 and older), meeting at Diakonhjemmet University College (Oslo).
2. Carers’ panel: 10. September 2008 (8 participants formal/informal carers), meeting at Diakonhjemmet University College (Oslo).

3. Mixed panel: 29th October 2008 (8 participants: old citizens and formal/informal carers), Furuseth nursing home (Oslo).

The panels were introduced to the EFORTT-project. Slides with pictures of different forms of telecare technologies were then presented for the participants, and formed a basis for the discussions.

Results/discussion:

1. Elderly citizens panel:

   It turned out to be very difficult to recruit elderly citizens receiving care-services for the panel. So despite especially targeting this group, none of the participants of the elderly citizens group received care-services. However, three of the participants were spouses or close relatives of patients receiving both home-based and nursing home services. The other three participants were engaged in various types of voluntary work: one as a ‘patient friend’ at a nursing home, and two as active members of ‘seniornett’, an organization working with teaching senior citizens how to access internet.
   In the discussions the participants stressed the need for telecare technologies to be used as a supplement and not replacement of human care. At the same time the panel emphasized the potentials of telecare. “Telecare solutions may give the carers more time for caring”, one of the participants stated. Other participants pointed out that telecare may improve the patients and next of kin’s feeling of safety and security. The group agreed that the equipment needs to be simple to use. But the use of telecare also implies a number of challenges, the group agreed. One such challenge is to provide safe means of storing sensitive information.
   A main issue was safety and security. And the group agreed that if being monitored by a camera (or sensors) increased their feeling of safety/security, it would be a good thing. But in order to make the use of a camera a good solution, there should be a possibility of switching the camera off. In this way certain situations and settings could be kept private, the group pointed out.

2. Carers panel:

   The carers’ panel consisted of a selection of informal and formal carers. The formal carers represented both institutional and home based care. This panel was considerably more skeptical about telecare than the elderly citizens’ panel. Much focus of the discussions was on limits of technology for care (work). Technology does not solve the problem of loneliness, and care-at-a-distance does not compensate for human care, it was stressed. The group agreed that the use of telecare must be voluntary. Issues of confidentiality were also discussed. Who can you trust? And what happens if the technology fails? One of the participants had hands-on experience with the use of telecare technology as her husband, who was suffering from dementia, had tested out a GPS-based tagging device. Her experiences were positive, both for herself and her husband. Having the GPS device meant that he was able to continue his daily walks in the nearby forest without fearing getting lost. And knowing her husband’s whereabouts made it possible for her to resume activities such as singing in the choir and exercising; activities she had not been able to do for years, she told the group.

3. Mixed panel:

   The mixed panel consisted of the participants at a voluntary carers meeting at Furuseth nursing home. The group consisted of a mixture of formal and informal carers as well as two next-of-kin, who were also elderly citizens. The panel expressed a clear interest in telecare solutions. One of the issues discussed was related to the payment for telecare equipment. Will the technology be distributed through the normal channels of technical aids, and hence be financed by State founding, or will it be a private/individual responsibility? If the funding of telecare technology is to be an individual responsibility, the result will be unequal access, the group agreed.

All the panels were recorded and typed out verbatim.

Netherlands

Panel 1: (Potential) Users

Date & location 10 November 2009, Utrecht. *Particpants:* 14 People had promised to come, 8 did come.

Panel 2 Informal carers -1

Date & location: 24 November 2009, Utrecht. *Participants:* Due to bad weather, of the 13 the participants that had promised to attend, 5 were able to make it to Utrecht.

Panel 3 Informal carers -2

Date & location: 2 December 2008, Amsterdam. *Participants:* Of the 11 people who promised to come, 7 people attended. All had a Surinamese background.

Structure of the panel

The meeting started by asking what ideas of good care the participants had and problems they feared for or wanted to see solved. This was to foreground needs rather than technologies. The technologies were introduced in the second part of the meeting: a monitoring device for heart failure; webcam communication with a professional carer or informal carer; internet & email; alarms & sensors; robot pets.

Consent

A 50 euro book token was given to all participants and a lunch was served at the start of the meeting.

Organisation

All meetings were chaired by Professor Willems and Dr Pols, reports were written by Pols and a freelance project assistant

Recording and transcription

The meetings were digitally recorded, a report was written on the spot, and the recordings were transcribed by the project assistant.

Deviations from the Description of Work:
Three panels were organised instead of two. The reason for this is that the recruiting of panel-members was difficult. Older people with chronic conditions had difficulties in travelling. Likewise, the informal carers found it difficult to take time off for a panel meeting. Utrecht was chosen for a meeting point, because this was easier for people travelling from different places in the Netherlands. For panel 3, Amsterdam was picked, as all the participants were from Amsterdam.

Because of this delay, we followed many avenues to recruit panel members, in particular an advertisement on a website about activities for older people (50+net), promptly supplied us with many volunteers. The National Platform of Informal Carers in Amsterdam had been busy organising their members at the same time, and this is the reason why we suddenly had more participants than intended and we did not want to disappoint them. And some were recruited via the carers supporting a webcam device program.

For these reasons, the panels took place later than planned. This had no impact on the other project activities.

Significant results
A first conclusion is that citizen panels are difficult to organise for this particular target group. Many people called to say that they were interested, but were not able to travel.

Most people attending said they came to the panels to *gain* information, rather than to give opinions. They particularly wanted to be informed about ‘where one could get’ telecare services and ‘what this would cost’. Most people did not have opinions about *medical* technology (which is the main source of development of telecare in NL). They dealt with these technologies by saying ‘if you need it, you will have to use it’ (if the doctor says so). Only one participant in 3 panels contradicted this. Some participants were really ‘hungry’ for *any* kind of telecare, although most argued for telecare that was flexibly tailored to individual needs.

All users expressed the fear that technologies would somehow make care less personal and humane. They feared technology would take the place of helping hands and supporting chats. ‘Human contacts’ were mentioned as the most important aspect of care to them.

Potential users often reported what we think is an exemplary fear for older people of today: the fear of living alone in one’s own home, without being able to contact someone if something happened to them (such as a fall). We analysed this as a typical fear that comes with the modern policies and ideals of staying home as long as possible. Alarms were the forms of telecare that got most enthusiastic responses, although people detested the design (the devices are ugly and have to be water/shower proof). People felt they needed someone to turn to for support when there was ‘trouble’.

Privacy considerations were often overruled by this fear of being alone and having an accident. ‘The most important thing, it seems to me, is that there is a webcam that goes through the house to see if I am not lying on the floor. Twice a day, I’d say.’

Interestingly, ‘trade offs’ between old and new forms of privacy were made. Participants expressed a reluctance to be looked after by many different persons in their house, and would then rather be watched by a web cam, not having to meet their various observers. They would see this as a winning back of their privacy. Or with GPS following people with dementia: the possibility to go out alone, being watched by GPS, is traded off with having to be accompanied all the time, which can be experienced as much more intrusive.

All users were concerned who would pay for the telecare services. They fear the accessibility of care will diminish when people have to pay for it.

Informal carers wanted telecare provisions that could help them support their spouse ‘at a distance’. Spouses living with the person in need of care would feel very supported if telecare technology would allow them to leave the house every now and then. The 24 hours ‘on duty’ and the fear of what might happen if they have to leave anyway, is particularly heavy on them. The informal carers feared that informal care would be more difficult in the future, with economic demands and people living further apart from their spouses. The informal carers expressed the fear that the persons they cared for would not be able to use a computer.

Dependency on technology is sometimes experienced as unreliable: what if the electricity fails? Many informal carers gave examples of the cared for who did not wear their alarms properly. They also worried that professional carers using telecare would make more mistakes, as they feel information is transmitted less reliably. Likewise, the reliability of internet information is questioned.

No users and informal carers liked the robot pets and thought they might be good for people with dementia. One of the panel participants had a little dog that might warn him if his attention was needed by his wife, providing alternative for communication technology.

The difficulty of the use of telecare devices by people with dementia was often expressed. One new idea for a telecare technology was suggested: bowel and bladder sensors that could alarm the informal carer when the patient needed the toilet but were not able to go by themselves. Finding a device to encourage/support older people to drink was also thought of as helpful.

England

Panel 1: Users and potential users

Date & location 14 July 2008, Preston. The panel met in a large multi-use centre attached to a church. *Participants:* Eight participants: seven women and one man, all over 65 years of age (up to 80+). This panel had been recruited through a local Older People’s Forum and seven were actively engaged in voluntary organisations. Two had been caring for their elderly husbands and were recently widowed, one had mobility problems and was a wheelchair user. Two used pendant community alarm devices. All were living independently i.e. not in sheltered or assisted accommodation.

Panel 2 Users

Date & location 24 November 2009, Morecambe. The meeting took place in the communal sitting room area of a building devoted to ‘sheltered housing’ for older people. *Participants:* 10: two men and eight women, all over 65 years of age (up to 90). This panel was recruited through a local Older People’s Forum. A member of the forum lived in a retirement apartment building (owner-occupied apartments) for older people. He had circulated information about the project on our behalf and we invited residents of the apartments to attend. Their building has pull-cord or push-button alarms in every room, a building manager is in attendance during working hours but in the evenings and at weekends alarm calls are put through to a monitoring centre several hundred miles away. Three of the panel members had been looking after frail spouses and were now widowed, two were still actively looking after frail and infirm spouses.

Panel 3 Informal carers - 1

Date & location 26 May 2009, Preston. The panel met in a large multi-use centre attached to a church. *Participants:* Eight: four women and four men. Panel members had been recruited through local Carers’ Forums. This group had a younger average age than the previous two. Two participants were in their late 20s, early 30s. All had caring responsibilities for close family members with long-term chronic health problems including mental health problems, learning disabilities, epilepsy, arthritis, and stroke. Most looked after older family members; an older man looked after an adult son and a young woman cared for a child, both dependents had complex needs.

Panel 4 Informal carers - 2

Date & location: 25 May 2009 Burnley *Participants:* Six: three women and three men. Three of the panel had been carers for their mothers who were now deceased. Two women on the panel were looking after two people, one for her husband who has Alzheimer’s disease and her elderly mother, another for her mother who has Parkinson’s disease and her daughter with learning difficulties. The sixth member of the panel was an active member of an Older People’s Forum and a lay inspector of residential homes for older people.

Consent/ethical issues:

The facilitators explained the EFORTT consent form to panel members and they were asked to sign to agree to take part in the research. Participants were paid a small honorarium for their time given to the discussion. We offered to pay for transport or childcare costs where these were needed: two participants asked for this help.

Meeting structure:

The meetings began at around 10.30am and ended at 4 o’clock; lunch and refreshments were provided by the project. At each meeting the research team members introduced themselves and invited the panel members to say a little about themselves and their experience of caring and of telecare (if any). The facilitators explained the EFORTT project briefly and gave a short presentation outlining the history and uses of telecare to date and examining what future developments might be. Panel members were encouraged to comment during the presentation and the facilitators then opened the discussion aiming to elicit the panel’s views on a number of questions including:

How do new care technologies shape, and get shaped by, care practices?
How do they define good care and how do they re/distribute tasks and responsibilities?
Where do the risks and promises lie for caring, and being cared for at home?

At the end of the meeting panel members were invited to take part in a similar meeting towards the end of the research period to see and comment on the findings of the team.

Recording and transcription:
The meetings were digitally recorded, and the recordings were transcribed by the project officer.

Deviations from the Description of Work:
No significant deviations, although it took longer to recruit and convene the groups than was planned.

Significant results
As our colleagues also report, it is not easy to convene panels for telecare user groups. The users themselves are usually frail, elderly, and unable to travel far; the carers' are often restricted by their caring responsibilities. The over-riding fear expressed by panel members was that telecare might become a replacement for human carers and that it would lead to increased social isolation and possibly depression. Some saw telecare as a manifestation of a 'selfish' society in which younger people are no longer prepared to look after their older family members, while others acknowledged that their adult children (usually daughters) were too busy working, and financially dependent on their work to be able to care for their ageing parents. A recurring opinion was that the newer surveillance devices were a form of control and intrusion and that such devices were reminiscent of 'Big Brother'. There was disquiet about the rising cost (to the users) of telecare as it becomes more complex and mistrust that costs would remain affordable. Respondents are concerned about the training which telecare call centre operators receive and the volume of calls they will have to manage once the service expands. Users and potential users were vehement that they would wish to remain in their own homes as long as possible.

Those who use pendant community alarms felt that these were beneficial, provided the response to calls is rapid, empathetic and appropriate. Users saw them either as a form of reassurance, that they could summon help in case of accident or emergency; or as a device offering liberation, enabling the user to push her capabilities and be more active, secure in the knowledge that help could be called if necessary. It was felt that the pendant alarm benefits should be extended beyond the house, e.g. garden or even further, i.e. mobile service.

The residents of the apartments with built-in alarms spoke positively about the monitoring centre staff who answered their calls. However they also expressed fears that if telecare becomes more widespread the monitoring centres might have to deal with larger numbers of clients and may be unable to provide such a personal and sensitive service. They were concerned about the service being 'contracted out' to larger and more distant organisations.

The newer telecare devices such as bed sensors, falls monitors and medication dispensers were viewed with more suspicion. Panel members could see ways in which

the technology might not be flexible enough to deal with the personal habits and idiosyncrasies of the user or ways in which the users themselves, if they suffered from dementia for instance, might not be able to cope with the technologies.

Panel members were sceptical about telemedicine: they doubted that a video-consultation could elicit the same quality of examination/diagnosis as a face to face consultation and some felt that electronic monitoring of chronic conditions, requiring users to take their own readings, could heighten the anxieties of the users. But some could see benefits both in financial savings for the health service and convenience for the patients.

Carers were less positive about telecare. They gave examples of how telecare could not help with the particular needs of the family members they cared for, citing among other things: the possible delay in summoning help; the problems of language for older Asian family members when trying to communicate with a monitoring centre; the need for constant care and attendance for seriously chronically ill family members, or their inability to cope with the technologies; the unreliability of technology and power supplies. In two instances the carers had improvised their own forms of 'domestic' telecare using a standard baby alarm and an internal telephone system. A British Asian carer said that telecare was unlikely be used within her community as it was assumed that family members would care for each other.

Reactions to the notion of robot pets were divided in all the groups, some saw them as demeaning while others thought they might be entertaining and companionable.

WP 4 Data Clinic

The data clinic is planned for February 11-12, 2010, and will take place in Rondane Høyfjellshotell, north of Oslo. The basis for this data clinic is the research and the outcomes of the first round of citizen panels (WP 3) and ethnographies (WP2) in each of the partner countries. Preliminary outcomes of these activities have already been presented and discussed in project meetings; data samples from the ethnographies are for example translated and circulated for joint discussion and analysis for the project meeting scheduled in September 2009. Based on these work-in-progress analyses and discussions, each partner country will produce a thematic analysis of their data for the data clinic that will be circulated together with translated data samples. Starting from the question underlying WP 2, about what emerging care realities and associated ethical questions that arise in different contexts and regions within the European space, the process of analysis is directed towards identifying changes in care as well as themes and issues arising in each of the partner countries, but also across these. It also takes up the sub-questions on new emerging arrangements and relationships of care, new distributions of tasks and responsibilities, new definitions of care and good care in particular, their evaluations, and implications for different stakeholders, and for gendered divisions of labour. Based on these common concerns and questions, a comparative analysis that takes into account both commonalities and differences will be developed.

WP5: EFORTT Conference

EFORTT Conference's Program is already defined and it will take place on 13th-14th of September in Barcelona, at the 'Convalescence House' http://www.uab-casaconvalescencia.org/

Apart from its architectural style, we have chosen this place because it's a study and conference centre connected with the UAB (Universitat Autònoma de Barcelona) and also the head office of the Institute on Ageing. That's why it is a landmark in the field of old age and caring studies.

The main structure of the conference is in place; definitive topics for discussion will be decided in due course following further fieldwork and empirical analysis. At that point we will identify speakers (12 people, 4 for each Theme) and invite institutions, study groups and agencies interested on the project. To date we have completed most of logistical work: Hotel for guests, meals and extra-conference activities, and as soon as we finalise the program and themes for discussion we will begin dissemination of information about the conference and send invitations. Meanwhile, we are working to find some extra financing between local institutions.

- Select and book a suitable conference venue in Barcelona **DONE**
- Compile a list of suitable participants, including industry and user representatives, and issue invitations (Months 27-8) **ONGOING**
- Prepare a list of suitable speakers and discuss topics for presentation. Prepare conference programme and other practical issues including translation services. (Month 30) **ONGOING**
- Design/host conference in a mode that ensures active participation from all participants (Month 31)
- Prepare draft report of conference and circulate electronically to all partners (Month 31)
- Prepare final report after receiving feedback (Month 32)

Preliminary conference program:

EFORTT Conference: Barcelona, 13-14th Sept. 2010

'Ageing with technologies: a participative conference on care in Europe'
September 13th

11:15h. **Reception and delivery of materials**
11:30h. **Welcome and Introduction**, (Plenary Room)
11:45h. Coffee Break

12:00h. **THEME 1:** (Plenary Room)
- 15': EFORTT Presentation
- 45': Speakers' Discussion
- 30': Debate

13:30h. Brunch

14:45h. Workgroup Discussion (4 groups)
16:00h. Summary of the Day - **(**Plenary Room)

18:30h. Guided tour to the Old City (Barcelona)
20:30h. Dinner at the marina port

September 14th

9:30h. **THEME 2:** (Plenary Room)
- 15': EFORTT Presentation
- 45': Speakers' Discussion
- 30': Debate

11:00h. Coffee Break
11:15h. Workgroup discussion (4 groups)
12:30h. Brunch
13:45h. **THEME 3:** (Plenary Room)
- 15': EFORTT Presentation
- 45': Speakers' Discussion
- 30': Debate

15:15h. Break
15:30h. Workgroup discussion (4 groups)
16:45h. **Plenary discussion** (Plenary Room)
Summary by rapporteurs
18:15h. Depart

WP6 is the project final report

WP7 Publication and dissemination strategy

WP leaders (Netherlands and Norway) will:

- Compile and circulate a list of suitable journals for refereed articles, in English and other languages **ONGOING**
- Keep a database of all papers prepared from the project, in all project languages, and circulate abstracts in English amongst beneficiaries. They will notify all beneficiaries when papers are submitted to journals and when they are published. **ONGOING**
- Organise the publication of a pamphlet in English that summarises project findings and can be given to conference participants at WP5.

- Encourage and assist partners to publish articles in non-academic journals, and other sites (web sites, industry and patient organisation magazines) to disseminate project findings to a wide range of potential users.

An agreement about authorship processes was worked out between the partners and forms Attachment 6 to the Consortium Agreement. This states:

EFORTT is a collaborative research project carried out in four different member states. There will therefore be a number of different kinds of publications arising from the study.

Types of authorship: Some of these are likely to be *multi-authored* (i.e. by all partners and their teams); others might be *team authored* (i.e. by the team at state level). Some may be of *mixed authorship* (i.e. by groups of researchers from two or more teams). Any proposed *single* authorship (i.e. by one individual only) of any publication using material from the project at either state level or European level, must first be negotiated with the Project Steering Group.

Order of authorship: Within any publication, paper or chapter, the order of authorship shall reflect the writing commitment of the individuals concerned and shall be subject to the procedures of the scientific journal as well as any institutional policies. Always subject to such procedures and policies, the order of authorship may be as follows: First named authors are therefore those who contribute the most text to the finished piece. Where the contribution is deemed to be equal then order of authorship may be alphabetical.

Duration: This procedure should run for the duration of the project (3 years) plus a subsequent period of three years.

Forms of publication

1. *Policy and Funders Reports*

Project Report to the EC: This will be led by Lancaster but multi-authored (i.e. by all partners and their team members)

Work Package Reports: These will be authored by the workpackage leaders and their teams

Other Reports at European Level: Multi-authored

Reports at State Level: Authored by the partner concerned, but EFORTT must be acknowledged

2. *Academic*

Books (to include monographs and edited collections): Monographs should be multi-authored. Edited collections may be single or joint edited but contain team authored or mixed authored chapters

Peer reviewed journal articles: Team authored if relating to state specific research (EFORTT should be acknowledged)
Mixed authored if relating to particular theme of interest
Multi-authored if relating to EFORTT as a whole

Special issues of journals: Can be single or joint edited but include team authored or mixed authored chapters

3. *Practice Based and Popular Journals*

Team authorship as appropriate; Mixed authorship as appropriate; Multi-authorship as appropriate

EFORTT based Publications

England

Alter Special Issue: Ageing, Technology & the Home: researching new care configurations (2009)

Roberts C & Mort M (2009) Reshaping what counts as care: older people, work and new technologies, *ALTER: European Journal of Disability Research,* Vol 3, No2, April - June.

Mort M, Roberts C & Milligan C, (2009) Editorial: Ageing, Technology & the Home -a critical project, *ALTER: European Journal of Disability Research,* Vol 3, No2, April - June. 138-158.

Spain

López, D.; Callén, B.; Tirado, F. y Domènech, M. (in *press*) How to become a guardian angel. Providing Safety in a Home Telecare Service. In Annemarie Mol, Ingunn Moser & Jeannette Pols (eds.) *Care in Practice. Adaptable Technologies and Fragile Bodies*. London: MacMillan

Tirado, F.; Callén, B. y Cassián, N. (2009) The Question of Movement in Dwelling: Three Displacements in the Care of Dementia. *Space and Culture*, 12(3): 70-91.

Callén, B.; López, D.; Domènech, M. y Tirado, F. (2009) Telecare Research: Cosmopolitizing
Methodology, *Alter: European Journal of Disability Research*, 3(2): 110-122.

Tirado, F.; López, D.; Callén, B. y Domènech, M. (2008) La producción de fiabilidad en entornos
altamente tecnificados. Apuntes etnográficos sobre un servicio de teleasistencia. *Papeles del CEIC*, vol. 2008/2, nº 38, CEIC (Centro de Estudios sobre la Identidad Colectiva), Universidad del País Vasco, http://www.identidadcolectiva.es/pdf/38.pdf

López, D. and Sánchez-Criado, T. (2009). Dwelling the telecare home: place, location and habitality. *Space & Culture,* 12(3), 343-358

López, D. and Domènech, M. (2009). Embodying autonomy in a Home Telecare Service. *Sociological Review*, 56(s2), Pages 181 - 195

López, D. (2009) Asegurar el cuidado: Redes, inmediatez y autonomía en un Servicio de Teleasistencia Domiciliaria. PhD Thesis, Universitat Autònoma de Barcelona, 2009

López, D. and Domènech, M. (2008) On inscriptions and ex-inscriptions: the production of immediacy in a home telecare service. Environment and Planning D: *Society and Space*, 26, pages 663-675

Sánchez-Criado, T. & López, D. (2009) La traducción del cuidado. La teoría del actor-red y el estudio de la interdependencia en la teleasistencia para personas mayores. *Estudios de Psicología*, 30(2), 199-213, 2009

Norway

Pols, J.; Moser, I. "Cold technologies versus warm care? On affective and social relations with and through care technologies', i *Alter, European Journal of Disability Research*, Vol 3, Issue 2, April 2009, pp.159-178.

Thygesen, H. (2009) Technology and good dementia care. A study of technology and ethics in everyday care practice. Centre for Technology, Innovation and Culture (TIK), University of Oslo, Phd thesis.

Netherlands

Pols, J., Schermer, M. & Willems, D. (2008) Telezorgvisie Essay over ontwikkelingen en beloften van telezorg in de Nederlandse gezondheidszorg. Amsterdam: AMC. [Visions on telecare. Essay about the developments and promises of telecare in Dutch health care.]

Pols, J. (2009) Big Brother is helping you. Domotica voor mensen met dementie en hun mantelzorgers. [Smart home technologies for people with dementia and their informal carers. Denkbeeld 5.

Planned and forthcoming publications

All

Telecare and national specificities. A comparative study. The paper describes how telecare is being developed in the participating countries.

England

Milligan, Mort and Roberts (forthcoming) 'From place to non-place? New care technologies and the home' In M. Schillmeier and Domenech (eds), New Technologies and Emerging Spaces of Care

Mort, Roberts and Milligan, on mobilising care and the normalisation of home as the best place for old people to be. Paper will think critically about how the rhetorics of telecare and 'ageing in place' produce the home as a kind of trap. This is also a critical engagement with literature on mobilities and is based on a seminar paper by

Mort and Roberts, presented at Lancaster. Planning to send it to a sociology or mobilities journal.

Roberts, Mort and Milligan, on the work of telecare monitoring centres. A paper based on our observations of call centre work and its emotional costs etc.

Milligan, Mort and Roberts. Paper for Social Science and Medicine – an elaboration of our work for MEDUSE and the outcomes of the Utrecht conference (FP6) and how this resonates with EFORTT findings.

Spain
Tirado, F. (forthcoming 2010) Cinepolítica y cinevalor: la gran transformación de la biopolítica. In Ignacio Mendiola (ed.) *Rastros y rostros de la biopolítica.* Barcelona: Anthropos.

Norway
Care in practice: On tinkering in clinics, homes and farms, forthcoming with Transcript Verlag, Bielefeld, eds Annemarie Mol, Ingunn Moser and Jeannette Pols.

Ny teknologi i omsorg: mot fremtidens eldreomsorg [New technology in care: towards future elderly care] – An introduction to telecare for students of health of professions, a textbook to be published by Høyskoleforlaget, Kristiansand, Norway 2010

Journal of Dementia Care – have expressed interest in telecare and EFORTT
Aging and Society.

Thygesen, H. & Moser, I. Dementia care as creative ethics. Chapter in book on telecare: *New Technologies and Emerging Spaces of Care*, Eds. Michael Schillmeier and Miquel Domènech. In press 2009/2010.

Thygesen, H. Chapter on ‘Ethics’ in official guideline to be published by the Norwegian Health Directorate: “Varsle – søke –finne. En Veileder i bruk av varslings- og lokaliseringshjelpemidler for personer med kognitiv svikt eller demens.” [Warning – seeking – finding. A guideline in the use of alarms and monitoring devices for persons with a cognitive impairment or dementia illness). In progress 2010.

NL
Pols, J. (forthcoming) Telecare: what does it help caring for? In: (Mol, A. Moser, I. & Pols, J. (eds) Care in practice: On tinkering in clinics, homes and farms.)

Pols has been invited to write a book on telecare in a series of Amsterdam University Press

Pols, J. (submitted) The heart of the matter. About good nursing and telecare.

Pols, J. & Willems, D. (in preparation) Promises of good telecare technology. Unleashing and taming the telekit.

Presentations, lectures and talks

England

2008 Mort 8 Dec FP7 SENIOR Project Workshop - Adaptive Software and Artificial Intelligence Meeting, Brussels Invited Speaker

2008 Milligan: Technological innovation and the shifting landscapes of care – Invited Speaker, School of Geography Seminar Series, University of Southampton, UK.

2008 Mort 20-23 August Technology and the reshaping of care, European Association of the Study of Science & Technology (EASST) biennial conference, Rotterdam.

2008 Milligan: 4 Dec Royal Geographical Society/Institute of British Geographers Annual Conference: New Care Technologies for older people: who cares, where? London, UK.

2009 Mort Feb 19th Department of Informatics, University of Oslo*,* Norway presentation to the Global Infrastructures Research Group. Invited speaker

2009 Milligan**:** 27-29 Aug 'Ageing, technology and the new landscape of care,' Invited Speaker, School of Population Health, University of Auckland, New Zealand.

2009 Mort & Milligan Sept 29**:** Ambient Assisted Living Forum: Innovative ICT Solutions for Older Persons – A New Understanding – Ethical Frameworks for Telecare Technologies for Older People at Home EFORTT, Vienna, Austria. Poster Presentation

2009 Roberts & Mort 27 May: Mobilising Care, Centre for Mobilities Research, Lancaster University 27/5/09

2009 Mort & Roberts 10 June: Action at a distance and bodies in contact, Warfare and Healthcare Workshop, Lancaster University

2009 Mort 7 Sept, Knowledge Sharing for Co-inquiry, Newcastle University, Invited Speaker

Spain

Domènech, M. y Tirado, F. Following older people around: regimes of engagement and kinepolitics, Congress: Warfare and Healthcare, Lancaster University, UK: 2009

Tirado, F. y Domènech, M. Tienen los artefactos técnicos afectividad?: teleasistencia domiciliaria y cuidado en España, II Encontro Luso-Espanhol de Sociologia do Conhecimento, da Ciência e da Tecnologia, Instituto de Ciências Sociais da Universidade de Lisboa (ICS-UL) 2009

Tirado, F., Michel Foucault: biopolítica e intuición de la cinepolítica
Congress:Aportes de Michel Foucault al pensamiento contemporáneo
Place: Barcelona 2008

Tirado, F. Cinepolítica y cinevalor: la "gran transformación" de la biopolítica
Congress:La biopolítica en las sociedades contemporáneas, Bilbao 2008

Tirado, F., Biopolítica y comunidad en la sociedad del conocimiento
Congress: Comunidad, identidad y políticas de gobierno en la sociedad del conocimiento, Bilbao: 2008

Domènech, M.; Callén, B.; Casan, N.; López, D.; Sánchez-Criado, T. y Tirado, F. Monitoring Care in Everyday Life: The Case of Outdoors and Mobile Tele-Care Services, Congress: Annual Meeting of the Society for Social Studies of Science (4S) & the European Association for the Study of Science & Technology (EASST) Rotterdam 20 – 23 August,2008

Tirado, F. y Cassian, N., Surveillance and Telecare. From Biopolitics to Cinepolitics in the Society of Knowledge, Annual Meeting of the Society for Social Studies of Science (4S) & the European Association for the Study of Science and Technology (EASST), Rotterdam, 20/23 Aug, 2008

Sánchez-Criado, T., Immunity beyond the home: The emergence of new forms of protection through telecare, Annual Meeting of the Society for Social Studies of Science (4S) & the European Association for the Study of Science and Technology (EASST), Rotterdam, 20/23 Aug 2008

Domènech, M. y Tirado, F., Ciencia, tecnología y ciudadanía: la cosmopolítica y la reinvención de la democracia, I Jornadas Hispano.Lusas sobre Sociología de la Ciencia, Conocimiento y Tecnología, Segovia: 2008

Norway
Hilde Thygesen, Smarthusteknologi i bruk – status og erfaringer fra et feltstudie, [Smart home technology in use: status and experiences from a field study], Smarthome Conference, Tønsberg 15-16 October 2008

Hilde Thygesen, Technology and future elderly care, presentation of the EFORTT-project, meeting for next-of-kin, Furuset nursing home, 29 October 2008

Hilde Thygesen, Good dementia care and technology: sustaining persons, respecting autonomy or enhancing surveillance?, PhD trial lecture, Centre for Technology, Innovation and Culture (TIK), University of Oslo, 19 February 2009

Hilde Thygesen, Smart home technology and dementia care, telecare project meeting, Centre for Care research, University College of Bergen, 25 February 2009

Hilde Thygesen, Ethical frameworks for telecare technologies for elderly people living at home, presentation of the EFORTT project, Research Forum, Diakonhjemmet University College, Sandnes, 20th April 2009.

Netherlands
Pols, J.Telecare-visions. Promises and developments of telecare in Dutch health care 4S/ EASST joint meeting, Rotterdam, 20-23 August 2008.

NWO Ethiek, Onderzoek en Bestuur. Lezing: Tele-zorg-visie. Beloften en ontwikkelingen van telezorg in Nederland. 2 oktober 2008. [Telecare visions. Promises and developments of telecare in the Netherlands, for the Dutch organisation of scientific research.

Lecture for Master students Medical informatics. Tele-zorg: waarom zouden we? Beloften en ontwikkelingen van telezorg in Nederland, [Why telecare? Promises and developments of telecare in the Netherlands] AMC Amsterdam May 2009.

Spitsseminar Zorg op Afstand [seminar Care at a distance] Lecture: Tele-zorg-visie. Beloften en ontwikkelingen van telezorg in Nederland. [Visions on telecare? Promises and developments of telecare in the Netherlands] Spitsseminar NICTIZ [Netherlands expert center for IT in health care] 27 Mei 2009. Report and videorecordings: http://www.nictiz.nl/?mid=180&pg=219&doc=188

Other activities
http://effortgescit.wordpress.com/ : Reference Blog from the Spanish Group (Universitat Autònoma de Barcelona) about EFORTT Project.

UK team: Wiki page.
A member-only Wiki site has been created to enable sharing of news and data between project partners. On this site we post minutes of local advisory group meetings; recorded and transcribed data from panel discussions with research respondents; news stories of interest to colleagues and links to articles, journals and websites related to the research.

UK team: EFFORT website.
A public website has been created to communicate the work of the project.
http://www.lancs.ac.uk/efortt/
The website sets out the aims and methods of the research and has pages describing the consortium partners; their local advisors; events of interest to telecare research; news and publications by consortium members. At the forthcoming consortium meeting (Amsterdam 24th – 25th Sept 2009) the team will discuss the format for a publications page on the website and consider publishers' differing copyright issues.

Conferences to visit and present work:

All
-AAL –conference in Vienna Sept 09
-EASST conference 2010 in Italy

Norway
Optimizing future health care services, Narvik University College, Nov 09
20th Nordic Congress of Gerontology, on Healthy ageing in the 21st century, to be held 30 may – 2 June, 2010 in Reykjavík – Ingunn Moser is invited as keynote speaker, interest in telecare as a theme

4th International In Sickness and In Health Conference 2010, to be held in Denmark. The ISIH-network is devoted to critical scholarship of power, practice and ethics in health care, and brings together an interesting interdisciplinary mix of people with interest in health care.

Monitor relevant DG INFSO and SiS project events

WP1 Project Management

Consortium management tasks and achievements

Project planning and status
Management of the project has proceeded as planned. This is the first, (18-month) report (**WP1**); the EFORTT project is now half way through. Plans are in place for the following 18 months, culminating in the final conference which is now booked for 13/14 Sept 2010 in Barcelona (**WP5**), prior to production of the final report **(WP6**). Plans are also in place for the project data clinic on February 11/12 as part of **WP4.** Both **WP2** and **WP3** and **WP7** are ongoing. All deliverables due in the first reporting period have been met: i.e. **D1.1** (here month 18) **D 1.5** (previously submitted at month 3). All milestones due in 1st reporting period have been met: i.e.
MS2; MS3; MS7; MS8; MS9; MS10.

A key task of the EFORTT management work package has involved the constitution and ongoing work of the Local Advisory Groups (LAGs). The role of the LAGs is to advise on the general direction of the project in each country, to widen participation within the project, consider progress reports and examine samples of data collected by EFORTT researchers. The groups also debate issues which occur in the process of the research. We will also use the LAGs to assist with project dissemination and development of invitation list for final feedback conference in September 2010. LAG activity in the partner countries is described below.

Norway
Two LAG meetings have been held (the third is scheduled for October 2009), on 13 August 2008 and 28th January 2009. In addition to EFORTT researchers the group consists of representatives from: the National Health Association, the dementia care organisation *Demensforbundet* (2 next of kin); the Norwegian Board of Technology; industry (civilian engineer producing technical aids for disabled people) Aabakken Industry and Design (www.aabakken.com); Ageing and Health (Norwegian Centre for Research, Education and Service Development); Geria (resource centre for people with dementia, the municipality of Oslo); the Institute of Informatics, University of Oslo.

Netherlands
The LAG has met three times on 15/08/08; 12/12/08; 12/03/09. It includes the group in Friesland where a telecare project is being studied. Members are the oncologist (G.J. Veldhuis) and a policy person (L. de Jong) of the Antonius Ziekenhuis in Sneek; a General Practitioner, former chair of the National Organisation of General Practitioners and now coördinator of the 'transmural team' (W. Bogtstra), a 'technology nurse' from homecare organisation in Friesland: 'Thuiszorgtechnologie Thuiszorg Zuidwest Friesland en Thuiszorg de Friese wouden.' (S. Thibaudier); the project manager of the Health Buddy service in the researched project (E. Wust).

In addition, the project is advised by Focus Cura, a company that aims to bring care and technology together (J. Thie, D.Dohmen) as well as M. Wink from PAL4. Other advisors are consulted individually: The Dutch organisation for E-health (P. Henneman); The National Patient and Consumers Federation (NPCF) (M. Meulmeester); 2 medical ethicists (M. Schermer, M. Hilhorst); a national policy

maker (E.Maat, ministery of Health, Welfare and Sports); a representative of the industry (J. van der Weijde) a professor of Medical informatics (A. Hasman); a policy maker in a homecare organisation (A. van Hout, Aveant, Utrecht).

Spain

The LAG has met three times: 7/07/08, 17/11/08 and 2/3/09. To develop the group, a map was drawn up to include the main functions and agents involved in Spanish telecare services. This operated as a guide to allow the selection of at least one actor from each of these functions. In this way we achieved a range of experience around home telecare: from health and social policy makers to providers, technological designers, researchers or older people's and relatives' associations. The following have participated: Social Welfare Municipal Council of Barcelona, represented by "Development and Welfare Association"; Elder People National Observatory-IMSERSO; Institute on Ageing-UAB; Tecsos-Vodafone Foundation; FOCAGG: Federation of Catalan Elder People's Organizations; ACFUC: Catalan Association of Elder People Houses' Users and Relatives; Red Cross-Catalunya and Red Cross-Madrid; Social Services from Terrassa City Council. LAG meetings have helped us in defining the fieldwork, methodology and users samples and LAG's participants have helped us, specially, to make contact with people interviewed.

England

The LAG has met at 6 monthly intervals on 23/06/08, 17/12/08 and 11/06/09. It includes practitioners and managers from statutory services e.g. occupational therapists (Lancashire Care NHS Trust), social workers, telecare project manager and telecare project trainer (Lancashire adult & community services). It also includes voluntary and 'third sector' agencies providing care and advice to older people such as Regional Development Officer Help the Aged, Regional Director Age Concern, the two largest national charities for older people (NB now merged to form Age UK: www.ageuk.org.). Also involved are industrial partners who develop telecare systems, devices and services: Chubb Community Care www.chubbcommunitycare.co.uk and Just Checking www.justchecking.co.uk both work with individuals and local/regional/national social care/health authorities. In addition there are academic advisors with expertise in ethics, care and ageing: anthropology of technological development; migrant care workers; human resource management; gender, environmental effects on health and depression; health geographies; qualitative and ethnographic health research; participatory design; studies of paid domiciliary care workers.

Problems which have occurred and how they were solved

No major problems have occurred.

Changes in the consortium

No major changes have occurred.

List of project meetings, dates and venues
EFORTT steering group and project meetings – it was decided to combine the steering group business meetings with longer project progress meetings.

Project kick-off meeting held Amsterdam Medical Centre on 13/14 March 2008 (attended by Lino Paula, FP7 EFORTT Project Officer) Minutes are on the *project wiki space.*

Second project steering group meeting held 15/16 Sept 2008 at Lancaster University, UK. Minutes placed on the wiki.

Third steering group held on 5/6 March 2009 in Barcelona. Minutes placed on wiki. Fourth steering group is in Amsterdam on 24/25 Sept 2009.

Impact of possible deviations from planned milestones & deliverables
No significant deviations for milestones or deliverables NB see above WP2 possible extra time for report of WP due to unavoidable fieldwork delays.

Any changes to legal status of beneficiaries
No changes have occurred.

Development of project website
UK team: the EFORTT website has been created by the Lancaster team to communicate the work of the project: http://www.lancs.ac.uk/efortt

This has been created with the help of colleagues in the School of Health & Medicine and the Faculty of Arts and Social Sciences, Lancaster University, and is hosted by Lancaster University's server. The Project Officer, Josephine Baxter has completed training in the use of web-writing software and now has responsibility for maintenance and updating of the site. The website sets out the aims and methods of the research and has pages describing the consortium partners; their local advisors; events of interest to telecare research; news and publications by consortium members.

In addition to the public website EFORTT developed a member-only wiki site which is used by all the participating colleagues to share and disseminate information. On this site we post minutes of the steering group and Local Advisory Group meetings; audio and transcribed data from panel discussions with research respondents; news stories of interest to colleagues, and links to articles, journals and websites related to the research.

The team has also produced a project leaflet which has been distributed widely.

Use of foreground and dissemination activities during this period

a) Some of the publications listed above involve the use of ‘foreground’ which has been combined with EFORTT research material. NB these are being combined and developed as part of the Publication & Dissemination Strategy **(see WP7**).

b) Other dissemination activities these are mostly either workshop and meeting presentations or conference presentations. For a list of these please see under **WP7** Publication and Dissemination Strategy.

Mort M, 12 May 2008, Ethics and e-Inclusion, High Level Workshop participation (Slovenian Presidency and European Commission DG Information Society) Bled, Slovenia: meeting participant.

Other

Two beneficiaries have had trouble with accessing the SESAM system for uploading their periodic reports (Form C) and this has caused considerable delay and frustration, as the system is new to most administrators.